

Volunteers' compassion helps grieving parents through infant death

BURLEY — Weak afternoon sun trickled through a window onto Amanda Harris as her thumb stroked the cool, slick glass of a photo frame cradled against her chest.

The photo is of her tiny son.

“This is all I have of him,” the Paul woman said. Photos, hand- and footprints, a minuscule diaper and a white gown adorned with a yellow duck. “These things are some of my most prized possessions.”

Born much too soon — at 21 weeks' gestation on Aug. 3, 2012 — Michael Allen did not survive. But he was real.

He weighed 9 ounces. He was 10 inches long. He waved his hands at his mom when the doctor performed the last ultrasound screening.

There's no joyful celebration for families of the 20 or 30 south-central Idaho babies each year who are stillborn or die shortly after birth. Instead, most hospitals offer infant-loss programs spearheaded by nurses, staffers and volunteers who understand these parents' pain.

They sew tiny clothing, make blankets and hats, paint memento boxes and help families take the first and last photos of their children.

They offer compassion and the gift of a few precious hours.

“I was able to have seven hours with him before the mortuary took him,” Harris said. “Eternity is not long enough to spend with your child, let alone seven hours.”

A dress repurposed

A miniature white gown with tiny beadwork lay atop Wendy Peterson's sewing workbench as she turned an infant boy's outfit made from the same satin right-side out.

The backs of the clothing would have Velcro closures, because the infant bodies that will wear them are fragile and can't withstand a lot of manipulation.

“They don't make any patterns for boys,” Peterson said, showing the tiny tuxedo she styled. The vest would be finished with buttons. A dapper bow tie would complete the ensemble.

The luxurious material? Harris' wedding dress.

After Harris lost her son, she donated the dress to Cassia Regional Hospital's infant-loss program to be made into layettes for perinatal deaths. Nurses and volunteers eagerly took up the cause and began working on them.

Harris' donation snowballed — spurring others to donate their wedding dresses.

Peterson, a registered nurse at Cassia Regional's birth center, expects to get four outfits from Harris' dress, mostly for boys and all with individual designs.

"We don't have any outfits for the boys," she said.

Peterson has experience sewing clothing — for her six children, then 12 grandchildren — but the clothing was never this small.

No one makes it this small, she said. And doll clothes aren't really appropriate for a baby's last outfit.

Dolls in varying sizes sit against her windowsill to serve as fitting models. As she sews, her mind sometimes wanders to the little ones who will use them.

"I think about the different families I've seen and how hard it was on them," Peterson said.

Society has come a long way in the past 60 years with acknowledging a family's grief after the loss of a baby, Peterson said. Sometimes mothers didn't get to see their babies after they died, let alone hold them.

Now parents decide whether they want to see and hold the bodies and how much time they want to spend. And nurses make sure parents have photos and mementos for later, even if they think they don't want to see the baby.

Everything that can be done to soften this time for parents, Peterson said, is worth it.

"It's the hardest part of labor and delivery," she said. "It's mostly a happy place."

A whirlwind of decisions

Six years ago, Declo mother Kara Ramsey and her husband, Matt, lost Braxton Heward at five months' gestation. A routine checkup showed no heartbeat.

The loss catapulted Ramsey into the uncharted. Still reeling from the news, she and her husband were hit with questions about what they wanted to do after Braxton's stillbirth.

"I just felt like I was in a whirlwind, and I didn't know the answers," Ramsey said.

When Braxton arrived looking pink and perfect, they were able to spend time with him before the mortuary took him.

Nurses encourage parents to capture those moments after a stillbirth, said Sally Edgar, a registered nurse who oversees the infant-loss program at Cassia Regional. "We always encourage those things because you can't go back afterwards."

The Ramseys buried their son in a small fiberglass casket, placed on top of his grandfather's casket during a simple, sweet ceremony.

"I felt such a sense of release," Ramsey said. But her grief lingered.

"I think it is the loneliest kind of grieving because nobody had bonded with the baby yet but me," Ramsey said. Expectant mothers start making a connection with the being growing inside long before it becomes a reality for others. "I felt so lost and alone and kept asking myself, 'Is this normal?'"

As her grief lingered for years, Ramsey reached out to the hospital and spearheaded the grief support group that Harris eventually joined.

"It's a group that I would have never chosen for myself," Ramsey said, the words heavy in her throat.

Little boy lost

Harris lost an ectopic pregnancy before losing Michael, so she and her husband, Joseph, were cautious about feeling joyful too soon. But after the 12-week mark, she allowed herself to feel excitement.

"I thought I was fine and I was having a healthy baby," Harris said. "I didn't even know what a stillbirth was."

