HARVARD CHILD BEREAVEMENT STUDY



A Child's Grief

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"Anyone old enough to love is old enough to grieve."—Dr. Alan Wolfelt



"When someone you love dies, you have two choices: suffocate in sorrow, or honor that life. Right after my dad died, it was our family pact—my mom, my brothers, and me—that together we were going to honor my dad's life. And that's how it's been. Every day I wake up and make sure to remember." Austin, now 17 and a senior in high school, was 15 when his father died.

He recalls going back to school a week after his father died. Most people, aside from a few close friends, didn't mention the death, or acknowledge it. "I guess they thought it would upset me," he told me on a recent school night, a stack of high-school textbooks and his laptop spread out on the family dining room table, turning it into a makeshift study area. "Sometimes I'd wished people would say—even now—'how are you doing?' because it doesn't just go away. You just

get better at dealing with it," he said, readjusting his chair, a container of Swedish Fish between us.

Later, Austin's mom told me, "My kids will be on this grief journey for a long time, there's no map; that's the tricky part."

One in nine Americans lose a parent before they turn 20, while one in seven lose either a parent or sibling. Nine out of ten children experience the death of a family member or friend by the time they complete high school.

According to the National Alliance for Grieving Children, a network providing resources and materials to educate and promote awareness of the needs of children grieving, "It can be challenging for parents to know what to do, what to say, and how to help children who are grieving." But, there are ways to help a grieving child, and resources to help families. The concept of involving children in the grieving process rather than sheltering them from or whispering about a

deceased loved one helps to acknowledge their grief, and permits them the opportunity to mourn the loss. "Grief is not a problem we are trying to fix for a child. It is an experience they are living."

What is Grief?

When someone close to a child dies—a family member, a friend, or another significant person—in addition to being a lifelong loss, the child also experiences grief. This grief is the child's internal response to loss, the feelings and thoughts on the inside—anger, sadness, anxiety, fear. It can affect sleeping and eating habits, and how a child performs or acts in school. Or with friends. It can raise scary, uncertain thoughts like "Who's going to take care to me?" "What if something happens to someone else I love?" "Will something bad happen to me, too?"

Children who have lost a loved one are more at risk than their non-bereaved counterparts for depression, anxiety, increased illness, and accidents. Educators, researchers, and counselors agree that providing support services for grieving children is necessary to address these risk factors, to decrease the risk of isolation, and to allow kids to express themselves and share with others, in their own time and own ways.

Grief doesn't have an expiration date; it's not a carton of eggs or a quart of milk. As Phyllis R. Silverman, a principal investigator on the 1996 Harvard Child Bereavement Study—the gold standard for how kids grieve—said, "grief doesn't end at a particular time." Contrary to a society that tends to say you need to "move on" grief is not something kids just "get over." While kids are resilient, they aren't resilient enough that they will be "fine" just because they're kids.

How to Help Kids Grieve

"Grief is not linear. It's not predictable," says author and essayist Hope Edelman. Edelman was 17 when her mother died at the age of 42 from breast cancer. At the time, there was no hospice in her community, no grieving centers or support systems to provide comfort or resources. In her acclaimed *New York Times* bestseller *Motherless Daughters*, Edelman notes, "[Thirty] years ago...grief had to follow a set, predictable series of stages or it was progressing incorrectly. Mourning was (and sometimes still is) treated as something that has to be overcome, not as a life-long process of accommodation and acceptance." But children no longer have to be "forgotten grievers." In addition to the rise of hospice care, there now are bereavement camps for children, websites for support, and resources. And there are over 500 centers that provide children grief support and services worldwide. "If there are no grief centers near you," Edelman notes, "or you don't have access to local support systems or programs, there are ongoing discussions on Facebook, and on the Internet. And if you don't have a laptop, you can always go to the library."

In an effort to stop perpetuating our culture's appreciation for confusing euphemisms like "Grandma went to sleep" or "Mom passed away," Edelman emphasizes the need to use real language, to be truthful, and "educate parents about why it's important for our kids to talk about death."

