The bond between a mother and her child is strong. With the first flutter in the womb, an attachment begins that will forever tie the woman to the child.

A mother gives life, with the birth of that child, and she also gives love.

Annette Reed knows about love. She also knows about life. Now, she knows about death.

By concentrating on the first two, she works feverishly every day to ward off the latter.

Annette is the mother of four-year-old Madison Reed. She and her husband Carl, and nine-year-old son, Kenny, live in Dublin. Carl is a social studies teacher at Dublin Coffman High School. Kenny is a fourth-grader at Scottish Corners Elementary. Annette is an OB nurse at Doctors Hospital West.
Madison is a bubbly little girl who lives within a circle of love that includes her family and friends, as well as a multitude of strangers. Her life's partners also include a team of doctors and researchers who work every day to keep the little girl with the big brown eyes alive.

Madison has SMA Type I (Spinal Muscular Atrophy), the leading genetic killer of children under the age of two. The disease destroys nerve cells known as motor neurons, which control voluntary movements such as crawling, walking, head and neck control and swallowing. Most deaths come from lung problems, Annette Reed said.

Initially, doctors told the Reeds, Madison fit the profile of the "typical" child with SMA. When she was 1, doctors dismissed the idea of providing special equipment to improve Madison's quality of life, her mother said. Some were "convenience items," like a special chair to help her sit up. Others, such as a nighttime breathing machine, and a feeding tube, keep her alive.

Annette and Carl dogged the physicians, convincing them that Madison was not "the textbook SMA child," and had the right to anything that would prolong her life.

While both parents are actively involved in maintaining Madison's life on a daily basis, Carl and others readily admit that Annette is the reason she celebrated her fourth birthday on Feb. 4.

"Madison is alive because of my sister-in-law," said Carl's sister, Sandy Mates.

"Annette's constant devotion and care is certainly the key to making Madison's life better and longer," Carl said.

That devotion comes with a price, though. Madison needs 24-hour care that only medical professionals trained in the treatment of SMA patients can give. While nurses come in one or two days a week in 12 hour shifts, the rest of the time that duty falls to Annette, a registered nurse. Madison doesn't like to be alone, and can't be left alone because breathing problems could prove deadly in a matter of seconds.

Annette sleeps in Madison's room. She's there when she wakes up, and begins the morning routine that takes several hours, removing secretions that build up during sleep, and feeding her through a stomach tube.

After her bath, where the water gives Madison the buoyancy that gives her more movements, Annette carries Madison downstairs, where she watches her favorite shows on Disney and Nickelodeon.

"Then I get dressed," Annette said.

There are a few mini-breaks during the week when speech, occupational and physical therapists come to the home. And, Madison is tutored by a teacher from the special needs preschool in the Dublin school district.

While some people would head to the mall, a movie or a spa when they got the infrequent 12-hour break,
Madison’s mom heads to Doctors, helping to deliver other women's children.

"It's a way for me to get out and continue to do something that makes me feel good," she said.

While she's had some excellent nurses for Madison’s care, it’s difficult keeping them, Annette said.

"Many find it hard to sit and watch Madison...It gets frightening at times. I find it hard at times when she ahs a medical crisis", she said.

Nurses get attached and quit because they don't want to be there the one time Madison does not come through a crisis, she said.

When asked about Madison's life expectancy, Annette said matter-of-factly, "Two years old...anything more is a bonus."

It is easy to see why people are attracted to the bubbly four-year-old who loves anything associated with princesses.

"She's so delightful and so much fun," said her teacher, Ann Loehrer. The two do art projects, read stories, sing songs and play games twice a week in Madison's home.

"She works so hard and asks lots of questions," she said.

"Every day with Madison is a wonderful day," Annette said. "She has no bad moods. She doesn't get mad...She gets frustrated sometimes, especially when I can't understand what she is saying."

She’s also intelligent and knows her limitations, accepts them without question, and goes on.

"She constantly brings me back to reality", Annette said.

The interaction between the mother and child is continuous and a joy to watch, said "Annette’s sister, Michelle Worrellia, who lives with the Reeds and helps out with the cooking, chauffeuring and some of Madison’s care.

"It's hard for me to see all that Annette has to do," she said. "She's a very caring person and would do anything for her children...her family."

Madison's illness affects the entire family, especially her brother.

The bond between brother and sister is intense and evident. Madison's eyes light up when Kenny gets home from school. He kneels down in front of her chair, picks up a balloon and the two begin a game of catch.

"He's so good with her, despite the age difference and Madison's limitations," Michelle said. "He was so happy when she was born and extremely sad when she was diagnosed. But now he has accepted it and moved on."
"She's fun to play with," said Kenny, who admits the two sometimes have typical sibling altercations.

"She gets mad at me, and I get mad at her; then we play," he said. "I wouldn't trade her for anything."

Kenny said he worries about his mom and all the time she spends with Madison: "She's in the house for three weeks sometimes."

There are others who make the 4-year-old smile and dote on her.

Neighbor Gwen Dawson pops in several times a week and spends time with the youngster and her mother.

"Madison has her own little personality," Dawson said.

Then there are the people who have helped the Reeds raise more than $200,000 during the past four years for SMA research at The Ohio State University.

And, said Annette, there are the students at Coffman and other Dublin schools who have made Madison a part of their lives. Each year, Coffman's Student Senate hosts a birthday party for Madison at the school and has collected thousands of dollars for the SMA foundation.

"Every year the party gets better and better," Senate president Meri Sulser said. "I like to think we helped her get to this point.

With all the love and caring, come trying times, too.

"It's hard for us to find time for each other," Annette said about her relationship with her husband. "We love Madison. She's here for us to love and is our main responsibility...Sure we make sacrifices, but I'm okay with it.

"Our lives have definitely changed...I can't go to the bathroom. Can't walk out the door. Can't take a break...But I wouldn't do it any other way. We have to go on."

With the care she's received, Madison "has blossomed," her mom said. The way her doctors wanted to proceed, her "life would be stagnant."

Looking at her daughter through mist-covered eyes, Annette said, "This is what God sent me and what he wants me to do. I used to question what I was put on earth for...This is it.

"When Madison is no longer here, it will be a whole different life, but she could be a teenager before we face that time," said Madison's mom, "or it could come tomorrow."