

What It's Like When Your Baby Has Died

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Saving babies. Supporting families.

Neonatology Today is proud to welcome First Candle as a regular monthly column. First Candle's efforts to support families during their most difficult times and provide new answers to help other families avoid the tragedy of the loss of their baby are without parallel.

My life is divided into two parts - before my son's death and after. Connor was my first child, and he died of Sudden Infant Death Syndrome (SIDS) at 3 months and 24 days. I barely remember the person I was. I do know that I was carefree and naive and at the same time arrogant. Arrogant to believe that unspeakable tragedy could only happen to other people. I credit Connor's death with making me empathetic - for recognizing that everyone has a story and if we open ourselves up to people, we connect through our vulnerabilities.

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The time between his birth and death is also a blur – after all, it was only four short months. I remember the normal first-time mom anxieties of worrying how to hold him to give him his first bath. But I also remember quickly falling into a wonderful routine. His death was like a bomb exploding - it happened so quickly without any warning. What began as a perfectly ordinary day changed in a second with the phone call from the daycare provider who uttered one of only two sentences I remember from that day; “There's a problem with the baby. He's not breathing.” After that, it was the chaos after the explosion, and all that was left was me standing in the rubble of my life.

As the CEO of First Candle, I speak to hundreds of bereaved parents - some within days of their baby's death and others many years later. (1) The new ones always ask me the same question - “When do you start feeling better?” There's never an easy answer to that. Again, it's similar to the bomb analogy. The initial pain and trauma thankfully don't last forever, but there are times when it comes back, such as seeing your friends' babies who are the same age your child would have been. The first birthday after your child has died and the first anniversary of his death is especially painful and instantly take a parent back to that day when life changed forever.

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Researchers now agree that the grief a parent experiences after the loss of a child is a type of PTSD. I was one of the lucky ones - I had the support of my community, family, friends, and co-workers. Others aren't as fortunate. There are parents who, after their baby



has died, must deal with insensitive investigators and state workers and are forced to re-enact the time of death using a baby doll. Families face the reality of having their living children removed from their homes because they are suspected of abuse. Recovering from these experiences takes years and even decades.

For the first year after Connor's death, I wouldn't let anyone take a picture of me. I just couldn't bear to see how sad, old, and tired I looked. Physical ailments are common among bereaved parents. Grief causes our immune system to crash and induces chemical reactions in the body that can last over a long period of time.

- Digestive problems such as loss of appetite or overeating
- Sleepiness and sleeplessness
- Heartache and chest pain
- Forgetfulness and memory loss
- Cognitive changes including general confusion and difficulty concentrating
- Emotional changes including sadness, crying, and prolonged weeping
- Respiratory problems including shortness of breath and asthma
- Panic attacks; i.e., sweating, rapid heartbeat, numbness, and tingling
- Confusion with an associated feeling of loss of control or a feeling of "losing one's mind"

I became pregnant very quickly after Connor died, which was the right decision for our family, but my second son has intellectual disabilities, and to this day, I wonder if it's due to the stress of grief I was experiencing.

As a society, we're not good at dealing with grief, and it can ruin relationships. The rate of divorce is high among parents who have lost a baby. Men and women often express grief in different ways, and it's difficult to understand if a spouse appears not to care or shut down. We often receive calls from men who are afraid to grieve in front of their partner because they feel they need to be "the strong one." Months after my son died, a friend was talking about how exhausting it is to have a toddler. I felt like screaming that I wish I had the chance to be that exhausted and had difficulty getting over what I perceived as an insensitive and thoughtless comment.

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comes at unexpected times – visiting malls and seeing children sitting on Santa's lap, hearing holiday carols, or even watching an especially touching commercial. I was one of the unlucky ones who never had a first holiday with my son. I recall deciding not to celebrate at all; it was just too painful. But at 6P on Christmas Eve, I changed my mind and decided to get a Christmas tree. It was as sad looking as I felt, the ultimate Charlie Brown Christmas tree. It was by no means a festive holiday, but it was a small glimmer of hope.

It's difficult for people to understand the choices a grieving parent makes or their behaviors. They don't make sense to us at times, either. All we know is that at first, we're angry, confused, sad, and numb. There's no timeline for how long these feelings last. Even when we begin emerging from the darkness of our initial grief, holidays and milestones can set us back. What we all need is patience and acceptance for how we choose to deal with our grief.

References:

1. <http://www.firstcandle.org/>

Disclosure: *The author is the Chief Executive Officer of First Candle, Inc., a Connecticut not for profit 501c3 corporation.*

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