

SIBLING LOSS

by Elizabeth DeVita-Raeburn

I had a brother. Ted was the elder by three-and-a-half years. He'd been there as far back as I could remember. What he did, I did, or aspired to. What he liked, I liked, or learned to. He was nowhere near as enthusiastic about me, which didn't impair my slavish attempts to gain his approval. At age five, I gave up Sesame Street and professed my loyalty to his favorite show, Star Trek. Spock was no Oscar the Grouch, but you do what you have to do. Getting to lie on my stomach in front of the TV, elbow to elbow with my brother, was worth the trade-off. Bit by bit, year by year, I assembled the pieces of myself—what I wore, what I thought, what I ate, how I played—mindful of my brother's critical eye. And then, one morning when I was six, I woke up, and he wasn't there.

Ted had been diagnosed with an immune deficiency disorder called aplastic anemia a week-and-a-half earlier. It's an insidious disease. On the surface, the symptoms are benign—pallor, fatigue, bruising, shortness of breath. With the exception of the bruising, it was like feeling a little run down. Meanwhile, however, his immune system was silently vanishing. By the time he was diagnosed, Ted's immune system was almost gone. And there was no treatment, only the stopgap of blood transfusions to temporarily replace the missing immune cells. Plan A was to keep Ted at home, let him try to lead a normal life, and bring him to the hospital for periodic transfusions.

But one night—the night he disappeared from the house—Ted woke up with a high fever. My parents panicked. They rushed him to the hospital, where they executed Plan B. The doctors put Ted in a sterile, ten-by-ten foot "bubble" room—a regular hospital room divided in half by a clear plastic curtain. The far half was kept sterile by an elaborate air filter built into the wall. The half near the door was as germ-ridden as the rest of the world. The only link between the two was a doorway sized opening in the plastic, near one wall, through which Ted's food and medicine would be passed. On the floor, a red strip of tape continued the curtain's line to the wall, the words "Do Not Enter" spelled out in red tape in front of it. The ventilation system on Ted's side created a steady, thrumming breeze that kept germs on the outside.

For eight-and-a-half years, this became our new normal. Then, without warning, he died. His death was an utter shock to me. My parents had always kept me in the dark about how dangerous his illness was. We talked about when he got out of the hospital, not if. It never occurred to me that my brother might not be in my life.

Anyone who's ever experienced a devastating loss will tell you that life has now been split into two planes: "before" and "after." The "before" life is the old life, the one you thought was normal, and would continue to be. The "after" life is the overwhelming, disorienting and upside down one that follows the death of someone

who was—and remains—critical to your internal wiring. And while any loss splits life into two pieces, I think there is something unique about sibling loss.

Siblings are central to our identity, even if we don't see them often or don't get along with them. Their loss often propels us to ask difficult questions about ourselves. Who were we when they were here? Who are we now? How have our families, and our roles in them, changed? Who is the funny one, or the smart one, now? It can be worse for twins, who are more prone to feel that their identities overlap, and who have often adopted a shared approach to the world from the beginning.

The problem, for twins and for siblings, is that their loss is often not recognized and not understood. People don't understand the depth of the loss, and are quick to put it into some made-up hierarchy of loss, as if some losses are worse than others. Sibling loss, by this screwy scheme, is not as bad as losing a child, or losing a parent. But there is no hierarchy of loss. When we lose someone, it's our loss, and it's deeply painful, whatever the circumstances.

What's worse for siblings is not that their loss is harder to bear, but that nobody recognizes it and acknowledges it. That makes it difficult for siblings, and twins, to fully comprehend and mourn what they've lost. What do siblings hear all the time when they've lost a brother or a sister? *This must be terrible for your parents.* As if it were so much easier for the siblings.

And siblings fall into this deceptive thinking. They don't talk about their loss, because they don't want to upset their parents. They try to be fine, to be strong, which is what others expect of them. They suppress their feelings and often become the people who take care of the rest of the family. Meanwhile, their own loss gets buried, goes unrecognized even by them, and their emotional issues go unresolved. Until it all spills forth—a year later, or ten years, or twenty years later. The sad truth is that no one gets a pass on grief and mourning. Sooner or later, the loss demands attention.

I wrote my book, *The Empty Room*, to try to understand what it means to lose a brother or sister. My brother died when I was fourteen. By my mid-twenties, I'd already developed an unhealthy litany of behaviors which I later realized sprang from unresolved feelings over my brother's death—eating disorders, alcohol and drug abuse, and a bizarre tendency to go numb when overwhelmed by emotional demands. It took the end of a bad relationship (one of many) and an abusive job to push me over the edge and into therapy, where I finally began to explore the significance of my brother's life, and death, in my life.

Several years later, I began to interview other people who'd lost siblings to tell me their stories. I'd never met anyone else who'd lost a sibling—that I knew of—and I wanted to know if there were similarities in our experiences. It turned out, there were—the fact that the loss had often been overlooked, the suppression of the grief, the complicated dynamics within families who often couldn't discuss the lost person, the identity crisis, the sense of something important missing, the difficulty moving on in life, and, in some cases, the sense of guilt for surviving.

Most importantly, the interviews also revealed what seemed to me important tasks, for lack of a better word, that those of us who have lost siblings need to accomplish in order to find a way to go on.

These are some of them:

Claiming the loss: Most people who have lost siblings get the message that the loss wasn't really theirs to mourn. They're told it's harder on the parents, or the children, or the spouse. And so they submerge their grief and try to muscle forward. It doesn't work. So the first step for any of us is to find a way to acknowledge for ourselves that the loss was ours, that it mattered, and that we deserve the time and space to mourn it. People find different ways to do this—by telling their story to a good friend, by writing about it, by making a scrapbook of the relationship, writing songs, etc. It doesn't matter how they do it, only that they do it. It's the first and most important step into learning to move forward.

Re-forming an identity: Losing a sibling can be like having an arm or leg amputated... you can function, but you might feel off balance, not yourself. Some people unconsciously even find "substitute" siblings via friends or partners. To truly integrate the meaning of the loss into your life, however, requires some serious thinking about who you were, on your own, and in your family, when he or she is no longer here, and who you are now that they are no longer here. What role did your brother or sister play in your life? Can you do some of the things he or she used to do for you for yourself? Are you forced into a family role you'd rather not play?

Carrying: Siblings are parallel travelers in life. We expect them to be there, in one way or another, throughout childhood, adolescence, adulthood and old age. We compare and contrast ourselves with them all the while. When it doesn't work out that way, we're shocked, and many of us are thrown off balance by the arbitrary nature of fate. Why him or her? Why not me? And most of us need to keep our siblings with us, to carry them forward in our lives. We still want them as reference points. It's a way of symbolically acknowledging the relationship's significance and our sense of continued connection to that person. Someone who lost a sibling to cancer might volunteer for the local cancer society. Someone whose brother was a runner might run a race in his honor.

What all this adds up to, of course, is that those of us who have lost a brother or sister need to have that loss recognized. It's not easier than losing a child, or easier than losing a parent, or harder than something else. It's our loss. It's important, and painful, for us. And we can't let anyone tell us anything different.