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## NARRATIVES ON PAIN SUFFERING AND RELIEF

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# Through the Eyes of Child: Reflections on My Mother's Death From Cancer

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### ABSTRACT

Before being exposed to palliative care, I had lived through 15 years of emotional suffering, beginning with my mother's relapse of leukemia. My mother died 12 years ago; however, the suffering did not end there. Palliative care helped me find meaning and purpose in my suffering. During her illness I received no explanations about what was happening to my mother, and I felt utter emotional loneliness. I received no help in coping with the uncertainties of my mother's life with cancer or of her dying process. The experience left me sad and angry. Sheltering a child from truth does not lessen fear or alleviate pain; it only causes feelings of confusion, anger, embarrassment, and shame.

**KEYWORDS** bereavement, cancer, end-of-life care, India, palliative care, pediatric, suffering

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### INTRODUCTION

My name is Mary Alexandra Macy and I am 23 years old. It's been 12 years since my mother died from cancer. For the past 5 years of my official adulthood I have spent endless hours dissecting and analyzing the meaning of her death. I studied immunology to learn more about the origin of her cancer. I went to therapy and diligently tried to unfold my buried life into the context of psychological theory. I dipped my feet into foreign seas and climbed mountains in majestic ranges, all to give meaning to her suffering and my purpose for having endured.

Five months ago I traveled to India on behalf of Child Family Health International to work with an incredible nongovernmental organization (NGO) called Pallium India (<http://www.palliumindia.org>). Pallium India works tirelessly to extend palliative care to patients and families suffering from pain throughout India and the developing world. There I studied palliative care theory and sat at the bedside of patients suffering from chronic pain, like my mother had. Under the guidance of Dr. Rajagopal, palliative care physician and founder of Pallium India, I learned that the suffering from my childhood left me with an important message. I began sharing the story of my mother's illness with medical staff and patients, and the feedback I received made my purpose for having

endured clear. I realized that I need to share my childhood experiences with people whose lives are affected by chronic pain and suffering. I learned that my raw, unedited narrative implicitly holds a unique and educational message of its own. I hope that my story is a lens into my experience as I lived it. And if it provides even a sliver of insight into how a child experiences the suffering and eventual death of a parent, then I have successfully highlighted the importance of palliative care.

### CANCER CALLS, AGAIN

Sirens scream outside my window, breaking the stillness of the fall night. My eyes open to red and blue lights flashing on my pink walls, and the vibration of footsteps flooding through the hallway outside my bedroom. Silently, I sneak out my door and peer around the corner of my parents' room, too scared to make a sound. Men in blue uniforms swiftly lift my mother's limp body onto a stretcher and rush her away. I listen to the sirens fade in the distance, as I stand motionless in the dark silence that follows. I am 8 years old.

Up until that night, 5 years of remission had passed since my mother's first bout with leukemia. Five years of cheering up and down sidelines at soccer games.

Five years of driving me to dance practices and winking from the front row at piano recitals. Five Christmases, five birthdays, five first days of school. Even though her cancer was relapsing, she refused to let it show until that haunting fall evening.

## A CANCEROUS LIFESTYLE

The next 3 years were spent navigating my way through normal life as a pubescent preteen, and actual life with my mom's cancer. Weeks consisted of blurry school days, hospital visits, and frozen TV dinners; months of late night emergency phone calls and forced sleepovers; years of treeless Christmases in the ICU (intensive care unit) and dusty piano keys. I remember a wheelchair at my fifth grade Shakespeare play. There she was: bald, weak, and withering inside. I was embarrassed. My mother's health cycled through months of improvement immediately followed by months of rapid deterioration. I was confused. She was my mother but she couldn't take care of me the way a mother should. I was angry.

