Spunkiness helpful.

Adalyn Carlson whirls around the room one minute and the next is prone on the floor as she fits together puzzle pieces, her brow furrowed.

“She’s our spunky one,” said Adalyn’s mother, Taylan.

Of the three Carlson children, Taylan said God gave Adalyn the personality to deal with cystic fibrosis.

“She holds out her arm so they can take her blood at doctor appointments and she’s always interested to see what’s going on,” Taylan said.

At 2 months old, Adalyn was diagnosed with cystic fibrosis—a condition that causes symptoms such as the buildup of mucus in the lungs and pancreas.

The development of mucus in the lungs makes it easier for bacteria to grow, Taylan said, which can cause repeated and life-threatening infections that scar her daughter’s lungs.

Mucus in Adalyn's pancreas blocks natural enzymes that break down food.

In addition to the disease affecting other organs, Taylan said cystic fibrosis also causes Adalyn's sweat to become salty which upsets the balance of minerals in her system.

Although Adalyn periodically wheezed during the interview Monday, cystic fibrosis is not evident on the outside.

She excitedly showed off a machine that vibrates her chest to loosen the mucus in her lungs twice a day which she then coughs up.

The machine, oral medicine to help Adalyn absorb the nutrients she needs and periodic treatment with antibiotics are weapons in the Carlson arsenal to help manage the disease.

Every three months, the family also travels to Children's Hospital and Medical Center in Omaha where Adalyn's throat is swabbed to see what cultures might be growing.

"Sometimes she has a serious infection we don't know about," Taylan said.

Adalyn was diagnosed with cystic fibrosis following a newborn screen which Taylan and husband, James, strongly advocate.

Shortly after turning a year old, Taylan said Adalyn was hospitalized for 1 weeks with pseudomonas, the most damaging kind of lung infection.

As Taylan and James and the rest of family deals with cystic fibrosis, the couple said they've learned to trust God's time.

"We're not in control of the situation," Taylan said. "She's God's child and there's a plan for her."

Taylan said the couple also treasures life more and tries not to treat Adalyn differently than their other children—5-year-old Amaiya and 19-month-old Audric.

Fortunately, medical advancements through the years have pushed average life expectancy for people with cystic fibrosis to age 30, Taylan said, noting that most children with the condition in the 1950s didn't live to start elementary school.

"We're really hopeful for Adalyn's future," Taylan said.

However Adalyn might need a lung transplant at some point which Taylan described as one of the riskier transplants.

To help give back the support they've received from other parents of children with cystic fibrosis and help raise funds to cystic fibrosis research, the Carlsons started a sweet corn fund-raiser last summer.

James, a farmer, planted half an acre of sweet corn that family members—including his father and two brothers—picked by hand.

The Carlsons piled the corn in two four-wheeler trailers and parked one along Highway 30 in

Gothenburg and the other outside of Arnold.

Customers were asked to make a free-will donation that resulted in the raising of about $2,300 for the Cystic Fibrosis Foundation from the sale of about 18,000 ears of corn.

They plan to do the fund-raiser again next summer.

As Adalyn and the other children grow, James said he's learned to not take anything for granted.

"When Amaiya was born healthy, we knew nothing about cystic fibrosis," he said. "Healthy children are not guaranteed."

More information about the disease can be found at cff.org.

ebarrett@gothenburgtimes.com

308-537-3636v