How Primary Care Providers and Staff Can Support Newly Bereaved People



The death of a child is a life-altering event. Individuals who interact with bereaved parents, siblings, caregivers, and other family members in the aftermath of tragedy have a unique opportunity to provide meaningful support during this crucial time. This fact sheet provides tips for primary care providers (PCP) and staff when connecting with newly bereaved families.



Primary Care Providers Can Make All the Difference

For bereaved parents, the death of a child is associated with a host of poor health outcomes, including cardiac events, immune dysfunction, depressive symptoms, poorer well-being, less purpose in life, more health complications, marital disruption, psychiatric hospitalization, dementia, alcohol use, and premature death from both natural and unnatural causes. These outcomes are not short-lived; one study found that, on average, bereaved parents experienced poor health outcomes for at least 18 years following the death of a child.

Bereaved siblings who experience the death of a brother or sister during adolescence are at heightened risk of premature death. For instance, bereaved sisters are at increased risk of completing fewer years of school, dropping out of high school, becoming pregnant as a teen, not attending college, and having an average reduction in income of 20 percent.

Primary care providers and their teams play a vital role in both the short- and long-term well-being of bereaved families. Universal screenings may identify depression and anxiety, but they fail to capture death as an underlying force or acceleration of poor health outcomes. PCP sensitivity and care in these uncertain times can have a profound impact on how bereaved parents, caregivers, and siblings cope in the short and long term.

Impact of Grief on Cognition and Understanding

Grief, particularly traumatic grief such as the death of a child, significantly affects brain functioning. Newly bereaved individuals are not just sad; their ability to understand, process, and comprehend information is impaired. Oftentimes, parents or caregivers may present as confused or disorganized by not being able to access information as basic as their child's date of birth or middle name.

Practical Tips

- 1. Screen for recent loss. The death of a child places bereaved parents and siblings at risk for many poor health outcomes, including premature death. Although there are no formal screening measures for bereavement, consider asking about recent loss during family history collection or other regular, routine screenings such as depression or alcohol use. Consider asking new and existing patients to list close relationships (spouse/partner, parents, or caregivers, siblings, or others with whom they live), including age and whether living or deceased. If deceased, ask for an approximate date of death. Age of the deceased at time of death and cause may offer insights into the severity of the loss and prompt the provider to consider additional screenings or interventions that could prevent associated poor health outcomes.
- 2. Acknowledge the loss and listen. It is important for bereaved parents and caregivers to be given the time they need to tell you the story of their child's death, should they choose to. Expressing condolences and listening to a family's experience is a vital part of collecting a relevant and complete social history. If this is your first time seeing your patient since their child died, recognize this is not a "usual" appointment and should not be treated as such.

- 3. Say the child's name. Using the child's name in conversation acknowledges the importance of their life. Don't worry about reminding bereaved parents or caregivers of their child; they are thinking about them constantly. Confirm with the family that you are saying the name correctly and ask if there is another name they would prefer you use (i.e., a nickname or other term of endearment).
- **4.** Convey and practice compassion. Listen and be kind. Consider how your questions and responses may be received. For many parents and caregivers, engaging or re-engaging in the medical system can be a painful reminder of their child's death.
- **5.** Adjust your pace. Because grief impacts cognitive functioning, it is important to adjust the pace of your examination, particularly in the early aftermath. Try to keep questions basic and simple; do not ask multiple questions at the same time. Pace your questions and speak slowly.
- 6. Ask about their mood, substance use, and suicidal ideation. A depressed and/or anxious mood is very common in bereaved parents and caregivers and is not cause for alarm. Addressing changes in mood, function, substance use, and any suicidal ideation are critical, but it is also important to note that wanting to be with their deceased child is not the same as wanting to die. The child may have died, but not their desire to parent.
- **7. Ask about other physical or health changes.** It is common for child death to impact weight, eating, or sleep patterns. Ask about these and other physical or medical symptoms that have resulted following the death.
- 8. Honor cultural and religious traditions. Always be responsive to how cultural and religious practices might influence the grieving and mourning process.
- **9. Provide community resources.** Provide written community resources, including mental health providers that specialize in grief, peer support organizations or groups, or substance misuse providers or groups (such as AA or NA).

Other Things to Keep in Mind

There are a variety of ways to offer compassion, dignity, and respect for bereaved parents, caregivers, and families. Here are a few more tips:

- There are no stages of grief. The stages of grief are a common misconception.
- Grief will last a long time. Bereaved parents and caregivers will not be "feeling better" in a few weeks or even in a year. It takes many years to adjust to such profound loss; their lives are forever changed.

Resources

- 988: Free Mental Health Hotline. If you or someone you know is in crisis, call or text 988 to be connected to crisis intervention and suicide prevention resources. Learn more at 988lifeline.org/get-help/.
- Substance Abuse and Mental Health Services Administration (SAMHSA) offers information on coping with bereavement and grief, visit samhsa.gov/communities/coping-bereavement-grief.
- The American Academy of Pediatrics Policy Statement offers information and resources for providers.
 Meaghann S. Weaver, Arwa Nasir, Blyth T. Lord, Amy Starin, Jennifer S. Linebarger, Committee on
 Psychosocial Aspects of Child and Family Health, Section on Hospice and Palliative Medicine; Supporting
 the Family After the Death of a Child or Adolescent. *Pediatrics* December 2023; 152 (6): e2023064426.
 10.1542/peds. 2023-064426.
- Evermore is dedicated to improving the lives of bereaved people. For more information, visit <u>evermore.org</u>.
 To access a national free Grief Support Directory, visit <u>evermore.org/grief-support-directory</u>.