Grief & Loss Centers

After Austin's father died, he exhibited anxiety and panic, he couldn't sleep at night, his body simulating heart attack symptoms. "A lot of people don't understand the health piece of grief," Austin told me. "The fear if it's happened to my father, it could happen to me. The anxiety that my mom was the only parent, that if something were to happen to her, who would take care of my brothers and me." So Austin's mother brought him to a support group. She wanted him around kids who were experiencing the same thing—loss of a loved one—because children "feel very alone in their loss, and the people in their lives might want to be supportive but can't."

"Every Thursday night my mom would drive my little brother and me to 'a place' in a preschool. We'd sit in uncomfortable metal chairs I didn't even fit into and say things like, 'Hi my name is Austin, and my dad died.' I thought, there has to be something better than this, more helpful for kids like me."

Support systems for grieving children have come a long way, with grief and loss centers around the country focusing on creating comfortable, inviting environments for its participating families.

Olivia's House

Olivia's House, a grief and loss center providing bereavement services and programs for children and their families, sits among a row of brick houses, a welcoming colorful garden in front, and a pathway leading to the backyard lined with memorial bricks. Warm, soothing colors give the interior a cozy, peaceful feel, many walls covered with murals of trees and other nature-like images. Its lending library is open to the public, and family-oriented rooms are filled with overstuffed couches and beanbag chairs, mirroring the comforts of home.

Melissa Pilat was 9 years old when her father died, 10 when her mother died, and 11 when her grandfather died. After her father's death, her mother brought her and her older sister, Megan, for support, to Olivia's House in York, Pennsylvania. Only a year later, the girls would again need Olivia House's support and services, to cope with their mother's sudden death. "I didn't really want to come to Olivia's House and neither did my sister," said Pilat, who went on to intern at the center. "I didn't want to talk about it. But here, I learned you can't just forget about people you loved; remembering them is how you keep them alive." Talking about and remembering the person who died is part of a child's healing process. Olivia's House provides activities such as collage and quilt making, and opportunities for the children to bring in loved ones' personal momentos to share with their group. "We have seen varsity jackets, fishing rods, bowling trophies, pictures, and much more ... we even had two children over the years bring the cremation urn into the group. Kids don't have hang ups that adults have about sharing," says Leslie Delp, Founder and Bereavement Specialist at Olivia's House.

According to a recent Harvard Business School study, rituals can also help alleviate grief. "As human beings, we may feel out of control when losing a loved one.... Mourning rituals ... give us back a sense of control. And feeling in control is one of humans' basic desires and needs." Rituals such as lighting candles or listening to a particular song or type of music can help children. The ritual of writing to a loved one on a special day—on their birthday, on the child's birthday, on a holiday—is a strong coping strategy as well. "Children can burn the letter, keep the letter, journal the entry, tie the note to a balloon and release it ... talking about their loved one becomes easier the more they do it; however, children will only talk about their loved ones with people they feel safe with," Delp shared with me.

"At Olivia's House, I learned different ways to cope and express my feelings," said Pilat, noting it was "nice knowing there were other kids going through the same experiences," and crediting Olivia's House as a place she can still turn to, nine and ten years after going through the program.

"It's an incredible role taking a child from victim to victor," says Delp, speaking of Olivia House's eight-week program. "A child's brain shuts down after the loss of a loved one and there's a period of numbness. About 6–12 months after the death, the brain reboots and the feelings of loss come to the surface. That's when the parents typically reach out to the grief center." (Olivia's House has graduated 1,400 families over the last 12 years. All have successfully completed the program.)

Week seven of the program includes a "children only" field trip to the local funeral home, where the funeral director answers any and all questions the group might have. Children go inside the hearse, in the casket-selection room, and they learn about the cremation process. Sometimes it raises stories about their own loss, explains Delp. The kids might talk openly about the casket picked for their mother or family member, or specifically about the memorial service. "When you make it normal, it takes away fears for the next funeral they go to."

