

How To Comfort a Grieving Child With Special Needs

Kids with disabilities may not have the language for their feelings of loss

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Published **January 2019** DFWThrive

Updated **January 30, 2019**



Boxes of tissues are conspicuously at hand throughout LightHouse for New Hope. It's a dated, unassuming building in Mesquite that's easy to miss while navigating the construction cones on Motley Drive. Inside, however, LightHouse is an ocean away from all the street traffic. The reception area is warm and inviting, and the children's rooms feature bright seaside murals and age-appropriate supplies like puppets and books and art materials. There is even a kitchenette and dining area where families can share a meal.

Still, nothing about LightHouse feels maudlin; it's simply a place where people of all ages gather to talk about loss—where they can openly express their feelings of grief and take comfort in the fact that as isolating as grief can be, they are not alone.

“After a loss, every person has the same needs in going through the grief process,” says president and founder Nancy Bollman, who guides me through the meeting rooms. “Everyone needs an active way to share and to heal.”

Children are grouped by age, but there is no hard signage to indicate that the brightly painted Sandcastle Room, for example, is designated for ages 5–8. The lack of labels is one way the center accommodates children with special needs and intellectual disabilities—with no rigid age divisions, children with an adjusted age can better integrate into a group of peers they can connect with.

“We had a young woman with us who was 24 years old,” Bollman explains, “but her intellectual age was 10, 11 years old. So we had her join the Sailboat Room, and she did very well with that group.”

Most of the children who pass through the center are considered typical, but over the years, the center has helped children with a range of abilities cope with a significant loss in their lives. Bollman says they've supported children and teens with attention deficit disorder, Down syndrome, intellectual disabilities and higher-functioning autism. She tells me about a child with Asperger's syndrome who came through the center: “He said, ‘When I felt my sister after she died, she was cold. Why was she cold?’ He wanted to understand the process.”

HEALING, NOT SHIELDING

As many of the experts consulted for this article point out, grief is not a linear process that everyone experiences in the same way, or even in the separate, distinct stages we often hear about. There is no single timeline for grief, and there is no standard progression from point A (loss) to point B (acceptance).

Furthermore, grief is not exclusive to the death of a loved one—especially for a child. Divorce, separation from a parent, abandonment and trauma are all forms of loss. Kids with special needs may feel grief when confronted with the ways they are different from their peers or activities they can't participate in.

“Grief is the loss of what we thought our life would be like,” explains Anastasia Taylor, a licensed clinical social worker with Alliance Child and Family Solutions in Fort Worth who has five children, two on the autism spectrum.

There are notable differences in how adults and children experience grief, in part because kids' and teens' brains are “not fully developed,” says Taylor. They are more likely than adults to experience what are often described as “grief bursts”—sudden, overpowering and very intense waves of emotion that might seem to come out of nowhere. Because children and teens are still in their formative years, they are in the process of forming their sense of personal identity. They have so many milestones, big and small, to reach before adulthood. Grief, however, can completely alter that interior landscape. “Milestones can bring up grief,” Taylor explains. “For example, if there is a divorce or a parent who dies, the grief which results from this loss will come up at key milestones in their lives”—like holidays, birthdays or the first day of school. There is no way to predict when these grief bursts might occur, or what even what shape they might take.

Children with special needs may feel the loss like their typical siblings and peers, Taylor says, “but it's harder because these kids may not immediately link to what is going on.”

Some children might be in the process of learning how to identify and communicate their emotions; others might be relying on therapeutic routines to manage their symptoms of anxiety. For all these kids, a significant loss can turn their whole world upside down.

Grief can undermine that child's sense of security and belonging—and they might not have the right language to describe it. That's why helping children build a grief vocabulary is such a critical component of programs like those offered at LightHouse for New Hope.

During a time of loss, it is natural for adults with the best of intentions to want to protect their kids from the full weight of this experience. But withholding information or minimizing a child's concerns can actually backfire and make a child feel isolated in their grief or make their feelings of anxiety even worse.

