

SUCCESS STORIES

We invite our visitors to tell their stories of how their advocacy has impacted the quality of life of their loved ones. We also welcome stories of what happens in “person-centered” or “person-directed” nursing facilities, from residents, families, or professionals who make it all happen every day. Please submit your success stories to contact@ourmothersvoice.org. We will post appropriate stories at this location on our web site to share with others, encouraging them to advocate for Quality of Life for their family members and all people in nursing homes. We will protect identifying information and may edit for length, but we will remain true to the stories submitted when we publish them.



**“Joy Cometh in the Morning”
By Carol J Hay**

True Quality of Life makes each day more enjoyable for every resident.

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KAYE'S STORY

Kaye has developmental disabilities, severe cerebral palsy and rheumatoid disease. She is very polite, and often inconveniences herself to keep from "bothering" others, especially the staff who care for her. Kaye likes a quiet environment in her home. When two new residents moved into her facility, the noise and disruption they caused made her think it might be time for her to look for another place to live. Her own personality just could not handle the constant agitation of the new residents. She knew those new folks needed the care provided in her current facility, and she was ready for a change anyway, so she took matters into her own hands. She approached the administrator and asked, "Do you have any homes for handicapped people?" She pointed to her walker, indicating she would require accommodation such as ramps and level floors.

The administrator, a little (pleasantly) surprised by Kaye's sudden assertiveness, replied that she did indeed have such places, and in fact a new home was being purchased at that moment. She told Kaye that her name had just become the first on the list of people to move in when the facility was ready. Kaye further told the administrator why she needed this change, and the administrator agreed to look for compatible personalities for this small facility, so that all concerned could have a peaceful existence. Kaye and her new housemates got along for the most part, enjoying one another's company and generally working out any differences they may have with the help of the staff. One day, however, three of the women were waiting for the administrator to come in to work. They marched into her office and said, "We don't like that sweetener stuff you make us put in our tea! It doesn't taste good. We want sugar!" The administrator reminded them that their health concerns (diabetes, overweight, and other considerations) meant that sugar was not to be included in their diets, by order of their doctor; however, a new sweetener had just hit the market that was supposed to taste like sugar and not have an aftertaste. She asked if they would try that product for a few days and let her know how they felt about it. They agreed, the facility purchased the sweetener, and the following Monday the women reported that the new sweetener was acceptable.

Several years later, state budget cuts threatened the funding for the residential service which supported Kaye and her housemates. Kaye again approached the administrator concerned that she would have no place to live if the cuts eliminated funding for her living arrangements. Kaye asked the administrator what she could do to let her legislators know how important her services were to her. The administrator helped Kaye by typing a letter which Kaye dictated, expressing her concern and the necessity for funding to keep her place in the facility – her home. She then asked to hand-deliver the letter. The facility arranged for Kaye to attend an event where her legislators would be present. Kaye hand-delivered her letter to each of her legislators at the event. Needless to say, funding for services for Kaye and for those like her was spared.

Kaye, who often remained quiet so as not to inconvenience others, certainly found her voice; and she used it loud and clear, even though her speech was severely impaired by cerebral palsy. Because her administrator and the staff who worked with her listened, Kaye was able to advocate for not only herself but also her housemates and disabled people all over the state, to secure a better quality of life. Kaye's story is one example of how person-centered care can empower people, and make differences big and small in the quality of life of individuals, groups, facilities, and systems.

TRISTAN'S STORY

Tristan was an 11-year-old boy diagnosed with Autism Spectrum Disorder. He was extremely bright, but had behavioral and social difficulties and the typical environmental stimulation issues.

Tristan's school was not meeting his developmental needs as required by federal law, but his mother did not know about that law. She dutifully followed the instructions given her by the school personnel in her efforts to control her child, who was responding to the school's mistreatment and failure to meet his needs by acting out toward teachers and other students, and bringing that anger home to his family. The school district was criminalizing Tristan's behavior, involving juvenile justice whenever Tristan had a behavioral outburst. They advised Mom to do the same. Understandably, Tristan began to display mental health issues. Unfortunately, those were also misdiagnosed, and he was placed on inappropriate medications.

His mother removed him from school and enrolled him in another school outside his home district. She drove him to school every day. The new school followed suit, continuing to involve law enforcement and pushing Tristan farther into the juvenile justice system. He was on probation at the age of 11!

