

October 2, 2024

My name is Mary Ann Johnson. My son, Scott Johnson, was a resident at Lakemary Center in Paola, Kansas from August 1984 until his death on December 20, 2021. Scott had been diagnosed with Prader-Willi syndrome. He was also autistic. He had severe behaviors. At the time Scott was admitted to Lakemary Center he was very obese. Obesity is part of Prader-Willi Syndrome.

We chose Lakemary Center because of their success with another Prader-Willi syndrome child. It took a while for us and for Scott to adjust to this new living arrangement. We lived 7 hours away. But soon Lakemary had him on a special diet and he started losing weight. He still was having a lot of behaviors. His behaviors were severe, but they found ways to help him control them. Being consistent was important.

He continued attending school at Lakemary Center and graduated at the age of 18. He then went into adult services at Lakemary Center. That was an “ugly” time. Consistency was important in Scott’s life. Change was not in his vocabulary. He did not do well. It took several different living arrangements before he was comfortable. Anna Perkins came to work at Lakemary shortly after the correct living arrangement was in place.

Anna was his case manager. She knew how to work with him. Scott liked his living arrangement. He loved his room. When there was a staff change, it did not work very well. It took a while for him to get used to that person. Anna was always there to help. Yes, there were still behaviors, but he was taught how to control them. Life at Lakemary became normal for him. It was consistent! Especially important!! His quality of life was good. Anna worked with staff to show them different ways to handle his behaviors and his eating challenges.

In September of 2021, Scott broke his hip. He was hospitalized and surgery was done. Trouble began. His life was changing, and he did not like it. Anna and the staff could not be there with him. His routine had changed. After his hospital stay, he had to be admitted to a care facility in Osawatomie KS. It was awful! They did not know how to work with Scott. He was in pain, and he was scared. The behaviors got worse. To go back to Lakemary he had to learn to pivot in bed and get out on his own to use his walker. The staff did not know what to do. Anna tried to teach them ways to work with Scott. There were different staff every day. That did not work. It had to be consistent. They fed him to keep him from screaming; He gained a lot of weight. Not a good situation!

Finally, right before Christmas, he was going to be able to go back to Lakemary. When they went in to wake him up, he had passed. He was 46 years old.

I will always feel that because of the care he received there, all the food they fed him, and the inconsistency caused his death. The staff at that nasty place did not listen to Anna on how to work with Scott.

It is so important to have the consistent care of a good Case Worker, one who knows his or her client. It is necessary!!! Anna Perkins was that Case Worker. She made sure that Scott's needs were taken care of. She made sure that there was consistency in his life!!!

Sincerely yours,

Mary Ann Johnson