

# Supporting Transition to the Bereaved Community After the Death of a Child

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Whether a child dies suddenly or after a long battle against a serious illness, the entire family is forced to make an unimaginably painful transition. This new reality may involve an adjustment in one's identity, a loss of community, and an entrance into a new community of bereaved families. Studies show that death of a child can have long-term adverse effects on parental and sibling physical and mental health; indeed, parents and siblings have an increased risk of mortality after such a death.<sup>1-3</sup> Although parental preparedness around end of life is fraught with complexities,<sup>4</sup> the goal of effective bereavement care is to help families heal and process a child's death while making the difficult transition to functioning with their grief and still finding joy in life and relationships.<sup>5</sup> Yet feelings of abandonment persist, suggesting the health care system needs to do a better job supporting families facing this devastating transition.

To better understand the unmet needs of newly bereaved families, Dr Levy (palliative medicine physician), Kristin Drouin (clinical social worker and bereavement counselor), and Dr Sood (psychologist) partnered with Ady Dorsett, a bereaved mother who developed and continues to oversee Hayden's Heart. Hayden's Heart is a well-established nonprofit organization that supports pediatric patients living with and dying from congenital heart disease (CHD) and

their families. Ady previously collaborated with Dr Sood on a qualitative study of the psychosocial needs of families affected by CHD, including bereaved families.<sup>6</sup> She then met with Dr Levy, Kristin Drouin, and Dr Sood to develop suggestions for clinicians on how best to support families anticipating and after the death of a child. The shared vision is one that incorporates Ady's insights based on her family's experience and the wisdom she has accumulated through supporting almost 400 bereaved families, together with the clinician authors' interprofessional experiences working with seriously ill pediatric patients and their families throughout their disease trajectory and after their death.

## HAYDEN'S STORY: ADY DORSETT

Our son Hayden was prenatally diagnosed with Hypoplastic Left Heart Syndrome, a life-limiting CHD. The path we chose for Hayden involved multiple cardiac surgeries. He had his first surgery at age 3 days and his second at age 4 and a half months. After a routine gastrostomy tube placement after his second surgery, Hayden's oxygen plummeted, which required an emergent bedside chest tube. Because of improper chest tube placement, he developed cardiac arrest. After 70 minutes of cardiopulmonary resuscitation and 48 hours of extracorporeal membrane oxygenation, our son was ultimately pronounced brain dead.



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In the days leading up to Hayden's death, we felt uninformed as to whether he would live and unprepared for the truth of what was happening to our family. When we were told the end was very near, we felt blindsided.

In the hours before Hayden's death, our nurse made hand and foot molds and the child-life team brought ink, paint, and other craft materials to make lasting prints. It was not until months or even years after his passing that I learned from other bereaved parents how much more we could have been offered to support our family in Hayden's last moments. It would have been beneficial to our family if a member of the hospital staff (eg, a death doula or bereavement coordinator) was specifically dedicated to support us as we said our final farewells to Hayden and to coordinate bereavement resources after his passing. We should have been informed of possibilities like cutting off a curl in the back of his hair, dressing him one last time, or giving him his final bath. It would have been helpful to have someone provide us with resources that were relevant for our family and maybe even handle awkward encounters in the hospital, including, in our case, a lactation consultant who advised me immediately after Hayden's passing to get bloodwork so I could donate the rest of my milk.

After Hayden's passing in the hospital, we did receive a folder with resources for bereaved families, but these were all local resources and we were not from the local area. Parents who just lost a child are likely in a fog and are not thinking clearly or comprehending much beyond the reality that their child is dead, much less sifting through a folder with therapists' names and phone numbers. Over the next few weeks

after Hayden's passing, we did receive support from his care providers via phone call and e-mail. More can be done, such as creating a bereavement care program that sends timely support to bereaved parents over the course of the first 2 years after their child's passing. Based on my experience working with bereaved parents over the past 8 years, the fog tends to lift somewhere between 6 months and 2 years after the death and supportive materials are likely to be best received at those times.

