

Labor of Love

Vicki Hughes and her husband, BJ, have been taking care of their 30 year old daughter, Jennifer, since birth. Jennifer was born with developmental delays and an uncontrolled seizure disorder, which was not identified until Jennifer was 7 years old. Jennifer previously participated in therapies, including Exceptional Equestrians, to gain as much strength and independence as possible, enabling her to walk, run, and participate with dressing and feeding herself. As Jennifer approached adolescence, her seizures began occurring on a daily basis. As a result, her delays changed dramatically and she became less independent. Jennifer can no longer walk independently and requires 1-2 persons to assist her since she is not capable of using an assistive device.

A typical day begins with Vicki and BJ getting Jennifer dressed and preparing her breakfast, usually oatmeal and yogurt. As a result of nerve damage and surgeries, Jennifer has little use of her hands and arms, and needs to be fed. They help maintain Jennifer's morning glow by washing her hair and face. Sometimes they add a piece of chocolate to Jennifer's breakfast, which really livens her up and makes her day, since chocolate and ice cream are Jennifer's favorites. They get Jennifer on the bus as she heads off to Rainbow Abilities Center, Monday through Friday. Jennifer gets off the bus around 4:00 p.m. and they begin their evening routine of washing up, eating a snack, and watching a little TV before dinner. Staying active is important to them so they maintain a regular routine of physical exercise. They often walk around the kitchen or basement, but when it's nice outside, they go for walks in the yard, which Jennifer loves to do. After supper, they get Jennifer ready for bed and read her a story before going to sleep. Her favorite remains Barney and Friends.

Jennifer loves animals and they love her. Jennifer has 3 small dogs, a cat and a horse. When Jennifer goes to the babysitter, their dog runs to sit on her lap. In addition to loving animals, Jennifer loves children. Jennifer and her dad enjoy listening to music together. Jennifer used to be a dancer. Even though her movement is limited, the music is still in her. Together the family enjoys going to church every Sunday. Everybody seems to know Jennifer in the community. Between bus drivers over the years, Autumn Hill State School, and Rainbow Abilities Center, she is well known. Vicki states that quite often people come up to them when they are out and about in the community and tell them that they are doing God's work, and thank them for demonstrating such love and care. "Caregiving is a huge deal. It truly is a labor of love. It can be very challenging and exhausting. You cannot do it alone. At least I would have not been able to do it alone," says Vicki.

Vicki and BJ have had to make sacrifices, including financial. Vicki's plan was to work full time but needed to cut back to part time in order to meet Jennifer's needs and still maintain a functional household. Vicki enjoys being outside doing yard work. "There is something relaxing and therapeutic about cutting the grass," she laughs. She also likes to read a good book but doesn't often find the time for it.

Vicki expressed she is greatly appreciative for so many things in her life. Her husband, BJ, has been hugely instrumental in the success of Jennifer's quality of life. They both say that they could not do this without the other. They also rely very much on the unconditional love and support of family and friends.

But most of all they are just grateful for Jennifer. "Having a child with Jennifer's condition certainly gives us a different take on life, but we wouldn't change it for the world. She is such a blessing to us all."