Grand Parents

Raising the children of parents lost to AIDS

August 13, 2018 By Daryl Hannah

When Nora Young's husband died, she was left to raise her daughter, Jasmine, primarily as a single parent. So when Nora discovered that she was going to be a grandmother for the first time, she was over the moon. The Chicago transplant by way of Memphis was ecstatic at the prospect of seeing her close-knit family grow.

Little did she know that the exciting announcement in 2003 of an addition to their small family—Jasmine was her only child—would also come with news that Jasmine was living with HIV.

"When Jasmine got pregnant with Jordan, her first son, that's when she found out she was HIV positive," Nora tells me. "She was very upset when she found out, but I calmed her down. I told her this is not the end and that there are medications that she can take to live a long, healthy life."

Nora, a home care nurse, had been reading about the advancements in HIV prevention and treatment medicines in various newspapers and magazines. She encouraged Jasmine to prioritize her health and get on treatment, for her and her unborn son's sake. Heeding Nora's advice, Jasmine started taking antiretrovirals.

"She was doing pretty good for a while, but the pressure of things got to her, so she stopped taking her medicine," says Nora, who continued to encourage Jasmine to stay on her regimen after Jordan was born, going so far as to pick up the medications from the pharmacy herself.

Unfortunately, Jasmine wouldn't stay on treatment long. A series of personal hardships made it more and more difficult for her to continue to take her medicine.

Jasmine lost her husband, Jason, to AIDS two weeks before the birth of their second son, also named Jason. She grew tired of hiding her doctor's visits and her medication from visitors and roommates. And later, after she came out as a lesbian, the woman she was dating and living with abruptly ended their relationship. Jasmine was heartbroken. She stopped taking her medicine altogether, and her health rapidly declined.

On August 5, 2013, Jasmine died. Suddenly, Nora, who was approaching 60, found herself grieving the loss of her only child and caring for her daughter's two HIV-negative children: Jordan, age 10,

and Jason, age 5.

Nora Young with grandsons Jordan (above) and JasonSaverio Truglia

The phenomenon of grandparents and other relatives serving as primary caretakers for children who've lost their parents to AIDS isn't new. Today, Jordan and Jason are among the millions of children in the United States and around the world who are rendered homeless or left to live with

extended family members or to languish in the child welfare system as a result of losing one or both parents to AIDS.

And although advancements in treatment and prevention have virtually eliminated mother-to-child transmissions—both Jordan and Jason are HIV negative—and have dramatically reduced the number of AIDS-related deaths, children are still being orphaned by AIDS.

“There’s no national data source that tracks the reason children end up in grandfamilies,” says Jaia Peterson Lent, deputy executive director of Generations United, a Washington, DC–based advocacy group that promotes programs and policies to connect people of different ages.

“What we do know is, recently, parental substance abuse is a major factor causing children to come to the attention of the child welfare system, but that is only a very small snapshot. For every child who is in foster care with a relative, there are about 20 kids outside of foster care being raised by relatives.”

Regardless of why children end up in the care of extended-family members, according to Lent, they tend to fare better when they live with family as opposed to strangers. They have better behavioral and mental health outcomes. They’re more likely to stay connected to their siblings and have a stronger cultural identity and a greater sense of belonging. They’re also less likely to change schools.

However, despite the documented emotional, social and psychological benefits of children remaining with relatives, the transition can nevertheless be hard for children and caregivers alike. Children are often processing the trauma of losing their parents, which may manifest as behavioral or academic issues. And unlike expectant parents who have several months to prepare for the arrival of their little ones, grandparents are often stepping into primary parental roles without the time or space to process their grief or get their finances in order.

In the weeks following Jasmine’s death, Nora had to bury her daughter, apply for guardianship of Jordan and Jason and register them for school. Not to mention, she was also caring for her dying fiancé, who had been diagnosed with Stage IV cancer.

Thankfully, Nora was referred to the Families’ and Children’s AIDS Network (FCAN), a federally funded program that serves children and families affected by AIDS. Two dedicated FCAN counselors helped her navigate the guardianship application process, connect with other grandparents in similar situations and sign Jordan and Jason up for a 10-week support group so they could be around other kids who’d lost their parents to AIDS.

Nora doesn’t know how she would’ve gotten through it all without those FCAN counselors. “Having the opportunity to cry and get support from people who were going through what I was going through was a real blessing,” she tells me.

When it came time to disclose to Jordan and Jason how their parents died, Nora once again turned to her FCAN family. For five years, she dreaded having that conversation, but she knew it was

important.

“For a long time, I was reluctant to tell them. I didn’t think they were prepared,” Nora says. It wasn’t until she and an FCAN counselor practiced and prepared for the talk that she felt ready to sit her grandsons down in their home and finally tell them what happened.

