

# GRIEF AND BEREAVEMENT SUPPORT

## In One-Person Child Life Programs

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Grief and bereavement support can vary between settings. With one-person child life programs, support can be much more challenging. Below are two interviews that were conducted with two child life specialists. Each child life specialist works in a one-person hospital setting in different units. Both participants provided information about their hospitals and grief and bereavement support programs. Questions were tailored for the settings as well.

**Jessica Lohre, MS, CCLS, Certified Child Life Specialist, Intensive Care Nursery, Thomas Jefferson University Hospital**

**Sarah Somers, MS, CCLS, CPST, Certified Child Life Specialist, Lutheran Children's Hospital**

**Q: Tell us about yourself and your role.**

Sarah: I have been at Lutheran Children's Hospital in Fort Wayne, Indiana for the last 10 years. We are a children's hospital within an adult hospital. I cover inpatient, outpatient clinics, our ER, radiology, surgery and NICU.

Jessica: I'm a one-person program in a hospital that doesn't have a dedicated pediatrics unit, just an intensive care nursery, which is where I "live" so to speak. So, my home base is the ICN, but with frequent consults throughout the hospital to work with children of adult patients or the occasional pediatric patient in the ED prior to their transfer.

**Q: What is it like to provide grief support in a one-person program or with limited resources?**

Sarah: It can be difficult, and obviously the emotional side of being a one-person program can be difficult. You can't just "tap out" if you need a break or if you need somebody else to pick up that weight. I am lucky enough that our spiritual

care department works very closely with us and my nursing staff as well in some areas where I'm more prevalent. In the ER, it can be more difficult if they don't know me. It can be a lonely process and emotionally lonely as well.

As far as resources, I try to do the best I can with what I have and try to come up with different alternatives. We used to have Music Therapy, and so they would do the heartbeat recordings with the stethoscope. That resource has gone away because we don't have the technology. We've found other ways like using the doppler and things like that to be able to still give that to a family, which I think is really beneficial. Your standard handprints, footprints, things like that, we're still very much able to do and it's actually a good thing. We have a program that follows our families two years after the death of their child that I pretty much do as well.

Jessica: I'm lucky in that I'm able to order (within reason) most physical resources that I need; however, I'm limited in resources in the sense that there's no other child life specialist who is experienced in obtaining things like prints and molds and can be a second set of hands. Luckily in most cases, bedside nurses are willing to help, but then it's a lot of talking them through what's needed, which adds a layer to things, especially when trying to simultaneously provide emotional support if there's family in the room. Not necessarily a bad thing since I can always ask for

the nurses' help, but I do recall from my previous positions how nice it was to have a second set of "child life" hands for things like bereavements that require so much extra care and support. There's also the emotional toll of having limited coworkers who "get it", so when these tough cases arise, I feel limited in who I can lean on for support and to debrief with. Since I don't have a home base on these adult floors, there's limited opportunity to build a good relationship with the staff, with such frequent changeover and various consulting units.

**Q: What kinds of activities do you offer when there is family beyond the parents and caregivers involved (siblings, other children, other adults) at the hospital at the time of death?**

Jessica: I have the flexibility to order most supplies I'd like, as long as I can justify it. I do, however, have very limited storage, basically a drawer in my office if I'm being honest. Child life problems, right?. So, I stick with easy to store things like small playdoh cups, coloring printouts, crayons, fidgets, and an iPad. I keep those on hand for diversionary items, especially for if tough conversations are happening with me and/or with the team, or just a lot of "waiting around". I have a solid supply of children's books about death, dying, and grief that I'll send families home with "for later," since often times, the parent/caregiver/relative is going through their own raw emotions and reactions during these times. If memory making is desired and if I assess it to be appropriate, I invite the child(ren) of the patient who has died or is dying to take part in creating the prints and molds. I've seen this as a really therapeutic way for the children to be involved and around 90% of the time, children are very much willing to take part.

Sarah: It can be tough, but I think a lot of times it's just trying to engage them whatever way they want to be engaged, whether it be by going to the room, standing at the doorway. It's definitely taking that role of advocate, especially when we have those other caregivers or family members maybe don't want those younger people involved. Why don't we ask them and talk to them and see what their choice is in this? I think, a lot of times it



takes on more of the role of advocate and trying to help facilitate the conversation about their loved one who has died.

**Q: What kind of support, if any, do you provide staff and vice versa? What do you think is missing?**

Jessica: In terms of physical support, I try to be as helpful as possible without overstepping. The nurses I work with on the ICN can be a tad territorial of their assigned babies and families, but the more they see that I will often take my lead from them and that I work hard to honor and respect families' wishes, the better rapport and trust I have with the nurses. This also opens up a lot of opportunities for education so that over time, I've built enough trust to not always have to "take their lead" so to speak. This has been slow but steady growth in the year I've been here but lately I can tell more and more that we've been making great strides. I try to be a listening ear for staff as much as possible. Most of the nurses just like to have someone outside of nursing to complain to, anything from shift/staffing related to difficulties with families. I try my best to educate and validate simultaneously. During more difficult cases involving bereavements, I notice the nurses very much lean on each other for support which I love, but again, tough as a one person to find my groove here. I have a few nurses who I've been able to debrief with, as well as the social workers, so it's just been a matter of finding these alternative avenues when I've been used to having a child life team in the past. In terms of what's missing, I know the hospital has a peer support network for tough situations and losses but I'm not too familiar with it and I think it's mainly targeted to nurses and physicians. On the ICN specifically, I know our social workers are spread quite thin so I'd love if our unit had some sort of therapist/counselor dedicated to working with the parents in a purely therapeutic way. There's so many people on the ICN team who are all dedicated solely to the parent's baby/babies, that I worry they lack support that's just for them. I do the best I can within my own scope of practice and training, but I would love if we had someone who could provide

mental health support to these moms, dads, and guardians.

Sarah: I think it's interesting the way that our hospital is in that it is a teaching hospital. So we have nursing students, physician students, chaplain residents. We always have a lot of people getting an education within the building. I think, a lot of times, with our staff and the rotations, it makes it really hard to build a relationship with residents. So now, over the last few years, we have a staff chaplain. He has been super beneficial in trying to help us, but again, I think it's really hard to expect the people who have seen the trauma and done the work to then be the one to lead the debrief or lead the support of the other staff members. We try and there's always room for improvement, but I remember, early in my career, my manager told me it was my responsibility to be the cheerleader for the staff. I was like, where's my cheerleader? So, I think that expectation is put on a lot of specialists now especially with numbers decreasing and programs getting smaller. It's hard because that leaves us without any support, so, what do we do and how do we make that work?

