

What Christmas Means to Me This Year
Forum Talk by Casey Scribner 12/13/20

My earliest memories of Christmas bring memories of my parents and grandparents and one memory that never left me was the love of Christmas lights. I recall laying on my stomach as a toddler hands under my chin just staring for what seems like hours at the changing colors of my grandparents' silver tree – red, orange, blue, green. Many years later I would learn that these captivating lights were generated by a color wheel but back then it was pure MAGIC. Back then Christmas was about lights and presents and shiny things.

As time went on, I was called to deeper things – I was called to “show up” for those I loved as a caregiver. This year is the first Christmas without my mom. It is a transitional year after 12 years as her advocate and daughter. She had early onset Alzheimer's and was diagnosed at age 64.

In caring for my mother I tried very hard to give her the patience and validation she had given to me. It was important to me that my mother lead the way and when it was time for her to transition to an assisted living, she let me and my husband know that it was the warmth of Christmas that she desired.

Behind me are a set of Santas that once belonged to my grandparents then to my mother and now me...Just prior to her moving into her new home My husband and I went to my mom's home on the Cape and got her large artificial tree and ornaments and the Santas and thus began the transformation to Christmas in my mom's apartment. The result of this was that it became Christmas year-round in my mother's new home. It was the warmth and comfort of Christmas lights and music and objects that helped to recreate the same wonderful atmosphere for my mother that she had once created for me and I like to believe

that atmosphere made my mom feel safer as her capacities inevitably declined. What I hadn't anticipated was that it had a similar effect on me, and we essentially created a cocoon free of the outside demands and conflicts in the world – it was a place of comfort, healing, and most of all JOY.

When my mother was diagnosed with Alzheimer's I remember saying to her that we would Thelma and Louise our way through Alzheimer's – what I was trying to say I think was that we would not give into or live in a stereotype that says that Alzheimer's can only be sad but rather that we would embrace the moment and live like it was our last day and grab whatever joy and connection we could before this disease would take her.

As it turned out we did just that. Alzheimer's afforded us the unusual opportunity to live life without filters and to embrace the silliness and joy that children do so naturally. We sang we danced, we played with stuffed animals, we watched the shiny lights and the ornaments, the animated TV specials, and most of all we embraced and held tight to one another. I'd love to take credit for having the insight to tap back into my childhood experiences, but my mother had already laid out the blueprint and it was just a matter of recalling those early experiences and transporting ourselves back to that place. What a gift to be able to go back and experience something I thought was gone forever.

It didn't actually matter whether it was Alzheimer's or cancer or some other typically sad disease that came in and threatened to steal away our time together – I learned not just with my mom but with my husband also who had a recurrence of cancer during this journey that **JOY, SORROW AND TIME ARE INEXTRICABLY LINKED**. It was the realization of time running out that emboldened us to resist wasting time and to embrace joy immediately. We could not change the fact that my mom had Alzheimer's, but we could choose joy – the same

type of joy reminiscent of the best of Christmas celebration. Impressed upon me was it's later than you think – make time for joy.

I was deeply moved by attending Rachel Goodwin's salon with Earl Kim's *Now and Then* concert about the bombings of Nagasaki and Hiroshima. I was specifically moved by the words of Ray Matsimuya. Ray spoke of his frustration around people assuming Hiroshima was a sad and depressing place because of what had happened there. A large majority of people in mine and my mother's life did the same with regard to my mother's Alzheimer's – wrote her off, assumed she was gone when she was still there. Surrendering to what that chapter in her life had to teach us led us directly to joy...which ties into the other point made by the speakers in the Earl Kim event which was that it was children who led the way toward healing and rebuilding in Hiroshima. I loved this one line: "**Children Ruthlessly Pursue Joy.**"

In many ways this is so because children have little concept of time. My mother too lost her concept of time and rather than a cage that kept her trapped – hidden in it was an unexpected gift that eventually set her spirit free. She gained something so important – she finally let go of the many worries she carried in life and lived fully in the moment. It was powerful and healing for me to witness that. I'm so grateful that so many of those final moments were lived in joy.

This year as I transition and try to find that joy I once shared so easily with my mom, I am compelled to acknowledge my grief but also to bask in the warmth of precious memories and to carry the message her lessons gave to me in my life today.

When I was in my twenties my mother gave me a sweet book of encouragement by Susan Squellati Florence called "Be All That You Are." As I go through this new season, I decided to nurture myself by

reading some other books written by this author and I would like to share with you a few pages from her book entitled "A Gift of Time."

Today is fullness like a fruit when it is ripe, like a benevolent rose fully opened to the sun, to the rain, giving of itself entirely...

Today can nourish and inspire us like no other time...

Treasure the moments of the new dawn, of the dew on the lawn, of the sun's journey through the sky...

And after the crimson light has fallen...when the lavender hue of first night remains, as the stars begin their ritual twinkle...

Let our hearts touch and be full of thanks...

THIS GIFT OF TIME IS ALL WE HAVE.