

'She has a quality life'

■ Clifford Lones, 75, carries his daughter Rachel, 37, back to her bed Tuesday after she was fed lunch (below) through a feeding tube. Rachel, who weighs 75 pounds, eats the same meals her family eats, only her food is beforehand put into a blender.



Note to the Reader:

This article was written before Terri Schiavo's death. You will notice many present-tense verbs related to Terri's story in this article.

FOR 21 YEARS, RACHEL LONES HAS LIVED WITH A FEEDING TUBE. NOW, IN LIGHT OF THE TERRI SCHIAVO CASE, HER PARENTS WANT PEOPLE TO KNOW THAT THEIR 37-YEAR-OLD DAUGHTER IS INDEED FULL OF LIFE.

There is a couple in Muskegon well qualified to express an opinion about the Terri Schiavo case.

Clifford and Janet Lones have a bedridden daughter about Schiavo's age who they've been feeding through a tube for the past 21 years. "She has cerebral palsy," her mother said.

But in the Lones household, there is no controversy over removing the tube or "end-of-life" issues. Rachel is a cherished daughter and sister who is an integral part of family life; she perks up when family members or visitors enter the room, and she pushes herself up on her forearms to see out the window.

She lives in a home filled with love and care.

Rachel Lones and her mother almost died in childbirth in 1967. Oxygen deprivation at birth damaged Rachel's brain; she has never walked or talked.

"A feeding tube isn't life support," said Clifford Lones, Rachel's father and the father of five older siblings.

Feeding Rachel through a tube keeps her from getting pneumonia, said Lones, 75.

"She eats what we're having," said Janet Lones, 72, Rachel's mother. When Janet prepares meals for the family, she adds vitamins and other nutrients just for Rachel and grinds her food in a blender.

Then Janet pours the meal into Rachel's stomach through a tube surgically inserted into her daughter's abdomen.

Rachel is a loved member of her family. A family portrait taken for her parents' 50th wedding anniversary includes a carefully primed and dressed Rachel together with her older sister and four brothers.

In the Lones home in Fruitport Township, Rachel spends her days in the family room in a special bed by the window and near her devoted parents, who are retired. They can tell how she's feeling by how she cries.

Rachel's brothers and sister are devoted to her, too.

Her brother, Dan Lones, traveled from Delaware to make a surprise visit Easter weekend. Her sister, Deborah Gowell, of Muskegon, also came for a visit.

"All of our children are such compassionate people. They were never ashamed of their sister," Janet said.

When the children in the Lones family were young, "each

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Originally published
March 30, 2005.

of my kids had chores, and one was working with their sister,” Janet said.

Her sister and brothers would help with Rachel’s therapy by reading her books, talking to her, and moving her limbs, Janet said.

“She’s aware. I know she has a quality life. I always worked to get her to her potential, whatever that was,” Janet said. Rachel attended a school for children with special needs until she was 18 years old.

Her parents said they do not consider Rachel a burden.

However, “it’s an ongoing struggle for us with Rachel,” said Clifford. He and Janet have made the decision to maintain a “positive attitude.”

“We love her. She responds to us and that gives us a greater reward than ‘doing our own thing.’”

Rachel, who weighs 75 pounds, is in generally good health for a person who is confined to bed. She had an operation in 1981 to fuse her crooked spine, her parents said.

Mary Free Bed Rehabilitation Hospital in Grand Rapids made her a special wheelchair to support her twisted shape, but in the last five years it became more difficult for her to sit up and go on outings with her parents.

Rachel visits Dr. James Twesten-O’Toole

for quarterly checkups. He said a comparison between the conditions of Schiavo—who [was] reportedly in a “progressive vegetative state”—and Rachel is “not exactly apples to apples.”

“Rachel’s had profound deficits since birth, can’t swallow properly, and is not able to properly move her extremities,” he said. “She has significant scoliosis and spinal deformities.

“Most recently, she’s had difficulties with respiratory secretions because she can’t cough and clear her throat,” said Twesten-O’Toole, her doctor for about the past two years.

Three years ago, her parents said she had a medical emergency when she started to suffocate as her lungs filled with fluid. Her parents had to call an ambulance.

“I thought she was going to die. I cried all the way to the hospital,” said Clifford, a retired minister.

From 1978 to 1982, he served as pastor of the church now known as the Henry Street Baptist Church. Then he served a church near Dover, Delaware, until he retired in 1995.

The Loneses said they decided to return to Muskegon to build their retirement home and be near their other daughter.

If Rachel outlives her parents, her sister

Deborah becomes her guardian. All of the legal work has been completed, they said.

Throughout his years in the ministry, many people learned Rachel’s story and she’s been an inspiration to many.

A Grand Rapids minister, Ken Floyd, told Clifford he counseled a pregnant couple whose tests indicated they might give birth to a deformed baby. Their doc-

tor advised them to have an abortion.

But Clifford said Floyd knew of the Lones family and told them Rachel’s story. They decided to have the baby, which was born perfectly normal.

When Clifford next saw Rachel, he said to her, “You saved a little baby’s life.”

Clifford said being Rachel’s father enhanced his ministry. He learned people don’t have control over what happens to them in life.

“But you can control how you react. We all live by the grace of God,” he said.

News coverage about Schiavo, and a story in Thursday’s *Chronicle* about a young man from Kalamazoo who is comatose and whose parents decided to stop his feeding, prompted the Loneses to speak up.

“Terri Schiavo is just like Rachel. It’s hard on us because they’re starving her to death. It makes us feel like we’re bad people for keeping Rachel alive,” Janet said.

Clifford said he sympathizes with Schiavo’s parents.

“We know what they’re going through,” he said.

The Loneses said they are concerned the emphasis on the Schiavo case could fuel the culture of death they see developing in the United States.

“When you’re no longer useful to society, you’ll be given a shot to die,” Clifford said.

They disagree with the Kalamazoo mother, Lori Marcinkowski, who said it is time “to stop being selfish and let him go,” in a newspaper story about her 20-year-old son, Gerold III, who was severely injured in an auto accident at age 4.

Clifford said a few years after Rachel was born, a woman in his church made a comment that “it would be better if Rachel had died.” But the couple shrugged it off.

“I feel God gave Rachel to me [to care for],” said Janet. “It’s not selfish.”

The Loneses raised six children on a minister’s salary and are “not wealthy.” The family paid for all of Rachel’s medical expenses until he retired, Clifford said.

Rachel receives Social Security and Medicaid benefits to help cover her medical expenses, Clifford said.

“Our prayer is that we outlive Rachel so we are here for her as long as she needs us,” her mother said. ■

The Loneses are members of Trinity Baptist Church in Muskegon, Michigan.

