

## **Epilepsy Diagnosis Forever Changes Lives of Mother and Son**

Caregiver Joanne Lewis, 49, says the top challenges of her epileptic son, Justin, 16, are not being able to talk, use utensils, incontinence and dressing. But epilepsy alone doesn't explain his incontinence or inability to communicate.

Doctors didn't diagnose his epilepsy until he was almost 2.

"Because of the late diagnosis, Justin has permanent and severe developmental delays," says Joanne, who works for the Missouri Department of Social Services.

Brain surgery at age 8 helped control seizures that caused Justin to fall and lose consciousness, but it didn't correct the developmental delays. Joanne says Justin will always need someone to care for him because he has daily seizures and his mental ability is that of a toddler.

A typical day begins early for the duo. Joanne gets up first, at 6:30 a.m., and makes breakfast for Justin. She gets his anti-seizure meds ready and grabs his PediaSure, a nutritional shake that he drinks seven times a day.

"Because Justin doesn't eat foods like a typical teenage boy, Justin's pediatrician requires that he drink seven PediaSure cans daily to help maintain the desired weight and vitamins for a boy his age," Joanne says.

Next, Joanne wakes Justin, and more often than not, he has to be dragged out of bed.

"He doesn't like to get up because the medicines interfere with his sleep," says Joanne.

After she gets Justin dressed, she lets him lie down before breakfast.

After breakfast, it's time to put on Justin's harness and backpack for the school bus. He attends the H. Kenneth Kirchner School for the Severely Disabled in Jefferson City from 9 a.m. to 3 p.m. Monday through Friday. The backpack contains an iPad, equipped with a program that allows him to communicate. He can push an iPad button that says hello to his teacher. The backpack also contains a change of clothes to address his incontinence needs and a paper notebook. Joanne and Justin's teacher use the notebook to communicate. The teacher writes in the book to let Joanne know how Justin's day went, and Joanne, in turn, writes in it at night so the teacher is aware of any issues the following morning.

Most days at 4 p.m., Joanne has a nurse's aide help Justin off the school bus, prepare a snack and get him situated until she arrives at 5:30 p.m. Then mother and son's nightly routine begins. Joanne prepares dinner, gets his anti-seizure and anti-drooling pills ready, which Justin usually takes with applesauce and PediaSure, and helps Justin eat, toilet and prepare a bath before undressing for bed. She also writes in the notebook to let the teacher know of any issues.

Joanne has already begun to prepare for the day when she is no longer able to care for Justin. She is creating a special needs trust that outlines how Justin is to be cared for and by whom. Until that time, Joanne and Justin manage to find some fun.

“Justin loves to watch basketball,” Joanne says. “That’s his favorite thing. And mine is bowling.

Without fail, every Sunday night in August through April, Joanne and her four-person team play in a league.

“As a caregiver, she says, “you need to find some time for yourself.”