

Coping with Grief and its Triggers, Whether Immediate or Prolonged

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first candle

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.

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For maternal and infant health care providers, this may mean helping parents who have lost an infant and are grappling with confusion, guilt, and grief and wondering if they will ever be happy again or if they should have another child.

The cause of this grief could be immediate, but it could also be in

different levels of the past. In March 2022, the American Psychiatric Association (APA) released the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DMS-5), which now includes an entry for Prolonged Grief Disorder. This may be diagnosed for adults experiencing symptoms of grief for more than a year following the death of a loved one. The symptoms may include emotional distress and difficulties carrying out daily activities.

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In a recent New York Times article (1), author Jill Balosky, who lost a family member to suicide, agreed, declaring that "grief is a forever thing." At First Candle, we have seen that even if parents are able to resume their daily lives, the grief of losing an infant never goes away, even after many years.

Suggested treatments for Prolonged Grief Disorder involve elements of cognitive behavioral therapy (CBT) as well as bereavement support groups. First Candle has found through its bereavement work that support groups can indeed fill a need and that it is helpful to offer different forms of support, enabling individuals to choose which is most comfortable for them:

- **Grief line.** This can offer one-on-one support, access to materials, and local support services where they are available.



Did you know that premature and low birth weight babies have a 4x greater risk for SIDS?

At First Candle we're educating parents, grandparents and caregivers about safer sleep to make sure all babies reach their first birthday. Learn more at firstcandle.org

- **Bereavement library.** Resources on surviving the [sudden death of a baby](#) and guidance on coping with anniversaries, birthdays, holidays, and considerations about having another child.
- **Peer-to-peer online support groups.** A safe and supportive environment for individuals and families to talk about pregnancy and infant loss. The groups provide an empathetic outlet for feelings of grief, anger, anxiety, and depression, with shared personal experiences, emotional comfort, and moral support. There are different groups for Sudden Unexpected Infant Death (SUID), stillbirth, and miscarriage.

The APA also notes that those suffering from Prolonged Grief Disorder may not seek help independently. This can be true whether the loss is recent or not; some individuals may need a healthcare provider's intuitive help in recognizing their emotional situation and in understanding the benefits of accepting help.

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This type of counseling may be challenging for some professionals who may not have training in bereavement support and whose focus has been on saving lives, not death. But some simple approaches can help both the provider and the individual work together. Some may not be needed if the death is not in the moment or recent, and some will still be relevant if the individual is still suffering after some time.

- **Listen.** If the individual wishes, let them talk and then fully listen.
- **Be open and sincere.** “I care and am here for you.” “I am so sorry.”
- **Recognize.** Say the baby's name.
- **Offer keepsakes.** A lock of hair, foot, and handprints, pictures.
- **Avoid clichés.** “It’s God’s will.” “God needed another angel.” “At least you have your other children.”
- **Explain.** Share what may happen next (e.g., if SUID: autopsy, coroner, funeral, etc.)
- **Identify grief support resources.** This could be a local support group, a hospital chaplain, or a First Candle support service.

There are also suggestions that we have found to be helpful, especially during the holidays:

- Sometimes the anticipation around an impending holiday is worse than the day itself turns out to be.
- It is also a helpful idea to have a personal plan that includes:
 - Getting plenty of rest
 - Exercising
 - Making time for yourself or the things you enjoy
 - Being kind to yourself
 - Doing what you are comfortable with and declining invitations you are not

Other elements to consider are:

- Do not be afraid to change traditions or add to existing ones
- Light a candle
- Add a special ornament or decoration in memory of your baby
- Donate a book to a hospital, church, or public library
- Volunteer during the holidays

And, in general, being fully engaged with an individual or with families may help the professional understand in which directions their interactive discussions and support may go. While there may be feelings of guilt, anger, fear, and depression common to all, everyone processes grief differently. Infant death can have an impact on the parents’ relationship, on the immediate and extended family, and also on the health care providers themselves.

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And providers may see a new flare-up of grief when certain triggers, such as holidays, occur.

There is no timetable for the cessation of grief.

References:

1. *Grief Is A Forever Thing, The New York Times.* <https://www.nytimes.com/2022/11/27/opinion/prolonged-grief-suicide.html?searchResultPosition=1>

Disclosure: The author is a Certified Doula, and the Director of Education and Bereavement Services of First Candle, Inc., a Connecticut-based not for profit 501(c)3 corporation.

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About First Candle

First Candle, based in New Canaan, CT, is a 501c (3) committed to eliminating Sudden Infant Death Syndrome and other sleep-related infant deaths while providing bereavement support for families who have suffered a loss. Sudden unexpected infant death (SUID), which includes SIDS and accidental suffocation and strangulation in bed (ASSB), remains the leading cause of death for babies one month to one year of age.

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As we indicated last month, we look forward to a number of new features as well.

1. An online submission portal: Submitting a manuscript online will be easier than before. Rather than submitting by email, we will have a devoted online submission portal that will have the ability to handle any size manuscript and any number of graphics and other support files. We will have an online tracking system that will make it easier to track manuscripts in terms of where they are in the review process.
2. Reviewers will be able to review the manuscript online. This portal will shorten the time from receipt of review to getting feedback to the submitting authors.
3. An archive search will be available for journals older than 2012.
4. A new section called news and views will enable the submission of commentary on publications from other journals or news sources. We anticipate that this will be available as soon as the site completes the beta phase
5. Sponsors will be able to sign up directly on the website and submit content for both the digital and PDF issues of Neonatology Today.

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If there are any questions about the new website, please email Dr. Chou directly at:

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