“If you shield them, you do them a disservice,” says Plano resident Jeanmarie Beno, 55. “The older they get, they'll eventually experience a death.”

Sidebar

GRIEF GUIDE

Grief resources specific to children with special needs are hard to find; however, many grief centers are able to accommodate children of varying abilities on a case-by-case basis. They are

also able to refer out for more specialized counseling. The best thing to do is to call and ask if the program would be a good fit for your child.

[CHRISTIANWORKS](#)

5440 Harvest Hill Road, Suite 140, Dallas
2214 Hemphill St., Fort Worth, 800/375-2229

[GRIEF & LOSS CENTER OF NORTH TEXAS](#)

4316 Abrams Road, Dallas, 214/452-3105

[JOURNEY OF HOPE GRIEF SUPPORT CENTER](#)

3900 W. 15th St., Suite 306, Plano, 972/964-1600

[LIGHTHOUSE FOR NEW HOPE](#)

2717 Motley Drive, Mesquite, 972/226-3110

Her son Joseph is on the higher-functioning end of the autism spectrum. He was 9 years old when he lost his paternal grandmother and 11 years old when he lost his maternal grandmother. Beno says the loss of both grandmothers made a lasting impression on him. “The No. 1 thing that helped him was his faith,” says Beno, adding, “but we didn’t shield him from anything, and he got through it like a champ.”

For Beno, it was really important that Joseph was included in the grieving process. The family talked about death, and Joseph fully participated in the funerals.

Because that’s how grief works: Everyone who experiences a loss needs the chance to grieve and fully participate in bereavement rituals, to the extent that they can, with the compassionate support of the people who love them.

FINDING THE WORDS

At the outset of a significant loss, the most important thing a parent or caregiver can do is “use short, direct, concrete, informative language,” says Taylor. “It is a must.”

Abstract or metaphorical language can be very confusing to a child. Saying that someone “passed away” or “left us” or “went to heaven” comes from a place of kindness, but these common expressions are hard to comprehend for children with learning disabilities or those who have concrete thinking patterns, as kids on the autism spectrum often do.

Metaphorical language also does not fully convey the significance of a loss. For example, suggesting that someone “left us” inadvertently implies that the loss is only temporary, and therefore delays the acceptance of that loss and compounds the experience of grief. “Explain ‘being dead’ and anchor it in language,” advises Kerri Newman, a licensed marriage and family

therapist and the program director at the Journey of Hope Grief Support Center in Plano. “Be open, honest, clear and concise.”

The trick is not to overwhelm a child with lots of information all at once, but offer the important points and give them the opportunity to ask questions. “Pause, and let the child process what you’re saying,” Newman says. “Encourage them to ask questions and be curious. Encourage lots of conversations.” You might not have all the answers, or even the right words to explain what is happening, she adds, but “[you] can say, ‘I don’t have that answer for you, but I’ll find out for you.’”

Parents should also begin the conversation by emphasizing that their child’s basic needs will still be met. A loss can pose a significant disruption to a child’s daily routines, and maintaining these routines is especially important for kids with special needs. “Routines lend themselves to feelings of safety,” Newman explains, so it is absolutely imperative that adults reassure children of those things that will stay the same.

Still, Newman cautions parents to often “expect things to get worse before they get better.” Taylor says caregivers might see outsize emotional outbursts, like “outbursts of laughter at inappropriate moments”—these outbursts function as an emotional release valve.

There might also be developmental delays or behavioral regressions as the symptoms a child was learning how to manage in therapy prior to the loss may be compounded by their grief.

As we walk through the Sandcastle Room at LightHouse for New Hope, Bollman tells me about an 11-year-old girl with an intellectual disability who was struggling with polyphagia—no matter how much she ate, she always felt hungry. Bollman says the girl’s insatiable hunger was already present before her experience of loss, but afterward it became dangerously exacerbated—and very alarming to her caregivers—as she tried to also process the emotions of grief.