Being honest with a child and encouraging questions sends the message there's no right or wrong way to grieve, and creates a more trusting and open atmosphere of expression. "All children really want and need is for the family to slow down, and be present to listen and share stories." But sometimes it's hard to talk to children, especially about painful issues like loss and death. At Olivia's House, the belief is to always put a book in the hands of child and parent, from its extensive lending library of 1,300-plus books on the subject of grief. Fixing a child is often a parent's goal, especially a bereaved parent, but "children do not need to be fixed; they need to be supported." It takes time to heal, and children shouldn't be rushed through the grieving process.

"Grieving is everything you feel on the inside but when you let people see—anger, crying, a tattoo that is mourning. We want people to mourn," says Delp.

The Dougy Center

"Grief is an important part of loss and there's no formula for it," says Donna Schuurman, executive director of The Dougy Center, a grief and loss center in Portland, Oregon, providing open-ended peer support groups for grieving children and families. According to Schuurman, the average stay in the program is 15 months, which allows families to go through the first year marker dates—Mother's Day/Father's Day, end-of-year holidays, graduations, birthdays, and face and answer questions like: How do we celebrate Thanksgiving? Mom used to make the turkey.

Schuurman notes that people are staying longer in the program than they used to, because they aren't getting the help they need elsewhere. If a ten-year-old's mother dies, she explained, other people don't understand that child's life has changed forever—how the child will navigate, how other people will treat that child. People aren't prone to mention the deceased parent, as if they've never existed; people are used to imposing what they're feeling.

Schuurman was in her 40s when her father died. Many people sent sympathy cards with an "I'm sorry" sentiment, but what she really wanted, she told me, was for people to ask, "what was your father like?"

"I wanted to talk about him," Schuurman says.

What the Dougy Center serves, what it offers to its families, directly responds to risks factors, like a child's feeling of powerlessness. Could I have prevented the death? Could I have caused it? One of the ways the Dougy Center embodies these risk factors (which may include depression, anxiety, increased illness, less optimism for the future) into their program, is with a predictable structure—1½-hour groups every other week (with a week in between for processing time). "We don't view grief as a pathological condition or something to rush through or get over. Rather, grief is a normal response to loss, and since our society in general does a poor job of supporting children and adults after death, their risk for isolation increases." The idea of children being with their peers, of sharing their feelings in their own time, in their own way, helps to restore a sense of control as well as a decreased feeling of isolation.

This is consistent with a study conducted through Arizona State University by principal investigator Irwin Sandler, along with fellow researchers, identifying the surviving parent or caregiver's positive mental health as the most important protective factor for a child to thrive, followed by the need for bereaved children to feel understood and to find the means to express themselves in open and honest communications.

"We don't look at ourselves as the 'grief experts' who will use 'grief school' for kids to do their 'grief work' so they can put the person and loss behind them and move on. Rather, we look at ourselves as providing a safe place for children, teens, young adults, and their parents/adult caregivers can share together as they deal with the loss of someone in their lives, and all of the changes brought on by that loss."

Parents aren't expected to have all the answers. Resources such as grief and loss centers, like Olivia's House and The Dougy Center, and websites such as the National Alliance for Grieving Children, are intended for this very reason—to connect parents to the information they need.

The Shared Grief Project

"The idea that kids are not alone is one of the most important messages a grieving child can receive," is the philosophy behind The Shared Grief Project, a website that features five-minute videos of sports figures' and celebrities' personal stories about losing a parent or sibling at a young age, and going on to live happy, healthy, and successful lives. Todd Arky, co-founder of The Shared Grief Project, was 12 years old when his father died. The idea to create something for his target audience—kids—to relate to and identify with, he told me, stemmed from Arky's time working at Manitou Experience, a bereavement camp. "That moment, watching the kids step off the camp bus and seeing kids like themselves, in a similar situation ... that moment is 80 percent of the experience."