When Harris started bleeding and cramping, an ultrasound showed Michael moving and waving his fists. But an infection threatened Harris' life, and she was told Michael had stopped growing at 18 weeks. The doctor said the baby would not live.

Harris could still feel him moving, and in desperation the couple called other hospitals, only to hear the same grim message.

"I still had hope," she said. "I was preparing for the worst and hoping for the best."

A nurse who had experienced a stillbirth explained to the couple what their son would look like so they wouldn't be shocked by his appearance and darkened skin.

Soon, as Harris cleaned up she felt Michael's tiny head — and then his body slipped into her waiting palm.

"It's something I cherish," she said. "Other mothers are there to pick up their children and comfort them when they fall. The only time my son fell and needed me to catch him, I was there."

She saw a pulse on Michael, but the nurse told her it was only from the umbilical cord. Harris wasn't so sure.

"I was scared to touch him because his skin was so thin I thought it would tear," she said. "I talked to him and told him I loved him and his heart stopped beating."

The nurse took Michael's body and made impressions of his hands and feet.

Many mothers plan what their babies will wear home from the hospital, but the Harris family had no clothing to fit this boy.

“When they brought him back wearing the layette it was like there was a light around him,” Harris said. “He deserved to have something beautiful to wear.”

The clothing helped her look at her child and come to terms with the death. The Harrises examined Michael’s hands and features, etching them into their hearts.

The hospital gave them a tiny box holding a bear, a blanket and a camera, and they took photos during the hours they spent cradling and touching Michael’s body.

“I don’t know the color of his eyes or who he looks like or who he would have been, but I do know what I have right here,” Harris said, touching the tiny clothing he wore. “It helps keep his memory alive and lets other people know him.”

Afterward, she bought a bear to hug — to ease the ache in her empty arms — and a stuffed donkey for 10-year-old son Zane, who still sleeps with it.

For months she couldn’t bear to go to a store because seeing baby clothes or hearing a crying infant caused waves of grief. Food tasted different, and colors seemed muted.

“If you imagine the mess after an earthquake, that’s what I felt like inside,” she said.

Though surrounded by supportive family, Harris felt isolated.

“Maybe people tend to stay away because they just don’t know what to say,” she said. “I felt like he didn’t exist to the rest of the world.”

Instead of comforting, well-meaning remarks often stung.

“Don’t tell someone to move on or that they can have more children,” Harris said. “And don’t tell them at least you have this other child.”

And don’t just turn your head away, she said.

“Say my child’s name.”

Just listen

Grief after a loss like Harris’ is completely normal, said licensed professional counselor Jeanette Bern, owner of Aspenwood Counseling in Burley.

“They were an active part of your life and part of everything you chose to do,” Bern said. Not only do parents lose the physical child, they lose their dream of that child.

“You lose that future,” she said.

While spending time with the deceased child is right for some parents, Bern said, for others it could produce post-traumatic stress disorder. Hospitals with infant-loss programs must be cautious to make sure it's the parents' wishes.

Grief after a baby's death, like all grief, has no timetable and is cyclical. People move in and out of the stages of denial, anger, bargaining, depression and acceptance. Grief, Bern said, can be triggered years later by the sight of another child.

"Grief doesn't ever really go away," she said, "you just learn to cope with it."

After the loss of her son, Ramsey sought a day that felt normal only to discover it didn't exist.

"You have to find the new normal," she said.

If loved ones are dealing with grief, listen to them and validate their feelings, Bern said; hear their pain without judging them. Those searching for comfort after a child's death should seek out a counselor or someone they don't know well who is willing to sit and really listen.

South-central Idaho hospitals also offer counseling and clergy visits to families who lose babies.

The first time Harris attended a grief support group after her son's death she felt angry that she even had a reason to be there. Over time, she realized the participants understood her loss through the windows of their own grief.

"Even though every story of loss is different I realized we are all grieving in our own way and it made me stronger," she said. "When you experience the loss of a child you have to let it hurt, bleed. You have to experience the rawness of it, then you can be ready to heal."

Healing moments

Four years after losing her son, Harris wanted to do something in Michael's memory.

"I don't want his memory," she said, "to be just another sad story of a child lost."

In October she and her husband made baked goods, held a fundraiser and donated \$450 to the hospital for purchasing stuffed bears for its memory boxes. And she donated the wedding dress collecting dust in her closet.

Harris hopes to continue raising money to purchase a CuddleCot to donate to the hospital. The refrigerated bassinet allows families to spend more time with a baby's body.

"I knew I wanted to help this program because they helped me, no questions asked," Harris said. "Maybe I can help another mom whose heart is shattered in a million pieces."

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