“It was a very sad situation,” Bollman says, but in the Sandcastle Room she was able to work through her grief with the support of peers.

GRIEF, INCLUSIVELY

All children should be included in the grief process in developmentally appropriate ways. That might mean attending the funeral service and sitting by a trusted adult, sharing a few words or a poem at the memorial service, or arranging cherished photographs and mementos at the wake. Children need to be full participants in this process (as much as possible) because it helps them come to terms with a change or a loss. It gives them a very concrete chance to say goodbye and to receive support from their loved ones.

When one of Taylor’s sons was 11, an aunt who was very involved in his life died. Taylor gave him the option to attend the funeral. He did, and a few weeks later, when the family was sharing memories about the aunt, he said, “Hey, remember the family reunion?”

Taylor says she was confused at first by what he was asking, before realizing that he was talking about the funeral, and all the family members who had joined them at the service. Being surrounded by so many loved ones brought him comfort. “He feels her loss at times,” says Taylor, “but we find activities that are appropriate to him to help him express his grief. He misses her, but it also makes him very happy to think about family reunions.”

Making the grieving process inclusive isn’t limited to funerals either. “It is important to keep talking about [the loss], and really encourage as much inclusion as possible,” says Newman. Finding ways to memorialize a loved one by sharing memories also plays an important role in grieving—like helping the child make a memory box with pictures and meaningful objects.

The Beno family remembers their grandmothers through stories and photographs. Beno describes the walls of their home as “filled with family pictures.”

“It is very important to keep the loved one’s memory alive, to share stories about them, to talk about them,” Beno says.

Her son Joseph, now 22, lives at home. As I talk to the family, Beno encourages him to share a few words about his grandmothers. Although put on the spot, he still has very clear memories of the time they spent together. “We would have vacations in New England,” he says, “and my dad’s mother would come over to the house [from Florida] for five days.”

The loss of both grandparents, one happening right before Christmas, was hard, Beno says. “But we got through it,” she adds. “As a family.”

In the Beach House Room at LightHouse for New Hope, there is a sturdy, canvas backpack stuffed with a bunch of beanbags—52, to be exact. Bollman calls this the “bag of grief.” Each beanbag is labeled with a unique grief reaction like “anger” or “isolation” or “guilt.”

Carrying all the beanbags can be cumbersome to the teens who meet in this room, but there are always a few who will still say they can do it. So, Bollman explains, the facilitators will say to the teens, “OK, but this is the bag of grief. You can’t take it off. You wear it everywhere you go—when you take a shower, when you go to bed, when you go to school.”

The message of the exercise is clear: The experience of grief is a jumble of emotions and reactions. Altogether, it is a huge load for a single person to carry. But kids at LightHouse for New Hope learn they don’t have to do it alone. And by helping each child find the right words for their experience—“sadness” or “confusion” or even “silliness”—eventually children and caretakers alike are able to unpack the considerable weight, one beanbag at a time.

CARING FOR YOU

What makes caring for a grieving child so challenging is that parents may be experiencing grief as well. But because they are also focusing on their child’s well-being and trying to maintain a sense of order, they will sometimes push their own grief to the side.

According to Kerri Newman, a licensed marriage and family therapist and the program director at the Journey of Hope Grief Support Center in Plano, it's not uncommon to see "a delayed grief response" in caregivers. Once the initial shock of a loss wears off and the family begins to settle into day-to-day rhythms, grief can suddenly hit a parent hard.

That is why it is so important for parents to seek out support whenever they can, which might mean a couple of sessions with a counselor, a grief support group or even just a little bit of time off. According to Anastasia Taylor, a licensed clinical social worker with Alliance Child and Family Solutions in Fort Worth, parents "need to have a break so they can be more effective in providing for their child's needs." She encourages parents to look for events that can give them that break—for example, some churches and other organizations sponsor respite nights.