"My mom showed my [little] brother and me Kyrie Irving's video last Father's Day," Austin told me. The NBA superstar, who lost his mother at age four, talks about how hard it still is to fill out forms, to see the empty space next to the word 'mother.' "I didn't know he had lost a parent like I did. Now when I watch him on the court, I think, wow, that's pretty cool. He's such a great player, despite all that's happened in his life."

The Shared Grief Project has grown by word of mouth. Arky's plans are organic, with an ongoing "wish list" of notable names for future videos, including, Stephen Colbert, Sean Combs, and Justice Sonia Sotomayor—all of whom lost a parent before the age of ten.

Modern Loss

"Unless you don't know anyone on the planet earth, you are going to be affected by loss," says Rebecca Soffer. In November 2013, Rebecca Soffer and Gabrielle Birkner, both of whom lost parents as young adults, started Modern Loss, a website providing resources, essays, and articles on issues related to parenthood and loss.

"I would have been so grateful for an online forum that provided not only legal, financial, and therapeutic resources in one place but also some personal essays from other people that made me feel like I wasn't the only one going through crazy, sad, funny, frustrating stuff," Soffer says, referring to the website as an alternative to traditional resources.

The site addresses the grief process openly and honestly, exploring issues such as how to talk to children about death, including a feature by Marjorie Ingall on the five best children's books about losing a loved one. One of her favorite book selections, Birkner says, is "When Dinosaurs Die" by Laurie Krasny Brown. "You can skip the parts that don't feel relevant to your circumstances—there are explanations of suicide, neo-natal death, drug abuse, and decomposition—but I'd encourage you not to," Ingall wrote in her review. "Kids crave facts, and shielding them may not do them any favors. They have a gift for understanding just as much as they need to, tuning out whatever they're not ready for."

Finding out a loved one has died via social media, Soffer explains, such as a Facebook status update with 150 "likes" underneath, is now commonplace. People can see that Aunt Millie died while lying on a beach, online at the grocery store, or sitting at their desk at work. "The use of a phone chain to convey news of a loved one's death has, for the most part, become obsolete," says Soffer.

"In some ways, social media can be a huge comfort to people dealing with loss: with two clicks, they can post a meaningful photo or observation on Facebook so their networks can bear witness to the

memory of their beloved lost person and offer insta-support in the form of comments and likes," Soffer says.

But the problem, she explains, is when people believe these comments and likes are enough, when they suffice as real support. When they don't take the extra step to make a phone call, write a handwritten note, or reach out directly to the person grieving the loss of a loved one.

Technology and social media, however, allow people to grieve more publicly, to create communities and support groups for themselves around loss, Birkner explains. Discussion groups and Facebook pages, like those connected to Hope Edelman's *Motherless Daughters*, provide ongoing support and healing, and information, resources, and news about loss-related events and upcoming conferences.

Bereavement Support Systems, and Services in Schools

After a loss, when a child returns to school—the classrooms, the hallways, the lunchroom, the playground—teachers, school counselors, and administrators have an opportunity to support and help shape the life of that grieving student.

In a survey polling K-12 educators, involving more than 1,200 members of the American Federation of Teachers (AFT) conducted in October 2012 by the AFT, the New York Life Foundation, Tiller Inc., and Hart Research Associates, seven out of ten teachers reported having at least one grieving student currently in their classroom.

While the educators acknowledge the importance of their role following a loss, and their desire to help a child through the grieving process, the most notable obstacle preventing them from providing this support was "insufficient training and/or professional development, with 93 percent of classroom teachers reported saying they had never received bereavement training and only three percent saying their school or district offered this training."

A week after Austin's father died, he returned to school. Teachers piled on the homework; final exams were looming. Still trying to cope with his extreme anxiety, the panic attacks, and lack of sleep, he was overwhelmed with the workload. Finally, the principal—a mother and recent widow—stepped in, advising the teachers to ease up on his assignments, and not require him to take finals.

