

### Liam and Jessica

#### Hope and help from the Ohio Home Care Waiver keep this Mom focused on the future

Life can change in the blink of an eye. Jessica knows this. It happened to her when her middle son, Liam, wandered off in the chaos of a family vacation and fell into a swimming pool.

Paramedics were unable to revive him. At the hospital, alone and in a strange city, with her son on life support, Jessica felt the burden of an impossible decision.

"I wanted to die. If he was going to die, I didn't want to live either," she admitted.

But Jessica became determined to bring Liam home to Ohio and make him well. "I put it in God's hands. I told myself, if God wanted him, he could take him on any machine."

Seven months later, Liam is home with Jessica and his two brothers. Danyal, a nurse, coos at him, suctions his mouth, and gently rubs his hands and arms. He's dressed like any 3-year-old – in Batman pjs, a huge mop of golden hair on his head. But Liam cannot talk, walk or hold his head up on his own.

A single mom, Jessica is resourceful and determined. She questions Liam's doctors, does research, and seeks out alternative therapies to help Liam's brain recover.

She learned about and raised the money for hyperbaric oxygen therapy, a unique treatment that may help reverse the effects of oxygen deprivation on the brain.

After his first round of treatments, Jessica saw improvement. Liam could open his eyes and seemed to react to things around him – someone turning on a light or his little brother racing into the room. Encouraged, Jessica raised the money for a second round of therapy scheduled to start soon.

Still, Liam requires round-the-clock care. Though he can breathe on his own, a machine helps regulate it and he requires frequent suctioning and repositioning to keep him comfortable.



*Clockwise from top: (l-r) Nurse Danyal, OHCW client Liam and Jessica; Jessica, Liam and Care Manager Kim; Jessica and Kim. Jessica is working to help Liam recover from an accident in a swimming pool. Liam requires 24/7 care and Jessica has two other boys at home. Through the Ohio Home Care Waiver, Liam has a Council on Aging Care Manager (Kim), and two nurses who help with his care.*

## OHCW Client Story Continued...

Medicaid helps cover the cost of most of Liam's medical care and equipment. But not the hyperbaric therapy or seemingly basic things like a special car seat. Another point of frustration has been occupational and physical therapy. Liam has aged out of Ohio's Help Me Grow program, which provides in-home therapy. So, Jessica drives Liam to therapy two times a month, watches meticulously, and then does the therapy with him three to six times a day at home. "Nothing hurts so bad as seeing him like this every day. I'll do anything I can to make him better," she said.

Jessica manages all this with the help of her "tribe." A close network of friends help fundraise for Liam's care and maintain a Facebook page, and two nurses, including Danyal, come to Jessica's home to help with Liam's care.

The nurses are provided by the Ohio Home Care Waiver, a Medicaid-funded in-home care option for children and adults who have significant disabilities and/or mental health needs.

When Kim, Liam's Ohio Home Care case manager, first met Jessica, she saw that she would need help if she was going to have anything left to give her two other boys, ages 2 and 9.

With help from the nurses 16 hours a day, seven days a week, Liam gets the care and attention he needs. A nurse goes with Jessica and Liam to doctor's appointments and therapy, and they help make space and time for everything else Jessica needs to do – homework, grocery shopping, playtime, baths and housecleaning.

"When I walk in the door, I see how much those other kids need her," said Danyal. "When I'm here, the other boys can have their Mom."

Jessica said the help is a huge weight off her shoulders. "My biggest priority is getting Liam better and making time for my other kids. [This program] helps me do that."

There's a lot of respect between Jessica and Kim.

"Kim is awesome. She makes sure we're OK. When I wasn't happy with one of Liam's nurses, Kim managed it for me so I didn't have to deal with that stress, too."

Kim is a veteran social worker, but she struggled to find words to describe what Jessica is doing. "I think I'm pretty good at keeping it together, but you are so strong. Your strength is inspiring. Despite your loss, you have hope."

Jessica does have hope. Not only for Liam, but also that she might soon be on the other side of this journey and be able to bring hope to others in similar situations.

"This is by far the hardest thing I've had to go through," she said. "I want to go to school and be a nurse so I can give hope to other families."