### **HELPING FAMILIES TRANSITION TO THE GRIEVING COMMUNITY: ADY DORSETT**

Two months after Hayden's death, we established Hayden's Heart, a nonprofit designed to support families affected by CHD. Because of our loss, we are especially passionate about assisting families who have experienced the tragic loss of a child. We host annual events and send financial grants and care packages to families. To assist in their transition to the grieving community, we also send bereaved families on mini getaways and host retreats under our sister nonprofit, Hayden's House of Healing. We have found partnering with hospitals easy when it comes to giving tangible items, such as care packages and funding for programs already in place. However, we continue to find it challenging to share printed resources, including information about our retreats, in hospital bereavement packages because we are not directly affiliated with the hospital.

### **LESSONS FROM OUR COLLEAGUES ON SUPPORTING TRANSITIONS IN MEDICINE: DRS LEVY AND SOOD**

The critical role health care providers play in helping prepare patients and families for significant transitions is well established in the literature, particularly for children with special health care needs. It has taken decades of research and

advocacy to design consensus guidelines for standard practices and to ensure financial support at a systems level for children with special health care needs and their families as they transition from pediatric to adult care.<sup>7</sup> Experts underscore the process of facilitating the transition of patients with chronic complex conditions from pediatric to adult care is "more than a transfer of care." It needs to begin early by anticipating future needs before the point of transfer while reassuring families there will be no interruptions in care. It means providing family-centered, comprehensive, and coordinated care, anticipatory guidance, and effective support systems.<sup>7</sup>

Other transition points for children with special health care needs and their families (eg, transition from prenatal to postnatal care, from hospital to home, or from home to a facility) have also been the focus of research and advocacy, with standard practices and designated professionals (eg, perinatal coordinators and discharge coordinators). Multiple professional medical organizations have agreed on consensus guidelines that assert "health care transitions are most successful when there is a designated professional, who, together with the patient and family, takes responsibility for the process."<sup>8</sup> Why not learn from our colleagues and adopt some of their philosophies and practices to support families in making one of the most devastating transitions a family can make: from caring for a child living with serious illness to grieving the loss of that same child?

**CLINICIAN AND RESEARCHER PERSPECTIVE: DISPARITIES IN BEREAVEMENT SUPPORT: DR LEVY, KRISTIN DROUIN, AND DR SOOD**

Despite the clear need, there remains no clear standardized practice on when and how to best support bereaved families.<sup>9,10</sup> Even more, the efficacy of specific bereavement interventions, such as camps, workshops, seminars, support groups, and online resources, remain relatively unknown.<sup>9,11</sup> And thus without standardization or an evidenced-based approach, practice variability remains a reality. That is, bereavement interventions may be offered but not consistently and not everywhere. It is precisely this variability in support that increases the risk of health care disparities among bereaved families during such a critical and vulnerable transition in their lives.

Our qualitative research on the psychosocial needs of families impacted by CHD highlights feelings of abandonment among bereaved parents and a lack of support for this unimaginable transition. Of 9 bereaved parents who participated as part of a larger caregiver sample,<sup>5</sup> 5 noted feelings of abandonment by the medical team and/or support system. One parent stated the following:

*To be honest, as great as our hospital and team were through our heart journey, we felt very alone after she died. There was very little in terms of support for us and our other daughter. We no longer "belonged" in the heart community. I'd like to see real support for families who have lost their battle congenital heart disease.*

Another parent noted the following:

*While the hospital had a bereavement person reach out to us, I wish the cardiac team could have reached out. It was just so abrupt to be intimately cared for while in hospital and then be sent home with nothing. I don't know if*

*meeting with anyone would've helped us process, move through our grief any better, but I just remember feeling abandoned and angry. I never really understood how the events that led to death transpired and everything seemed OK until it wasn't.*

Although the total number of bereaved parents in the sample was relatively small, their children received care across 8 US hospitals, suggesting feelings of abandonment and insufficient support may reflect the lived experiences of bereaved caregivers across care settings.

