



balancing act

BY HEIDI STEVENS

hstevens@tribpub.com | Twitter @heidistevens13

Talking about stillbirth, a loss rarely discussed

It's a leap of faith to open your life up to strangers.

Faith in the strangers, that they'll receive you with grace and goodwill. Faith in yourself, that you won't crumble beneath the weight of their attention.

Lynn Persin took the leap, choosing to start a blog in 2011 to chronicle the progress and perils of raising her son, Aleck, who was born that year with arthrogryposis, a rare congenital disorder that causes multiple joint contractures and weakens muscles.

Doctors told Persin and her husband, Craig, that Aleck would never walk or have full use of his arms.

Aleck turns 4 in October, and he's walking quite beautifully, but his life is complicated by machines and therapists and difficulty with such day-to-day tasks as eating. It always will be.

Persin, 38, began narrating her son's life online as a way to update family and friends on his various treatments and milestones. She continues the blog for less logistical reasons.

"It's become my therapy," she told me recently over coffee at a cafe near her Logan Square home.

And because it's therapeutic and because the readers — family and friends, with a few strangers mixed in — have shown grace and goodwill, she recently ventured into a darker place.

Lynn and Craig lost their baby girl in 2010. After an uncomplicated pregnancy, the baby died inside of Persin after 8½ months. Doctors were unable to explain the death, even after an autopsy, which is terribly common in the case of stillbirths; roughly two-thirds of all stillbirth deaths go unexplained, estimates the Star Legacy Foundation, a national nonprofit devoted to stillbirth research and education.

A stillbirth is defined as a baby who dies at 20 weeks of pregnancy or later. A pregnancy that's lost before 20 weeks is medically classified as a miscarriage. Experts estimate 1 in 160 pregnancies end in stillbirth each year in the United States.

"We felt like we were the first people in the universe to go through it," Persin said.

On July 9, for the first time since her loss, Persin wrote about the experience on her blog. She, Craig and Aleck had recently visited their baby girl's grave site. "It was a lovely summer day at the cemetery," she



ERIN HOOLEY/CHICAGO TRIBUNE

Lynn Persin exchanges a kiss with son Aleck while husband Craig looks on. Aleck inspired her to start a blog, on which she recently opened up about a baby girl she lost in 2010.

wrote. "Just cloudy enough to echo our souls, just warm enough to wrap us in a hug."

Her site crashed from the traffic. Ten thousand people read the post in a single day, she said. She heard from her New Jersey elementary school classmates. She heard from friends of her parents. She heard from strangers.

Many wrote to express sympathy. Several wrote to share their own stories of loss, which brought Persin a sense of comfort.

"The whole 'You're not alone' feeling has been really important to my husband and me since we started down this insane journey," she told me. "Since we first lost the baby to then having our son and his neuromuscular disorder, we've been on this constant quest to feel less alone."

Grief is excruciatingly isolating. Grief in a maternity ward is especially so. From the security guard who kept adding smiley faces to the badges of people visiting Lynn and Craig, to the anesthesiologist who wished Persin a carefree congratulations during her rounds, the signs were stark and immediate that people weren't accustomed

to a tragedy like theirs.

"Every step of the way, you're made to feel that much more alone," Persin said. "It really puts you in this no man's land kind of a place."

People rarely talk about stillbirth. I spoke recently with a dad whose baby girl died unexpectedly at 40 weeks in utero. "I didn't even know what a stillborn was until it happened to us," he told me. "Everyone keeps telling you about SIDS, but no one ever talked about this."

Joey Miller, a licensed clinical social worker at Wellspring Health Associates in Chicago, specializes in perinatal loss. She counsels families who experience the death of a baby during pregnancy, during delivery or shortly after.

"It can be a very isolating and lonely path," Miller told me. "We talk about things like breast cancer and heart disease and stroke — as well we should. But we don't talk enough about when a baby dies. I will lobby until my last breath to raise awareness and increase education and sensitivity every way I can for these parents, because it's not about the length of gestation; it's

about the depth of attachment."

Miller says a baby's death is a "double loss."

"Sometimes parents find out they're pregnant, and they have that child's whole life planned, with all the hopes and dreams that go into it," she said. "When a grandparent — or even a parent — dies, it's a loss for the future, but you're comforted by the memories. When a baby dies, it's a loss of everything future — all your hopes and dreams — but also everything past. Maybe you have an ultrasound picture, but you don't have memories with this person, and that's very disorienting and dizzying for parents."

Often the friends and loved ones of a couple who've lost their baby don't know how best to comfort the grieving parents, adding to their feelings of isolation. The Star Legacy Foundation site offers advice on what not to say: "You can have more children." "God needed an angel." "It wasn't meant to be." "God doesn't give us more than we can handle." "You'll feel better once you get back to your normal life." That last one in particular.

"The grieving is not over, ever," Miller said. "We can go on to find happiness and joy in our lives, but that definitely takes work, and it's not about getting over it, which to many parents implies forgetting."

We'd all do well to remember that when approaching grieving parents, she said.

"The depth and duration of a parent's grief greatly outlasts the depth and duration of other people's sympathy," Miller said. "People will bring food, or people will bring flowers, but after a few weeks or months, they go back to their own lives. Parents don't get over this."

And people's needs change over time. If they weren't ready to talk at first, they may be ready later. If they wanted lots of company at first, they may be ready for privacy later. Just check in, Miller said. "You may or may not want to respond," she suggests saying. "But I want you to know I'm thinking about you."

Read the blog post

To read Lynn Persin's July 9 blog post about losing her baby, go to www.smartaleckpersin.com (type "goodbye all over again" in the search field).