

Coping with Infant Illness in the NICU During the Holiday Season

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The National Perinatal Association (NPA) is an interdisciplinary organization that strives to be a leading voice for perinatal care in the United States. Our diverse membership is comprised of healthcare providers, parents & caregivers, educators, and service providers, all driven by their desire to give voice to and support babies and families at risk across the country.

Members of the NPA write a regular peer-reviewed column in Neonatology Today.



Educate. Advocate. Integrate.

“From now on, your troubles will be miles away...” sings Frank Sinatra in the classic holiday song; however, this is not the case for many individuals. For some, the winter holidays tend to be associated with elevated rates of anxiety, nostalgia, and particularly perinatal depression (Goyal, 2018)—a reaction has been referred to historically as “the holiday syndrome” (Cattell, 1955). For families with an infant in a neonatal intensive care unit (NICU), the winter holiday season can be particularly difficult. Many parents experience a sense of disillusion, as their anticipated joy is swiftly replaced with long nights by their child’s bedside. Parents may also grieve the loss of expected holiday events and experiences during their first winter holiday season with the newborn. NICU providers have the unique opportunity to assist fami-

lies in anticipating and combating these challenges. This article introduces ways to help families in the NICU cope with during the winter holidays season, and perhaps bring a spark of joyful spirit into their lives.

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No matter the time of year, it can be challenging to face the demands of daily life and simultaneously cope with an infant’s illness and hospitalization. Financially, balancing family responsibilities and the NICU can create difficulties. Time spent traveling and at the hospital means increased expenses for travel, childcare for older siblings, and less availability to work (Treyvaud, 2014). These restraints can create more stress and associated burden for the family. Additionally, spiritual faith may be questioned during times of crisis (Clark, 2003). The winter holidays only compound these challenges.

A normative challenge for families, in general, is the additional expenses associated with the holiday season. This can be exacerbated for families with an infant in the NICU, particularly if the hospital is located at a distance from the family’s home and involves significant travel or necessitates overnight accommodations. In addition to financial and logistical barriers, the holiday

season places more pressure on parents to spend time with extended members of the family. By spending time in the NICU, parents may miss traditional familial gatherings and celebrations. Parents may become overwhelmed, and siblings may find themselves spending much of the holiday season with extended family members or caregivers instead of their immediate family. Notably, a key challenge for families in the NICU is adjusting to a new normal (Doering, Moser & Dracup, 2000). These parents likely envisioned a warm holiday at home with their new infant, surrounded by family. However, the NICU can be a harsh contrast to the comfort of home; the lights, sounds, emergency situations, and multiple machines can be a jarring experience (Carter, Mulder & Darlow, 2007). Providing the quality care families with an infant in the NICU receive, the complexity of these factors must still be considered, particularly during the holidays.

There are several avenues through which providers can help. Financially, families can benefit from assistance with affordable transportation and overnight housing (Dobbins, Bohlig, & Sutphen, 1994). Organizations such as the Ronald McDonald House provide financial support to aid with medical care and transportation, and overnight housing for families in need (“Ronald McDonald House Charities – What We Do,” 2019). Providers should also be knowledgeable about nonprofit organizations dedicated to the provision of assistance during the holidays, specifically to families with a child in the NICU, such as Silvie Bells (“Silvie Bells – About,” 2019). The utilization of these resources could make a significant difference in reducing families’ financial barriers.

There are a number of NICUs that have utilized parent support groups to increase social support and adaptive coping. These groups have been shown to aid parents in navigating their relationships with nursing staff, as well as connecting with other families (Turner, Chur-Hansen, & Winefield, 2015). During the holidays, more emphasis on these groups can be useful, such as

creating specific holiday-themed group topics. Implementation of themed parent activities, such as crafting gifts for their child, can be a great way to provide a distraction and offer a creative outlet. At the Children's Hospital of Philadelphia (CHOP), parent activity groups include decorating onesies or knitting seasonal infant hats. Holiday family photoshoots within the NICU, like the ones held at the Rush Medical Center in Chicago (Rush SpecialKare Keepsakes), can also help to maintain a sense of normalcy (Schwarz, Fatzinger, & Meier, 2004).

Other holiday activities that can be integrated within the NICU for parents and siblings may include pictures with Santa Claus, caroling, gathering candy from Mrs. Claus, snowflake stations, and gift drives available for families to participate in the festivities without the need to leave the hospital. Additionally, providers may consider enlisting volunteer assistance from past graduate families of the NICU. As they have previously experienced the NICU with an infant of their own, these families can provide first-hand support and expertise. These volunteers could also assist with running parent activity groups, infant cuddling, or participating in holiday activities during this difficult time.

It is well-documented that utilizing a family-centered approach to care encourages partnership between families and providers, and improves parent, child, and family outcomes (Griffin, 2006; Harbaugh & Brandon, 2008). With that in mind, it is important to remember that each family experiences the holidays differently. Among those that observe specific religious holidays in the winter season, customs and sentiments can differ vastly. To accommodate this range of experiences within the NICU, there can be an increased focus on creating a welcoming and supportive environment overall.

It is very important to ask families what holidays they celebrate, if any, to get a better grasp of their individual perspective during this season. A non-exhaustive list of common winter holidays includes Christmas, Hanukkah, Kwanzaa, Yule, St. Lucia's Day, St. Nicholas Day, Fiesta of Our Lady of Guadalupe, Three Kings Day, Omisoka, and the Winter Solstice ("December: A Month of Multicultural Holiday Celebrations," 2017). Further, it is important to keep in mind that not all families observe religious holidays in this

season or at any point in the year. Some families may benefit from leaning on their religious practices and spiritual faith, which can become strengthened by the challenging NICU experience (Brelsford & Doheny, 2016). However, it is important always to exercise caution when approaching the subject of religion or spirituality. Keep the focus on each individual family's unique values, practices, and traditions. Additionally, providers should be aware of resources within their medical center dedicated to pastoral care/religious services that families can utilize, if applicable.

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An extended stay in the NICU can be a challenging experience for families, especially during the holidays. Fortunately, there are many ways that NICU providers can help to ease parents' distress, and maintain a sense of holiday cheer in their NICU. As a final note, it is important for providers themselves to practice self-care. Check-in with yourself regularly. Remember to take time to tend to your physical and emotional needs the same way that you would care for your patients, and finally – happy holidays!

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