

Blazing a Trail for Other Family Caregivers

Rachel Hiles grew up as an only child and the only grandchild to her grandmother, Barbara, who is now 81. Barbara took care of Rachel while her mother worked so they naturally grew close, forming an inseparable bond over the years.

Rachel began her caregiving journey in 2013 when Barbara lost the house that she had lived in most of her life. After going through this traumatic experience, Barbara began having trouble remembering and soon after, she had her first colostomy procedure.

After recovering from the procedure, Barbara remained independent in her home for about a year while Rachel checked on her couple times a week. In May of 2015, Barbara fell and fractured a vertebra. While in the hospital Barbara developed diverticulitis in her colon which resulted in another colostomy procedure. Barbara stayed in hospital for three weeks and spent three months in a rehab facility. During that time, Rachel visited Barbara every day making sure she received proper care. In September 2015, Rachel became Barbara's primary caregiver as she required more help than ever before. Barbara continued having trouble with her memory. She could no longer drive and required a walker to get around.

Rachel continues to visit Barbara every day after work. She prepares her dinner, creates a menu for the next day, and sorts through the mail. They recap the day's activities with the help of a daily sheet that Rachel created to help both of them remember key points of the day, which also includes a section for pain and colostomy tracking. Rachel spends a lot of time on weekends preparing for the week ahead doing laundry, shopping, medication set-up, and making a schedule for the week. Barbara also has friends, family, and a "day lady" to take her to appointments and assist with daily activities.

Rachel's ultimate goal is for her grandmother to age in place at home and be involved in her community as much as possible. She has relied heavily on technology to provide oversight of Barbara while she is not there. After having a serious fall, Barbara agreed to get a medical alert device. Rachel used this as a stepping stone for Barbara to become more comfortable with technology, as it has taken some convincing.

"The future of caregiving through technology is exciting to me. As millennials, we are on the front edge of technology to allow people to live independently in their homes," says Rachel. She installed the "Nest" thermostat, which has helped her regulate the temperature in the home, monitor who comes to the home, and alarms her if Barbara has fallen. Technology has significantly reduced Rachel's stress as a caregiver.

Rachel and Barbara are a generation removed from each other and have different personalities. Getting along with each other as adults and having a caregiver relationship has been a unique experience for them. "It can be gritty, emotional, and messy," says Rachel. But she will always cherish the time she spends with Barbara.

“The younger generation doesn’t recognize themselves as caregivers. There are resources out there for people who take care of loved ones. There is a need in helping families realize that they are caregivers and figure out how we can break down barriers and help everyday people get what they need. The best thing people can do to support caregivers is to listen to the family’s needs, instead of imposing their viewpoints. Every family is different.”

Rachel also says “It is impossible to take care of others if you don’t take care of yourself. It is easy to get burnt out. Build in time to take breaks. There are ways to do this that don’t cost money. Be creative and find what’s important and do what you enjoy.”

Rachel works full time at Missouri Family to Family Resource Center, housed at the UMKC Institute for Human Development, working on initiatives that support people with disabilities and their families. Rachel feels blessed to work where she does because it has allowed her to have more awareness of resources and policies that affect families and those with disabilities. She has learned values and tools for how to be a good caregiver.

Rachel will be doing a Caregiving Consultant Training in 2018 as well as facilitating quarterly meetings for Family Caregiving. Her goal is to start a Caregiver support group so people can get together to connect. If you want to read more about Rachel’s caregiving story, you can visit her personal blog at <http://takingcareofgrandma.com/>.