**CLINICIAN PERSPECTIVE: DR LEVY**

As a pediatric palliative care physician, I am often in the position of partnering with primary medical providers and subspecialists to care for patients at end of life. Over the course of almost 10 years, I have witnessed clinicians struggle with how best to support families once the goals have shifted toward a comfort-directed care plan (ie, home with hospice) or after a child's death. In either scenario, the primary provider's role in the child's care has shifted dramatically. The prescribers are no longer prescribing. Sometimes, there is a clear delegation of bereavement support to other team members, including hospice or social work. And other times, particularly without hospice, there is not. But where does that leave the primary provider embedded in any given family's support system? How do we gracefully say goodbye without abandoning our bereaved families? Although my experience is certainly not generalizable, I wonder if this is a symptom of a larger pattern: a need for a shift in perspective and a need for a more standardized approach to bereavement support. Providers need to recognize they still have something to offer, even after a child's death, when the

prescription pad is no longer helpful but compassion still is.

**JOINT VISION: DR LEVY, ADY DORSETT, KRISTIN DROUIN, AND DR SOOD**

It is unacceptable that such disparities in bereavement support exists and that parents still echo sentiments of abandonment. We can do a better job. We need to take the lessons learned from our colleagues who have worked diligently to advocate for standardizing the practice of transitioning children with special health care needs to adult care. A practice that prioritizes improved access, anticipatory guidance, care coordination, and resources. The same philosophy can be applied to the pediatric patients and families living with life-limiting illnesses facing a short life expectancy. These families need, and deserve, continued support to avoid short- or long-term adverse health outcomes because they are facing the death of a child. We know resources exist. Health care systems should strive to provide a uniform package that streamlines resources and connects all interested families to the appropriate resources early and routinely (Table 1).

**CONCLUSIONS**

Although there are limits to what medicine can offer to prolong the life of a child with a serious illness, there is so much more we can do to ensure optimal bereavement support to families facing the seemingly impossible transition to life after the death of a child. Psychosocial clinicians, such as social workers, counselors, child-life specialists, clergy, psychologists, or psychiatrists, trained in grief support can help caregivers and siblings navigate changes in individual identity, sense of purpose, roles and responsibilities, and overall well-being. Through advocacy, research, and care

**TABLE 1** Suggestions for Grief and Bereavement Support by Phase of Illness

Phase of Illness	Support
At the time of diagnosis	Provide anticipatory guidance about disease course and prognosis Complete a psychosocial assessment, including history of grief and loss, to determine a plan for supporting entire family
During periods of decline	Confirm goals of care align with medical plan Offer psychosocial and spiritual support Provide honest and clear information regarding the child's current medical status and prognosis
Perideath	Introduce designated professional to oversee transition to bereavement support (if someone has not been previously identified) Discuss location of death (if there is >1 option available) Offer memory-making activities <sup>a</sup> Offer ability to create comforting atmosphere with preferred music, scent, and lighting Offer to facilitate access to spiritual support Invite additional family members Allow parents to lay in bed with and/or hold child Offer assistance with funeral arrangements
Bereavement	Offer participation in bathing and dressing child (post mortem) Check in with the family throughout the first 90 days Continue outreach at regular intervals throughout the first 2 years Bereavement counseling offered for 13 months Provide family with information about local and online resources Offer funding to support attendance at bereavement retreats and camps

<sup>a</sup> Memory-making activities may include handprints, fingerprint impressions, molds, photographs, lock of hair, and a heartbeat recording. Activities may be supported by philanthropy and other alternative sources of funding.

coordination, institutions will hopefully standardize the devastating transition a family must make after the death of a child. Standardizing bereavement support can ensure all families have access to the same resources, without interruption, to mitigate feelings of abandonment through the full realization of family-centered care.

#### ABBREVIATION

CHD: congenital heart disease

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