Images of her cancer stand clearer in my mind than images of yesterday. When I close my eyes I can see the purple and green carpeted hallways of the cancer ward and the shiny white floors of the ICU. I can feel the overwhelming scent of stale sanitation. I can smell the abundance of plastic: plastic meal containers, plastic IV bags, bundles of plastic tubes forcing cocktails of liquids into her skeletal arms. I can see green lines and numbers blinking on black computer screens, pink vomit buckets, and a gray oxygen monitor permanently clipped to her left index finger. I can see her peeling yellow hand tremble as it lifts to cover her tracheotomy hole; I can still hear the startling gasps for air in between her few forced words. I remember walking down a long sanitation hallway, washing my hands several times and covering myself in robes and masks before entering her post-bone marrow transplant room. I was visiting my mother in the hospital while my soccer team was eating lunch together between games on a Saturday. I felt alone.

There were days when my mother did not recognize me, and days when her state of confusion was so intense that I felt like the mother and she the child. Despite my youth and the fact that I was never informed about the details of her illness, I knew the cancer should have taken her life by then. I was sad, I was confused, and I was angry. She was fighting for me, but all I wanted was relief from our cancerous lifestyle. I feared the sight of her, the smell of her,

and the sound of her broken voice. I made excuses not to visit her. I was silent; I was ashamed.

## MY MOTHER'S DEATH

My mother died early on a Tuesday morning, February 6, 2001. I was home alone watching *Little House on the Prairie* with my backpack on when my father slowly pulled into the driveway. His eyes were swollen and scared, and those terrible words were the first out of his mouth. All the emotions that were bottled up inside me suddenly exploded. I was so angry that I refused to accept the news of her death and went to school immediately after hearing it. I remember sitting in a full math class with tears streaming from my eyes when my teacher approached me. Reality hit when I was forced to whisper the words out loud: "my mom died today."

I was not prepared to be motherless at 11. Even though nobody knew she was going to die that morning, they were not surprised. Still, no one ever talked with me about the possibility of my mother dying. I was thought too young to be involved in conversations about cancer. Instead, I got sorrowful smiles and hugs from church members dropping off weekly meals. What I needed was to be informed about her illness and prepared for her death. I needed my father to explain why my mother didn't know who I was at times, why she was so thin, and why she couldn't touch me. I needed him to tell me that if she died we would be OK, that she would be OK. I needed my mother to prepare me for when my body matured and changed. I needed to know how to make apple pies for Christmas, how to replace our dead flower gardens, and how to take care of my dad. I needed to be somewhat involved in the conversations that were happening all around me but never with me. Even as a child I needed to be less sheltered and more informed, less surprised and more prepared.

## THE ROLE OF PALLIATIVE CARE IN HELPING CHILDREN

Palliative medicine realizes that cancer is more than a prognosis and more than a patient. It recognizes the family, the lifestyle, and the story behind every cancer diagnosis. Palliative medicine also addresses the importance of explaining illness to children and preparing them for life after the death of a parent. These are the things that I so desperately needed during those three painful years before my mother's passing. Palliative care reminds friends and family that sheltering a child does not lessen their fear or alleviate their

pain; it only causes feelings of fear, confusion, anger, embarrassment, and shame.

## MY MESSAGE

It took me 12 years to share the details of my experiences. Perhaps I was too young to comprehend the significance of it at the time, and too vulnerable to open up in the years that followed. Telling my story means reliving it in a way, and for years that seemed unbearable. However, writing this narrative has been an incredible journey of healing. Many tears have been released while scribing these words, and many more have fallen in the nights that followed. It took multiple drafts to organize the images of my mother's

cancer in a way that others could try to understand, but in the end I found catharsis. Pallium India helped me realize my purpose for having endured those terrible years of suffering.

Today I write this message on behalf of the millions of children who are living with ill parents, and for those who have already experienced loss. I hope this narrative is successful in spreading the silent message of children watching their parents suffer, and quietly suffering themselves. I hope my message is strong and clear: keep children informed and keep them prepared, because too often are they scared, confused, and suffering all on their own.

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