"Our teachers aren't intended to be experts," psychologist, grief educator, and counselor, Dr. Alan Wolfelt, of the Center for Loss and Life Transition in Fort Collins, CO, told me. While we hope teachers will have the sensitivity for grieving students, they refer to their school system to provide the resources and training. In order to help educate our school communities—so they can better serve their grieving students—proper bereavement training is necessary.

Grief centers like The Dougy Center and Olivia's House provide workshops for schools, lead classroom discussions and training sessions, with the goal of properly equipping the people who will be in the school community on an ongoing basis with the proper bereavement training. Similarly, Dr. Wolfelt

presents workshops and training for schools, intended to bring continuing grief education to school communities.

In 2013, the New York Life Foundation, in partnership with the Center for School Crisis and Bereavement, led by grief expert Dr. David Schonfeld, convened with over ten school community associations representing educators (including the AFT), administrators, and school mental health providers, to develop and distribute industry-endorsed resources for the public school system.

"We call it the Coalition to Support Grieving Students," explains Heather Nesle, President, New York Life Foundation. "The Coalition is an important, unique collaboration of a wide range of associations which will work collectively towards one goal of creating a resource to support students across the county."

These resources are intended to address the current gap in bereavement support and resources in schools, to help serve educators and other members of the school community with practical and straightforward information. Expected to rollout later this year as a practitioner-oriented website through a multimedia approach, it "will be a major step forward in helping educators have a deeper understanding of the issues of childhood grief and giving them tools to help grieving kids," says Nesle.

While these efforts are making a dent in bereavement support systems, our communities are still illequipped to cope with the number of grieving students in our schools. "It strikes me—if schools are prepared with fire drills, they should be prepared in advance if someone in the community dies," says Shuurman. If there's no plan in place, Shuurman notes that the school community should get one in place, with policies and procedures, so they are not making important decisions in a crisis, after something has already "happened." The idea of uniformity and consistency, she explains, is essential in the planning process, as is asking the primary question, "What kind of community do we want to build?"

Conclusion: How Far Have We Come?

"I don't think we've progressed further in coping with death," Shuurman told me. "We've gone backwards in fact. Communication is different. Social media takes over as soon as someone finds out."

While encouraged by the number of grief centers and resources in our country, "we need not believe 'we've arrived,'" Dr. Wolfelt told me. "We still have a long way to go. We need to do more outreach; we are still 'mourning avoidant' as a culture."

While the instinct is to overprotect, our children are natural mourners. They need a "significant adult" who brings sensitivity, honesty, a sense of inclusion and compassion, and allows children to be their own experts. We can't take away or "fix" our children's pain, anger, or fear; but we can support them through their grief process.

"I wouldn't be the person I am today if my dad hadn't died. My grief has shaped me," Austin, told me, explaining he was quiet, and more intense with his schoolwork prior to his dad's death. "After my father died, my family and friends became a priority; I understood how fragile life can be, how not to take anything for granted. My town, their support, made me realize I have a lot to be thankful for, that maybe I didn't realize before."

In Summer, 2015, Austin's family plans to open Adam's House, a grief center in Connecticut, to serve children and families like his own—those coping with the loss of a loved one.

"Adam was a great father and husband," Austin's mom says. "Something should represent his legacy, with his name on it, to help and teach people through their grief journey." Adam's House will closely resemble the program of Olivia's House, with a comfortable home-like setting, and with Leslie Delp serving as its mentor.

"Just like our family pact—not to forget—Adam's House will continue to honor my dad's life, and it will educate and empower other families to cope with their loss—and give them the tools to live their lives to the fullest."

We wrapped up our conversations about Austin's grief journey, sitting on the family's back deck, a mid-afternoon breeze passing between us. As we got up from our wicker chairs, I realized I had forgotten to ask the question I had been meaning to pose, the one that had been lingering since our first talk. "So, how are you doing?" I asked. Austin smiled, with what seemed like a look of understanding, and contentment. "I am happy," he said. "Really, really happy. And excited for the next chapter of my life."

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