

A Mom's Grief from the Loss of Her Baby Is Unique and Profound

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Saving babies. Supporting families.

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.

Prolonged grief disorder (PGD) is common, distressing, and persistent in mothers whose infants have died from Sudden Infant Death Syndrome (SIDS) and have lasting implications for their health and well-being. This comes from a study released in Pediatrics that was conducted by Dr. Rick Goldstein, Program Director, Robert's Program on Sudden Unexpected Death in Pediatrics and Assistant Professor of Pediatrics, Harvard Medical School.

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SIDS is the leading cause of death for babies one month to one year of age and, combined with other sleep-related infant deaths, claims the lives of 3,600 babies every year. Formerly known as Complicated Grief and alternately called Persistent Complex Bereavement Disorder, PGD is distinct from PTSD or depression. It involves persistence of "separation distress," characterized by significant emotional pain and yearning, in addition to cognitive, emotional, and behavioral symptoms, more than six months after a significant loss. It is also associated with diminished health and quality of life for the mother and can affect the lives of living and subsequent children in the family.

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Bereaved parents in the study reported difficulties discussing their experiences of loss and seeking assistance to support the grief, which is further compounded by the stigma of blame that surrounds many SIDS and sleep-related infant deaths.

These findings are important to how pediatricians and bereavement support programs such as First Candle can help address a mother's grief months and even years after a SIDS death. While every bereaved mother grieves differently, many turn to each other to find support from people who know what they are going through. To find somewhere to talk about and share memories of their child. Especially when it seems other people in their lives have stopped asking — a silence that can add to the pain.

Barb Himes, Director of Education and Bereavement for First Candle and a SIDS mom herself, notes that the organization's bereavement support program is a central focus of their mission. "Every day, we receive calls and engage in online conversations with parents who are struggling with grief that is paralyzing. For many, their families, friends, and colleagues simply cannot understand the level of despair they live with for months and even years. Dr. Goldstein's study demonstrates that the grief a mother experiences after the death of her baby is unlike any other."

As Dr. Goldstein notes in his study the painful ‘pangs of grief’ although not a mental disorder per se, are a key feature of pathological grief and the strength and severity of separation distress suggests the importance of attachment bonds between mothers and their deceased babies. This can have an impact on a woman’s bonding experience in a subsequent pregnancy or their parenting of other children.

In the traditional grief cycle, acceptance eventually becomes the major factor; however, with moms experiencing PGD, this is not the case. Participants in the study noted that the emphasis on acceptance fails to recognize their challenges as mothers who are responsible for maintaining memories and the value of their deceased child’s life. They shared the difficulties they face over time as their deceased infant is less remembered or considered, noting that it contributes to their anger and their inability to embrace acceptance.

In recognizing the signs of PGD, pediatricians, and OBs can help parents deal with their grief and support them in their journey.

First Candle is a national non-profit committed to ending SIDS and other sleep-related infant deaths while providing bereavement support services to families who have experienced a loss. Learn more [here](#). (1)

References:

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

Disclosure: The author is the Director of Education and Bereavement Services of First Candle, Inc., a Connecticut not for profit 501c3 corporation.

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