

Finding Meaning in a Parent's Cancer Diagnosis: Teens Tell Their Story

BY BRIE BERNHARDT, MSW, LSW



As a Master's in Social Work student at the University of Maryland Baltimore, I had the opportunity to work closely with the Saint Agnes Cancer Institute, which offers support programming for youth affected by parental cancer. Located in Baltimore, Md., Saint Agnes seeks to educate and engage these children and teens by normalizing the experience of having a parent with cancer and allowing them to interact with other teens like themselves.

Upon beginning my time at Saint Agnes Cancer Institute, I was introduced to five very special teens whose parents were at that time undergoing cancer treatment. Having personally experienced the cancer diagnosis of a parent while still a teenager, I saw a large part of my own experience as a teen reflected in the stories of the youth at Saint Agnes. (As a 17-year-old, my mom was diagnosed with breast cancer, and a year later my dad was diagnosed with prostate cancer.) The turbulent fluctuations of emotion that I felt during my parents' cancer journeys were now a reality for these kids, and I empathized with their long list of questions that accompanied this new season of life—questions about how their parents' diagnoses would impact their daily lives or their ability to enjoy their senior year and go to college. I heard in their stories a familiar feeling of guilt—as if they were being selfish and insensitive for being worried about how their parents' cancer would affect *their* lives. Only having later learned that these thoughts were typical of someone my age did I recognize that what I needed most during my own parents'

diagnoses were resources to help me navigate my feelings at the time. I longed for someone to tell me that my feelings weren't abnormal or inappropriate but instead natural and normal. As I continued to listen to the thoughts of the Saint Agnes teenagers, while retracing the steps of my own journey, it became increasingly apparent that what I lacked as a teenager during my parents' diagnoses was also what these five teenagers desperately needed—an interactive resource aimed directly at their experience.

The idea for *Making It Mine* was born out of the desire to provide teenagers with a participatory resource for reflection that did not previously exist in the cancer literature. Though most cancer support resources

focus almost exclusively on the cancer patient, teenagers experiencing cancer secondhand through the diagnosis of a parent or loved one have largely been left out of the conversation. The reasons for this vary but include limited social work support, high patient volume, and physician schedules that do not allow adequate time to properly identify these needs. Though some resources exist, these materials are limited and not easily available to families undergoing treatment. This population requires a delicate approach to crafting reading material that is tailored to engage teenagers by helping them process in a participatory way. Allowing the five teenagers at Saint Agnes to write their own stories struck me as a useful method for



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engaging this population because it endowed them with a sense of ownership and active reflection.

When I explained this storytelling approach to the teenagers at Saint Agnes Cancer Institute and my hope to provide a resource for other teenagers in the future, it was as if someone had said to them for the very first time: *“Your story is important, and it deserves to be told.”* The teenagers shared their experiences with me, and I supplemented their stories with the stories of five adults who were teenagers at the time their parent had cancer. This method allowed a retrospective look at the ways our experiences as teenagers impacted us as adults. I added short anecdotes, poems, stories, and blank pages with journaling prompts throughout the book, allowing readers to process their own stories as they hear from those featured in the book. After capturing the teens in watercolor portraits, the cover art was designed with a mixed media focus to illustrate the different dynamics that are introduced by a parent’s cancer diagnosis.

Since writing this book, I have heard from parents on numerous occasions, who have

shared with me, *“I wish my teenager had this book when I had cancer.”* The impact on a parent when receiving a cancer diagnosis is immeasurable, and in my experience as an oncology social worker, the very first thought that often comes to mind for parents is not their cancer stage or treatment course but, rather, their children. To be able to provide this resource would mean not only greater support for teenagers but also greater support for parents.

On February 2, 2018, I held a book signing at Saint Agnes Hospital to commemorate *Making It Mine*, featuring live readings from the book by the teenagers whose words are captured within.

In attendance were those who contributed to the book, including artists, graphic designers, and photographers, along with the families of the teenagers who shared their personal experiences. Additionally, there were medical oncologists, oncology nurse navigators, former and current patients, student interns, and the assistance vice president of Saint Agnes Cancer Institute. Books were available for purchase, with the option of purchasing a book that would be

donated to a local cancer center.

Saint Agnes oncology social worker Jennifer Broaddus and I also spoke that evening, sharing the many conversations that led to the creation of the book and recounting the effort it took to make the finished product something that would be enduring and valuable to teenagers in the future. We thanked everyone in attendance and commended the participating teenagers on their bravery for sharing their stories and for affording us a window into their vulnerability. I explained to the audience how the ideas and stories shared in this book can become a concrete symbol of hope to other teenagers—present and future—who will find comfort in its pages when they too experience a parent’s cancer diagnosis.

Making It Mine can be purchased directly from Amazon.com. Proceeds from the book will go to fund support programming for families of the Saint Agnes Cancer Institute.



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