

The wound that doesn't heal: when a parent loses a child

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It is said that time heals all wounds. Maybe for some, time does heal their wounds. But for others, the wounds cannot be healed – never. You can learn to live with those wounds, but they are not healed; there are just open wounds. On 6 February 2010 my daughter, Caitlyn Elizabeth, passed away at the age of seven after a several-year fight with a neuro-degenerative disease. She fought her disease for a long time, but like so many other children with terminal diseases, in the end, she lost. I lost. My wife, Chris, Caitlyn's mother lost. Our family lost.

Even though people cognitively know that children die, it has been my experience that people often do not know how to respond to the death of a child. This is especially true here in the United States where the death of an infant or child is relatively uncommon. More specifically, people do not know how to respond to you – as a parent – after your child has died. It has been my experience that family, friends, colleagues, and others avoid mentioning a child after he/she has died. They avoid saying his/her name and avoid telling stories that include him/her. Often, they do this to help you, as the bereaved parent, or at least that is what they thinking they are doing – helping you – by not bringing up your deceased child. But it does not help; it can actually be rather upsetting because you feel like your child is being forgotten or excluded for something over which he/she had no

Abstract

Even though people know that children die, often they do not know how to respond to the death of a child. More specifically, people do not know how to respond to a bereaved parent after his or her child has died. This essay addresses the complex and often contradictory feelings that bereaved parents can feel particularly in response to the actions of those around them – family, friends and colleagues – who actually mean well. Unfortunately, for a bereaved parent, even with the support and well wishes of others, things do not always get better with time; things can actually get worse. For some bereaved parents, the loss of a child is too much; it is similar to a sore or wound that cannot heal and eats away at a person until nothing is left.

control. And while you do not want your child to be excluded, oftentimes you yourself want to be excluded; you avoid holiday and birthday celebrations, get-togethers, and other events that involve family, friends, and colleagues. They do not understand why you do this; they say they understand, however they do not. They also do not get why you shy away from certain movies, television shows, and songs that were once your favorites. They cannot comprehend why certain pieces of your child's clothing and toys are so precious. Everything that is 'normal' about life, at least to them, no longer applies to you, and as such, people do not know what to do or say, and so often they just stop dealing with you altogether, only compounding the loss.

Family, friends, colleagues, and others will try to console you by saying they know what you are going through. They will tell you they understand because they have lost a parent, a sibling, or a close friend. This is not comforting; rather, it can actually be infuriating and offensive. You know the person saying this is only trying to comfort you, but you want to tell them to go to hell because he/she has no idea what you are going through. Losing a parent is horrible, but it is normal in the sense that parents are supposed to pass before their children. As someone who has lost both of his parents and his child, I can tell you they are not even close. The destruction and fallout from the loss of a child is exponential compared with losing a parent.

For many parents who have lost a child, there are also complex and contradictory feelings of sadness and relief, and this can be especially true for parents of children who had complex medical conditions that included disability, pain, and suffering. You are devastated that your son/daughter is no longer with you, but you are also relieved that he/she is no longer in pain and is no longer suffering. You are also relieved that you yourself no longer have to watch your child suffer, and that now, at least to some extent, your own personal situation will improve. The stress and anxiety of what is happening with your child when you are not with him/her – when you are at work, dealing with your other children, at a doctor's appointment of your own – are no longer there. The constant worry about when the next downturn in his/her health will come and when you will end up in the hospital again is no longer present. These feelings can make you feel like a horrible parent and awful human being.

For many of us there is also an unabating tiredness and exhaustion that never subsides. Maybe it is due to the fact that for some parents this has gone on for years, that is your child's illness. It takes a toll on you – physically, mentally, and emotionally. It is 12 years since Caitlyn passed and I still have not caught my breath. I am still exhausted all the time. Additionally, I aged prematurely due to my experiences. I remember seeing other parents at doctors' offices and specialist clinics when Caitlyn first got sick, and I remember the burned out and exhausted looks on the faces of so many parents, and how every little thing they needed to do seemed so demanding and taxing. I did not get it then, but I do now.

Many of us who lose a child ultimately figure out how to move forward after our child's death, but not all of us. Unfortunately, some of us lose interest in our spouses and marriages, or stop being a parent to our other children. We walk away from jobs and careers. We turn to drugs, alcohol, and other distractions for the temporary escape they provide. Some of us decide not to go on and leave this life altogether. Those of us who choose to continue in this life though can develop a silent longing for death, so that we can hopefully be reunited with our son/daughter.

Sadly, things do not always get better with time; they can actually get worse. For some of us, this is especially noticeable when you hit the point in time when your child has been deceased longer than he/she was alive and on this Earth. The *Diné*, or Navajo, an American Indian nation of the American Southwest, refer to cancer as 'the sore or wound that does not heal,' or '*lhóód doo nádzhíí'* in their language (Csordas, 1989). The loss of a child is also a sore or wound that does not heal. And just like cancer, this loss can eat away at a person until nothing is left. Wounds generally heal with time and care. There are, however, situations where they do not heal, such as when an infection sets in or if the damage is too extreme for healing to occur. I do not know if the loss of a child is akin to an infection or extreme damage; maybe that depends on each individual parent and his/her situation. I continue to live my life and live it as fully as I can, however it is a life that is damaged and will never be fully restored, even under the best circumstances. Mine and my family's lives are divided into two periods: Caitlyn's Life and After Caitlyn's Death.

While all of the above may be true, at least from my experiences as a bereaved parent and now as a researcher who works in the area of pediatric palliative care and hospice care, when people ask me how many children I have, I say three – Demitria, Kylie, and Caitlyn. I spent seven years being Caitlyn's father during her life, and I still have duties and responsibilities to maintain her legacy and memory, even after her death, and I will continue to do so until I join Caitlyn on the other side.

References

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