A Stirling Example

Suzan Stirling learned she had HIV when her son and daughter were diagnosed with the virus. She and her (HIV-negative) husband refused to let that stop them. Quickly addressing her health needs and those of her kids, Stirling soon had her family thriving again. They even adopted another positive child, from Ethiopia. But one more challenge awaited: disclosure.

January 1, 2008 By Suzan Stirling

It was a turning point—a subtle surrender on my part—as I struggled to understand my teenage daughter and keep up with my ever-evolving role as mother. This past fall, Alee, then 16, was coming into her own, and she was ready to challenge my stance on how and when she should disclose that she, like me, is HIV positive.

“I don’t want to hide it anymore, Mom.” Alee lay stretched across my bed, arms propped behind her head, staring at the ceiling. Her face was set with determination.

“Is that so?” I asked. I was upset and had every reason to be. After all, we’d had an agreement, and she’d broken it. All I’d ever asked was that she come to her father or me before disclosing to anyone. That way we could discuss it, talk to the parents first and pave the way a little for her. So far, it had worked: She’d been able to come out to a few close friends without the whole school finding out. I crossed my arms over my chest. “I’m disappointed you didn’t talk to me first.”

The room fell silent, a momentary calm, before Alee rose up. “He’s my friend, Mom! He’s not going to tell anybody else, and even if he does, I’m cool with that. Nobody’s going to freak out or anything. Kids today learned about all this stuff in eighth-grade health class. It’s not like it was 10 years ago—he understands. All my friends will!”

“Who exactly is this ‘friend’ we’re talking about?”

She mentioned his name, adding, “All I told him was that I’ve been positive since birth.”

Now I knew why she hadn’t come to me. “Of all people, Alee, you told *him*? You know his mom works at your brother’s school. He’s the last person I’d want you to tell.”

“Why does it matter?” Her eyes were lit. No way was she backing down.

“Try to understand. It’s not just about you. This is about your brothers, too—our whole family!”

She looked me hard in the eye. “Is it really, Mom? Or is it about you?”

I stopped pacing the room, her point taken like an arrow to the spine. She was right. She was telling me, in plain English, that keeping a part of her identity a big, dark secret wasn’t working for her. She’d been telling me for a while. I just hadn’t been listening.

“Alee, I’m sorry. I only wanted what I thought was best for you.” I slumped down on the bed, next to her.

She put an arm around my shoulder. Her voice was soft. “Mom, you haven’t done anything wrong. Things have changed, that’s all. I’m almost 17. You don’t have to worry so much about me anymore. I’m tired of hiding who I really am. I want to come out. It’s time.”

“It’s not so much the kids at your school I’m worried about. It’s their parents. I don’t want you to end up like Ryan White.”

“Who’s Ryan White?”

“You’re serious?” I looked at my daughter. “Ryan White was…” I paused, remembering the ’80s. I’d been just a little older than Alee when I’d first seen his face plastered on the news and heard the word *AIDS*. Images of a dying 13-year-old Ryan now raced through my head. “Ryan White was just this kid…” The last word stuck in my throat.

“Mom, what’s wrong?”

“It’s hard to explain. None of us understood back then. When he came out, he was treated awfully. He was ostracized by his whole community—kicked out of school. He was just this sweet kid whose life was made a living hell because he had AIDS. He fought the system and eventually won the right to go back to school, but the kids there taunted him. The parents weren’t any better. His family finally moved.” I blew my nose. “He was no different than you—no different than your brothers. I don’t want you to go through anything remotely close to what he had to endure. We live in a small town, Alee. What’s everyone going to think?”

“I really don’t care about what anyone thinks. I’m not ashamed that I have HIV. And if someone tries to give the boys a hard time—it’ll be Captain Clobber to the rescue!” She grinned, her right fist making circles in the air.

I laughed, wiped my eyes. This child of mine, this almost woman sitting beside me, had suddenly grown her own dreams and her own mind. I hugged her close, and it was hard to let her go. My baby was growing up. She wanted to be real with the people she cared about. She wanted to be true to herself. Alee had said something that really stuck with me when she’d said, “Mom, I’m not ashamed.”

She wasn’t ashamed; I’d done something right. My kids weren’t ashamed. Why was I? Wasn’t that

just what you did when you had HIV? Blame yourself for being too stupid to use protection? Blame yourself for your children's struggles? It was my fault, everything—because of me my children—Alee and her brother Mitchell—had HIV. Damn right, I felt guilt and shame.

Would I have had children if I'd known I was positive? I can't imagine my life without them, so yes, I would. But given the choice, I'd have waited for the impending treatment advances that would have given my children terrific odds for being born HIV free. My monumental mistake: thinking HIV could never happen to me.

Eleven years had passed since my husband, Clay, and I sat in a darkened private hospital room, watching in helpless denial as our (then 5-year-old) daughter fought her battle with a killer we couldn't see, let alone name.

A large clock ticked away the minutes as Clay and I waited for Alee to be returned from the testing room. This last test had been more extensive. We'd had to stay longer, and there'd been the possibility of complications. I felt a swift kick beneath my rib cage, and my hand instinctively went to my distended abdomen. The baby inside wiggled and rolled, sending terrific ripples across my stomach.