“Afterward, I asked them if they were OK, and they said yeah, but I don’t know what the impact will be,” she continues, her voice trailing off.

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As I interviewed Nora and her grandsons for this article, it struck me how similar their story is to mine. I’m also HIV negative and lost my parents to AIDS.

Like Jordan and Jason, I was very close to my grandmother before she died. She lived in a rural part of South Carolina that seemed shrink-wrapped in the 1960s. I spent long stretches of my early summers playing in her rose garden, picking plums and grapes, and climbing trees.

As with Jordan and Jason, my sister and I are five years apart. Although, as the younger sibling, I take special issue with Jordan’s description of younger brothers as “annoying.” And also like them, I know intimately the pain of losing both parents to AIDS at a very young age.

My father contracted HIV while he was incarcerated. Upon his release, he transmitted the virus to my mother. Less than two years after returning home, my father died of AIDS-related complications. Two years later, in 1992, I lost my mother to AIDS.

Both of my parents were dead by the time that I was 7 years old. Although I vaguely remember my father’s passing, nothing really prepared me for my mother’s death when it happened.

Not the nurse’s horror upon arriving at our single-wide trailer to find my mother sprawled out on the kitchen floor, covered in half-cooked white rice. She’d been trying to make dinner for my sister and me but had lost all the strength in her legs. As her legs gave way, she’d knocked the simmering rice onto herself and the floor.

Not the weeks that she spent in the hospital as doctors monitored her “iron and blood levels.” I would much later come to find out that during these visits, which caused my sister and me to live with our maternal aunts, my mother was undergoing blood transfusions.

Not even my mother’s bedridden state, which rendered her unable to attend her own mother’s funeral, had prepared me for the inevitability that she was going to die.

But there, at her hospital bedside, at the prompt from an aunt, I said goodbye to my mother for the last time as I placed my right hand in her left. She turned her head to look at me and mouthed the words I love you.

The next morning, she died.

As Jordan and Jason know—or at the very least are learning—the loss of one's parents to an AIDS-related illness isn't the end of AIDS. Like all other deaths, the loss is final and permanent and can overshadow birthdays, anniversaries and other milestones, making them feel incomplete and lacking. But the loss of a parent to AIDS also forces one to learn to navigate a world where the stigma around HIV and AIDS is still very real and can never not be part of one's story.

Nora and her grandsons, Jordan (left) and Jason, are still grappling with their loss.Saverio Truglia

It wasn't until well after college that I felt comfortable telling people that my parents died of AIDS-related complications. When I was Jordan's and Jason's age, people always assumed that my biological parents were attending parent-teacher conferences, helping me with my homework at night or giving me money to spend on frivolous things, and I let them. I did so because I wanted to be seen as normal. What teenager doesn't?

For me, being Black, gay and terrible at sports in rural South Carolina was isolating enough. I didn't need or want to be any more different. But deep down, I always knew lying about my parents was wrong. Lying also seemed to make the memories fade faster. It wasn't until I met other people who were living with HIV and AIDS or who had lost their parents to AIDS that I

realized how much pain and heartache I had caused myself and my family.

Today, Jordan, 16, and especially Jason, 11, have few memories of their parents. When asked what, if anything, he remembers about his mother, Jordan speaks in generalities. “She was kind and nice, nothing bad,” he says. However, when asked how he feels about her death, his pain is much more palpable. “I miss her every day. Every day is harder than the other. I think about her all the time. Even when I’m not thinking about her, memories will pop up.”

When I speak with Nora, Jordan and Jason, it’s obvious that they’re all still grappling with their loss. Part of me wishes I could tell Jordan and Jason that one day they will get over the death of their parents. That in a finite number of years, their yearning to sit on the couch and watch TV with their mom again or to visit her favorite restaurants will subside and magically turn into joy. But sadly, that wouldn’t be the truth.

In fact, you never get over the loss of a parent, especially if he or she was taken from you at a young age. You’re never not looking at the door hoping that your mother or father one day appears and ends the painful charade that has been your reality. After more than two decades, I still avoid Facebook, Twitter and Instagram on Mother’s Day and Father’s Day, and I know I’m not the only one.

Instead, what I would tell Jordan and Jason, and every other kid missing his or her parents, is to hold on to the memories you made. You can keep your parents alive in spirit by speaking their names and their truths. By sharing your story, you are dismantling stigma and uprooting shame, and that is powerful.

And most important, give yourself and your family space and time to grieve. It’s the only way to harness your innermost strength.

“A lot of people said that I was doing a wonderful thing by raising my grandsons,” says Nora. “Eventually, I realized that I saved them, but they saved me too. I needed them.”

And the world needs more Noras.

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