Sisterly Love!

January 2022 Caregiver of the Month, Melissa Frey and Rebecca Monroe
Missouri Department of Health and Senior Services

Tammy, the oldest child of her family, was born with Leber's Congenital Amaurosis (LCA), as well as intellectual and developmental disabilities. LCA is a rare inherited eye disease that caused Tammy to be blind at birth and led to additional neurological degeneration. Tammy became deaf around the age of six, and unable to walk at the age of 12. At age 19, Tammy had an Anoxic Brain Injury (ABI) which resulted in diminished abilities; she required the use of a ventilator to breathe. Tammy has two sisters, Rebecca and Melissa. Their brother, Corey, was born with developmental and physical disabilities and passed away at the age of 5.

Tammy's mother, Jenny, devoted her life to her children. Jenny cared for Tammy at home each and every day and tirelessly advocated for in-home nursing care. She knew the best place to care for Tammy was at home, even if it meant she would take on all the responsibilities. Tammy has always been a central part of the family. Jenny always found ways to make sure her children bonded and had a special connection. Life revolved around family and the commitment to care for Tammy. Jenny was the ultimate example of compassion, patience, and endurance.

When Jenny passed away in 2017, Melissa and Rebecca unexpectedly found themselves being caregivers for Tammy, whose complex medical conditions require a high level of nursing care. They had no idea about what would be required for Tammy's care. Melissa stated, "We had no idea about the next steps and had to learn it all on our own. Our mom had discussed her wishes for us to care for Tammy if she ever passed away, but I wish we would've talked about this in more detail, planned, and trained for it. This would have saved a lot of anxiety and tears." Tammy's uncle moved into the family home shortly after her mother passed away. He has been a constant comfort to the family and the main reason Tammy has been able to stay in her own home. He is a steady presence to Tammy and is always talking to her and telling her stories.

Tammy receives around-the-clock nursing care and is completely dependent on others for all daily living activities, in addition to needing monitoring and care for her ventilator. Rebecca and Melissa both serve as primary caregivers to Tammy. They are responsible for providing care to Tammy on a regular basis and filling in when nursing staff are unavailable in the home. Tammy's acute needs can prove challenging. On occasion, they receive a late notice that nursing staff will be unable to fill a shift and must be available at a moment's notice.

One promise Melissa and Rebecca made to each other early on in their caregiving journey was that neither sister would work a shift alone. The sisters' abilities for caregiving complement one another. Melissa states that Rebecca is better at details and provides the majority of nursing care while she offers a more comforting role. They feel fortunate to have each other's support and acknowledge that many other caregivers do not have this option. Caregiving for Melissa and Rebecca may mean working their day job for 8+ hours, then working an overnight nursing shift for 12 hours, and maybe even having to return to work the following day depending on scheduled items or deadlines. Melissa realizes the luxury of having her sister by her side and "can't imagine doing this by myself."

In addition to being caregivers for Tammy, Melissa and Rebecca both have families of their own, as well as demanding careers. "Our spouses are the best! They always take care of our households and whatever else as we manage our caregiving duties." Melissa is the Executive Director for an agency that provides case management to individuals with developmental disabilities. Rebecca is a Licensed Professional Counselor for a community health organization. Growing up with Tammy, the two have always been able to empathize with individuals with developmental disabilities, but being a caregiver for Tammy has definitely given them a new sense of empathy for other caregivers.

When she is not working or caring for Tammy, Melissa loves to read, journal, and watch her sons play baseball. In her free time, Rebecca enjoys swimming in the summer, watching her daughter play basketball, and cleaning.

Tammy enjoys car rides, massages, music, and having her uncle tell stories. Tammy also enjoys experiencing movement and touch. She has a "shaky vest" (percussion vest) that is used to break up mucus in her lungs. She loves the different vibrations of the vest and it will usually put her to sleep! Tammy is extremely smart. Tammy learned sign language at an early age. Melissa and Rebecca learned how to sign into Tammy's hands (much like Helen Keller learned), communicating 'yes,' 'no,' 'kiss,' 'all done,' 'bye,' and 'Tammy.' Due to her ABI, Tammy has been unable to sign back. Although she is non-verbal and deaf, Tammy still likes to be talked to and can communicate in many other ways. She laughs, smiles, cries, and likes to tease. She is very loving, has a great sense of humor and enjoys animals and babies. In her childhood, she often lined her bed with stuffed animals. Tammy loves the smell of lilacs and has a lilac bush in her yard.

Melissa and Rebecca celebrate holidays and birthdays with Tammy in the family home and find ways to carry on family traditions. They make a special point to include other family members and Tammy's nieces and nephews in these celebrations.

Melissa and Rebecca want other caregivers to know: "You're not alone; take it easy on yourself; ask for help when you need it; and it's ok if you don't know it all! Even with help it's still hard, but WORTH IT."