The door opened, and Alee was wheeled in. She slept peacefully beneath a bleached-white blanket, her skin pale and her eye sockets dark and deeply sunken. There was little left of the vibrant child she'd been only a few months before. We'd seen numerous specialists and had dozens of tests performed yet still had no answers. I'd put all my faith in this new doctor. Surely, he could help us.

When the doctor entered the room, he'd changed from his scrubs into a red button-up shirt. He almost looked approachable, like someone you'd invite over for dinner. His voice was soft and low. "Alee did well," he said. He looked in her direction, but not before I caught a glimpse of something in his eyes. Was it defeat?

"So, the test went OK?" I asked.

"Yes, everything we find is normal. Her colon, her intestines—all normal. I just don't find anything indicative from the tests we performed today. I'm very sorry."

It was too much. We'd just put our child through this for nothing. "Then why is she so sick? Why can't she eat?" It was the billion-dollar question, one that had been asked so many times before. Now this doctor was letting us down too. The room fell silent. Clay began to stroke Alee's head and weep.

The doctor weighed his words. "I'm deeply sorry that I can't give you more. I will prescribe a pill that will help with food absorption. Bring her back in two weeks. If she's no better, we need to discuss putting her on a feeding tube. He scribbled something on the pad, handed me the sheet and walked out the door.

A car's honk echoed from the street below. People hurried down the sidewalk on their way to work. The world outside continued to move, but for us, in that tiny room, life had stopped.

We returned home. I spent the hours while Alee slept sleuthing through online medical journals, hoping to find some sort of clue as to what was wrong with her. I'd been sitting there for hours when my back began to throb. I stood up, stretched and then felt a whoosh of wetness between my legs. My water had broken. Mitchell had decided to come three weeks early.

It was a fleeting moment of joy: diapers, bottles, midnight feedings and a cooing baby boy. But then, on day 7 of having him home, something began to go terribly wrong.

"Clay!" I shook my husband awake. "It's the baby. He's not breathing right!"

We sped back to the hospital, where Mitchell was admitted into the ICU. He had pneumonia. After a long stint in the hospital, he recovered enough to come home. There were around-the-clock breathing treatments and entire nights I'd spend just watching him breathe.

Then the unthinkable—Alee suffered a stroke. I was losing both of my children and no one could tell me why.

I was at my mother's house when I got the phone call that saved their lives. It was a new pediatrician. We'd seen her only once or twice since Mitchell's last release from the hospital. She was quick to the point.

"Something in your son's blood work warrants an AIDS test."

"AIDS test?" I was stunned. "But how could my baby…?"

"Mrs. Stirling, he would have had to have gotten it from you. I suggest your entire family be tested."

I put the receiver down and looked at my son, sleeping in his bouncer. Then I looked at my mother, who was trying to talk to me, but I was a million miles away. *AIDS*? It couldn't be. Yet in that instant, I knew that it was.

One by one, we were tested. Alee, Mitchell and I were positive. My husband was not. I'd contracted the virus before I'd married and carried it for nearly a decade without knowing it. I was in shock. My children were going to die and so was I. My only thoughts were that I had to be there for them—see them through. After that, my only hope was that I'd soon follow.

The year was 1996 and both of my children were dying of AIDS. My husband and I watched in desperation and prayed for a miracle. It came in the form of a gritty blue powder. Protease inhibitors had arrived! We'd mix the powder into spoonfuls of chocolate pudding, clap and cheer, and somehow our children would swallow the sticky brown mess. This new drug, in combination

with two others, brought them back to us. Daily, we saw improvements. It was (and still is) the most phenomenal thing I've ever witnessed.

Months turned into years and our children remained healthy, and then a couple of years ago some might say that Clay and I went a little loco when early one morning in 2005 we sat down at my laptop and typed into the search block two little words—*AIDS orphans*. At the time we'd told ourselves that we were merely looking for a child to sponsor, but we both knew the truth. We were looking for a child to call our own, a child who needed us as much as we needed to find him. Immediately, two viable hits appeared on the screen. I clicked on the first one. On the site, we watched a video. Near the end we found him; the little boy who would become our son was living in an orphanage for positive kids in Addis Ababa, Ethiopia.

It took some doing, but one year later, he planted his feet on American soil. I lifted Yonas into my arms and kissed his forehead. He was thin and burning with fever. The clothes I'd sent for his journey were filthy and smelled of urine. He looked into my eyes and began to sob. It wasn't exactly the homecoming I'd imagined, but I didn't care. He was home and he was safe.

Today, Alee, 17, Mitch, 11, and Yonas, 6, continue to thrive. Although at present their disease is under control, growing up with the stigma of HIV continues to be almost as complicated as the disease itself. Only someone living with it can truly understand the innumerable challenges and bias we face from those who choose to remain uneducated as to how HIV is and isn't spread. So much so that even today, disclosure, for many of us, remains a huge issue. My goals today are to facilitate HIV awareness and to raise my children to be exceptional adults who ultimately survive the epidemic we call AIDS.

Coming out wasn't an easy decision for our family, but I truly believe that something good will come of sharing our story. I think my daughter said it perfectly when she simply stated, "Mom, it's time."

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