



Now I lay me down to sleep

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[HEATHER GREENWOOD DAVIS](#)

SPECIAL TO THE STAR

On the day the family portrait was taken, Amanda Diamond couldn't decide how to dress her youngest daughter.

To avoid the wrong choice, she threw all her baby's best outfits into a duffle bag and brought them to the studio. It was important that Hailey look her prettiest. This would be her first professional photo shoot. It would also be her last.

Less than three weeks after these pictures were taken, Hailey died. Her passing wasn't a surprise, though.

And in many ways, it was a triumph.

Diagnosed on Christmas Eve with Type 2 Gaucher's Disease — an incurable genetic disorder in which the body lacks an enzyme necessary to break down a type of fatty cellular waste, resulting in damage to organs and the nervous system — doctors had given the five-week-old another 14 days or so to live.

She was dependent on a feeding tube and an oxygen tank, but within days Amanda and her husband, Chris, made the difficult decision to care for Hailey at their Keswick, Ont., home, and to let her die there.

But the child defied the odds. And now, almost six weeks after her release from the Hospital for Sick Children, she was ready — her body frail and less than a pound heavier than her six-pound, seven-ounce birth weight — for her close-up.

The shoot, which included the Diamonds' three-year-old, Alexis, was a gift from a stranger who is now considered a treasured family friend.

Heather Rivlin (<http://www.heatherrivlin.com>) is a professional photographer who specializes in black-and-white portraits of families, children and expectant moms. She's also the first Torontonian to be affiliated with Now I Lay Me Down to Sleep, an American program that links volunteer photographers in the U.S., Canada and the U.K. to families with dying infants.

Parents can find local photographers by visiting the website (nowilaymedowntosleep.org). Photographers will already have signed an agreement to take pictures without charge and provide families with a digital slide show of images, as well as negatives from the session.

So while Rivlin's time would normally cost hundreds of dollars, she offers her services through the



HEATHER RIVLIN

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A few weeks before their baby daughter Hailey died of an incurable genetic disorder, Chris and Amanda Diamond and their three-year-old daughter Alexis spent several hours with Toronto photographer Heather Rivlin.

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program at no charge.

"It's not truly altruistic," says Rivlin, "because although I am not paid, I'm getting a lot in return. I don't think the family understands the gift they've given to me."

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beautiful she was.

**How beautiful she is. How glad I am that
we brought her home.'**

Chris Diamond

Father

And while for some photographers a gravely ill baby would be a difficult subject, Rivlin is a trained social worker who has spent some time working in a neonatal intensive care unit, and she feels it's the perfect way to combine her talent and expertise.

"I joined the organization because as a mom I can't imagine losing a child," she says. "Every one of us hopes that we make a difference in the lives of others with our chosen career paths. I am no different."

Rivlin sent emails to the bereavement teams at area hospitals, advertising her involvement. That's how Amanda Diamond, 30, a special-needs assistant in schools, and Chris, a 35-year-old auto mechanic, heard about the service. They called the photographer immediately to set up an appointment.

The Diamonds had tried to capture Hailey's tiny hands and feet with their home camera, but they're amateurs, and the pictures weren't quite right.

The session took place in Rivlin's studio in the Avenue Rd. and Lawrence area. The fireplace was turned on to keep little Hailey — who turned out to be most beautiful with nothing at all on — warm.

Amanda made sure that Hailey was fed just before the shoot, so that her garish yellow feeding tube could be safely removed for the photos. They went directly from the session to Sick Kids to have it re-attached.

And for three painstaking hours, the Diamonds say, Rivlin was patient, kind and accommodating as she took the photos that would define a short but significant life.

"We thought, `What an unbelievable thing she is doing,'" Amanda recalls, the tears beginning to well. "Because that's all you have left. When they are gone, that, and what's in your mind, is all that's left."

The Diamonds picked up the album of prints Rivlin had made for them about two weeks ago. They looked through them as a family. A few days later, at 10:35 in the morning, Amanda was holding her infant with one hand while dashing about the house doing mundane tasks with the other, when Hailey quietly slipped away.

Amanda noticed a change, checked her pulse and called her husband to tell him to come home. When he arrived, together they removed the oxygen tubes that helped her breathe, and they began to

grieve.

In the days that followed the infant's death, and as they planned the funeral that took place yesterday, the Diamonds turned to the pictures for comfort. "Every day I look at the photos," says Amanda, her fingers lightly caressing the bound black linen album that has Hailey's name written in script across the front.

Chris agrees. "I just think how beautiful she was. How beautiful she is. How glad I am we brought her home," he says.

"Looking at the pictures makes her feel real," says Amanda, connecting eyes with her husband and wiping away tears. "Sometimes you think, 'Was that a dream? Did that really happen?' I'm looking at the pictures thinking, 'Yeah, she really did happen. She was here.'"

Donations to Now I Lay Me Down to Sleep can be sent to 1153 Bergen Parkway, #M103, Evergreen, CO 80439-9501, or made online at nowilaymedowntosleep.org (The organization is in the process of becoming a registered charity in Canada).

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