Tristan's mom had consulted mental health services, and Tristan was taking multiple psychotropic medications. He began to develop involuntary body movements and tics, which only served to make him stand out even more from his classmates. They contributed to Tristan's difficulties by making fun of him and reporting him to his teachers, who in turn punished him because of his behavioral issues. Of course, all this escalated the situation to a crisis state. The so-called "professionals" were pushing Tristan into incarceration, or alternatively, institutional placement in inappropriate facilities.

Our Mother's Voice provided Tristan's mother information about the federal law governing education of persons with disabilities, and about psychotropic medications in children. Mom toured an agency that enables people with disabilities like Tristan's to thrive in their home communities with proper supports. With this knowledge, Mom hired an attorney specializing in advocacy for children like Tristan, who assisted Mom in confronting the school district with their violations of federal law and educating them in their responsibility for meeting Tristan's developmental needs. Mom gained confidence with this knowledge, and became a strong advocate for Tristan.

Tristan is now a teenager who loves school, is thriving in the schools in his home district, and is receiving appropriate supports for his needs. His medications have been reduced and changed to appropriately manage his mental health issues. The tics and involuntary body movements have subsided.

Tristan will always need specialized services and supports, but empowering his mother with information about federal law and proper treatment for Tristan's developmental disabilities has truly made the difference between tragedy and success for this child!

MELODY'S STORY

Melody is a friend of my sister's who contacted her despondent because her father, diagnosed with severe dementia and living in a nursing home, was not able to feed himself. This fact was noted in his plan of care, as was the requirement that he be assisted by staff to enable him to eat. He had to be fed. One day Melody arrived at the facility to find no staff with her father, and his lunch in his lap. She saw that he had lost weight. She didn't know what to do.

With the information we provided her, and with encouragement from my sister to bolster her courage, she subdued her emotions, wrote down all her observations with date, time names, and specific descriptions of what had transpired. She cited both good and bad observations, and with the negative ones identified violations or failures to follow the plan of care.

She went to the facility's Administrator with her documentation, and a long conversation with him. Almost immediately, she noticed changes. Staff behavior changed. Staff assignments became more consistent. Care plans were followed. And one staff member is no longer at her father's facility.

Her father passed away recently, but the quality of his last days was improved dramatically because of Melody's advocacy. And he leaves a lasting legacy of improved quality of life for all the residents who still live in that nursing home.

HOW OUR MOTHER'S STORY ENDS

Our Mother lived for 5½ years in long-term care with severe, late stage, and end stage dementia. The first months were terribly difficult for her and for us, as we advocated for needed systemic changes in her facility so that not only she but also the other residents would have a better quality of life. The process took a few years, and just as with all human endeavors, it remains ongoing.

This story is about the difference advocacy made in her quality of life. Our Mother went from having infections and dehydration every six weeks to having over two years of good physical health. She went from agitation and not being on the correct medication regimen to being treated by a geriatric psychiatrist with a knowledge of the brain changes in dementia and how different medications act on those changes. He prescribed the correct medications. She stabilized and had moments of alertness until the last months of her illness. She went from not having meaningful activities to engaging in moments that were important and meaningful to her. She received the therapies necessary to keep her moving as much as her condition allowed, and to keep her able to take in nutrition and hydration by mouth as long as possible, even though her underlying condition meant that she could not be “rehabilitated.” Because of these therapies and an enlightened dietician, she was able to receive a modified diet which included provisions for whole foods on days when she was alert, even though her ability to chew and swallow was compromised. With stable staff assignments, her caregiver learned to recognize changes in her status, so that decisions could be made regarding how or whether to provide whole foods. Her staff also learned to recognize “atypical” indications that she may not be feeling well – and that she was not simply being “noncompliant” or “lethargic.” They began to look for causes for these changes and address those causes.

Our Mother benefited from the change in organizational culture that was brought about in her facility. We are grateful that she lived long enough, if not to know what happened and why, to experience in her own way the improvement in her quality of daily life that resulted from her advocacy for herself and her fellow residents. Our mother's voice, although silenced by dementia, continues to speak through us as empowered advocates to impact the lives of not only loved ones, but those we have never met.