



## Personal Story of How to Help Yourself and Others

A few months after our son Tyler died from SIDS, a well-meaning neighbor bent down to four-year-old Jennifer's eye level and asked, "Well, are you feeling better now about your brother?" and with a four-year-old wisdom and candor, Jennifer replied, "Nope. He's still dead."

As the mother of a baby who died 16 years ago, I might offer the same reply today. Even though time has softened the jagged edges of grief, my son is still gone. In examining my own feelings about a loss that is no longer new, I questioned if I was alone in wondering what has been the effect of my son's death on me and on my family....years later.

When grief is new, it is overwhelming. It invades every part of our lives and refuses to be ignored. Thank goodness it is true that time helps, and even heals a great deal, but it doesn't erase the fact that a child lived and died. In my many discussions and correspondence with families whose loss has been five, ten, twenty, or more years ago, this is clear – no matter how long it's been, we don't forget. We may not think of our child every day, but we remember. And we'd really like it if others would remember too.

"After the first birthday and anniversary, no one called," a mother shared with me. "I felt I was the only one who remembered she had lived. Do we get to remember for only one year?" Many parents realize that the responsibility for remembering seems to rest on their shoulders, and they have come up with touching, creative ways to honor their child's memory. Candle-lighting, tree planting, balloon releasing, kite flying – all are tangible ways to quietly say "I remember you." Other families donate to medical research or to charities of their choice in their baby's name. For Tyler's seventeenth birthday, our family donated a children's book to our local library. It's not much, but it helps us remember that his brief life mattered, and it makes us feel good to know other living children will pick up this book and enjoy it.

Although my grief is no longer new, I find that it sometimes comes back with strength that surprises me. My ears still perk up, and my heart still races each time I hear a newsflash about infant death, each time I pick up the paper and see a too-small headline briefly describing the latest research theory. I've been involved long enough within the community to realize that theories come and go, but I'm still an optimist, and my heart still plummets when I reach the end of the broadcast or article and realize we've not yet solved the mystery. I don't think I'm alone as I revisited the "if onlys, what ifs, I should have's" that new risk reduction information brings up. And yes, of course, I am grateful and supportive of ongoing research efforts, and I do know I did the best I knew to do with my son...but still...

Other milestones can trigger those memories of pain. Wonderfully happy events such as family birthdays, graduations, weddings, births, often bring tears of joy, but for some of us the tears sting as we look with love at the celebration and realize that one important person is missing. As the years go by, we will rarely mention his or her name at these happy occasions, but please be sure that although we are delighted and relieved that life does, indeed, go on, we still miss our child. We still see the empty chair.

One of the hardest parts about being a 'seasoned griever' (as someone in our Years Later session described us) is that there are so few people with whom to talk about our child. As the years pass, there are fewer opportunities to just reminisce. One father had this to say, "Everyone in my family still talks about my grandfather who died at 80. No one thinks it's unusual to say his name and to talk about our memories of him. And yet it feels somehow 'strange' for us to bring up the few memories we have of our son, especially now that it has been so many years."

It has been so many years...but it still hurts. Not the agonizing, blinding pain of the early days, but sort of a soft ache, with occasional deep pangs of grief. We will always be the parents of a child who died; our family will always be missing an important member. It is impossible to realize the many ways in which the loss of a child continues to impact our lives....perhaps it is enough to accept that it has forever changed us, for better or for worse. We understand that death is a part of life, and that acknowledging our losses is a necessary part of living and moving on. And we are...but we are carrying our memories with us.

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