No Longer the Caregiver-Now What!

Lorna Larsen RN, BScN Team Shan President (teamshan.ca) Cancer Knowledge Network Blog (April 2013)

The instant your loved one loses their life, life as you know it changes. There are no words to describe the profound sadness and the process of grieving begins.

The parental caregiver role alters based on the age of the child, your relationship with your daughter or son and the role expectations of other loved ones in their life. My daughter, Shanna, friends and family called her Shan, was an independent young woman. Shan was living at home, preparing for a teaching career and other adventures when she was diagnosed late with metastatic breast cancer. Shan had graduated with a visual arts degree, was coaching figure skating and working as a swimming instructor and life guard. She was looking forward to joining friends in Europe before heading off to Teacher's College. Shan's dream was to work with young children. Once diagnosed, Shan asked that I stay with her through her treatment journey and assume her caregiver role.

As Shan's primary caregiver, I had the opportunity to be with Shan twenty four seven. I accompanied Shan for her tests and treatments and assisted her with basic needs during her hospital stay. At Shan's request, I communicated with the medical and nursing professionals and shared her questions and concerns. Most importantly, Shan was not alone. I was with her.

When Shan got seriously ill, I would manage her daily care both in hospital and at home. I would advocate for her and ensure basic comforts. Family and friends visited daily to assist with her care, help her get outdoors and keep her company. Kindness and love were shared with Shan until her passing. Shan was only 24 when she lost her life to breast cancer. The cardinals were singing and the magnolia trees were in blossom.

No longer the caregiver, I faced my own grief journey. Initially, life passed me by and I no longer felt a part of it. I was barely existing. I found it hard to comprehend that there could be life after Shan's death. I wanted the pain be taken away. I cried a sea of tears, but it was never enough. Over time, the small and self imposed circle of support around me began to widen and meaningful changes brought brief moments of joy...the sounds and sights of nature, human kindness, the taste of a wonderful glass of wine, a delicious meal or special time with friends. Slowly I could again enjoy music, art and other treasures of life.

They say that time heals, but I had to work very hard to get through my loss. I found books and traditional supports helpful, but they were not enough. My strong support network of professionals, friends and family helped me take the necessary steps to heal. I also followed my own instincts. It took years for me to feel that I was truly living again, but there was always hope.

I found I was on three roads during my journey and all needed to be travelled. At times, I referred to my journey as a marathon and at some point I was finally able to see the finish line.

The first road was to preserve Shan's memory. I collected photos, created scrap books and framed her art work. I shared special items with her friends and made quilted jackets from her

clothing. There were also memory bears, mats, a quilt and a work of art created. My husband and I set up a memorial art award at Shan's high school and friends established memorial sporting events. Trees were planted, gardens built and other tributes shared in Shan's memory.

I also worked through my own grief, the tears and the physical and mental anguish. Grief counseling and therapy assisted with this process. I relied on things that had supported me in the past...hiking, yoga, time with friends. It was on this road that I also experienced a spiritual journey that helped me grow and understand life and death. It was a slow journey with a positive result.

The third road took me to where I am today. I was encouraged to make a difference for young women following in Shan's footsteps. I had a career in public health, specializing in health promotion. I had advocated for young women as a health care professional and now felt a passion to fill a gap in breast cancer awareness.

In a country where cancer is the leading cause of premature death in women and one out of nine will face breast cancer in her lifetime, I felt this was an issue I could address. Awareness and education of breast cancer is vital to young women. They need to understand their risk of breast cancer in order to make appropriate breast health choices and be empowered to seek appropriate medical attention.

Named after Shan, Team Shan Breast Cancer Awareness for Young Women (Team Shan) <u>www.teamshan.ca</u> is a Canadian charity dedicated to making a difference for young women following in Shan's footsteps. I am proud to be Team Shan President.

Team Shan activities take place in high schools, communities and on college and university campuses across Canada. We have reached tens of thousands of young women. They have understood their breast cancer risk and are taking action to make healthy lifestyle choices, know their bodies and their breasts. Young women have thanked Team Shan for being on campus and appreciated not being forgotten in breast cancer messaging. Team Shan is making a difference.

Team Shan has become my purpose, my ongoing 'now what' and that is special to me...a marathon I can continue to run.

