

Community Heroes Give Back During Alzheimer's and Brain Awareness Month *"Sandwich Generation"*

Joel Berman, Caregiver, Bayside, WI

Joel is a part of a growing community called the "sandwich generation" – meaning they care for an aging parent and children under 18. Joel's parents, Joan and Jerald, have been married for 60 years. Over the last decade Joel and his family have noticed his mother "slipping" while she and their father were still in their home. Common observations like losing things and hygiene issues became a challenge. His mother has a history of Alzheimer's disease in her family, so this was something her children were watching for.

Joel stepped up his involvement over the last 2 ½ years. His mother was experiencing extreme anxiety and couldn't be alone and was struggling to manage basic hygiene and medication management. Basic upkeep and cleaning of their home became too much for his parents and his mother increasingly had verbal outbursts. It also became apparent she was not safe to drive, so the family had to take her car away.

Joel was frustrated with the health system in place for his parents. "Her primary doctor should have recognized red flags years ago," says Joel. "She had several medical conditions and it came to light that she wasn't taking her medications, which ultimately led to an ER visit where she was treated for low blood sugar, malnutrition and confusion." The family went with their mother to a geriatrician and she was diagnosed with dementia and Alzheimer's. The doctor told them to consider assisted living.



Navigating the System

The decisions that came with a transition like this were insurmountable for Joel's parents. While his father was in good health, he was unable to make these life-changing decisions. Joel became their Power of Attorney and shifted a huge amount of his time to helping manage what their next steps would be.

Once Joel became involved in the decisions-making for his parents, navigating complicated services became a mission for him. "I have a passion for public service," says Joel. "I want to ensure there is effective use of funds to serve the public."

There are obvious financial implications with a transition to living in a community and Joel was facing the reality of supporting his parents financially if he couldn't secure services for them. "This process has made me more aware of the shortfalls of Medicare for those living with Alzheimer's," says Joel. "So many cannot afford private pay for the homes they need." Joel researched everything he could on Medicaid, in order to ensure she could afford to live in a memory care facility. He took over daily financial management for his parents to understand what social security and other income sources they had to work with. He also started "camping out" at the County Aging Department to advocate for his parents and make sure proper paperwork was in place. His father is also a veteran so he investigated what VA options were available that they hadn't been taking advantage of. "I needed to help my parents get financially stable," says Joel. "This was important to make sure they were medically stable and safe."

Another hurdle to his parents' transition was the sale of their home. Joel had to hire a realtor and contractors to help modernize their home, in order to get it on the market. He had to sort through a house full of 60 years of memories, purge and donate items and move his parents to their new residents. "It has taken a toll on our family for sure," says Joel. "I feel like I'm running 3 lives, but that's just what you do for you parents."

Transition to New Homes

“We knew my parents had to move, but that didn’t make it any less traumatic for them,” says Joel. “My dad didn’t have the capacity to care for my mom and he needed more social interaction himself and to see his peers. It took us a year and two near-death experiences to finally get her moved, because she wouldn’t acknowledge a problem.”

Joel’s mother has now been in the memory care center at the Helen Bader Center at the Ovation Jewish home for about a year. While she has a good understanding of some things, she believes she has only been there a few weeks and that she is going home soon (her doctors have advised family not to tell her she is there permanently, as it would be too upsetting). His father is now residing at Deerwood Crossings Senior Residence – Independent and Assisted Living, also owned and operated by the Jewish Family Services of the Milwaukee Jewish Federation.

Balancing Caregiving

“We’ve had a lot of life changes,” says Joel. “We’re balancing many pieces that we weren’t in the past.” Full-time work, 3 children and primary point of contact for parents is an overwhelming responsibility. As primary contacts for his parents, Joel and his wife get regular calls from the memory care center for his mom. Joel’s mother-in-law is also in deteriorating health so they are managing that as well. Joel has a 24-year-old daughter who is a nurse, a 22-year-old son who is in college and a 17-year-old son who is high school.

Joel is a Project Manager at Direct Supply. He has many occasions where he had to leave work for an emergency, which is a common challenge for the “sandwich generation.” His company, which makes products and services for the senior community, has been supportive of Joel and given him the ability to work on nights or weekends, when emergencies have come up. Direct Supply has their own advocacy group and is supportive of public policy supporting seniors.



The Tough Conversations

Joel has some very practical advice for other “sandwich generation” caregivers or anyone who suspects their parents are struggling with the early signs of dementia:

- **Get on your parents Health Insurance Portability and Accountability Act (HIPAA) form.** “As early as you can, make sure you’re able to meet with their doctors and freely discuss your parents’ medical conditions,” says Joel.
- **Engage a geriatrician**, who specializes in elder care. “Don’t go to a primary doctor if you suspect any symptoms of dementia,” Joel advises. “When my mom was diagnosed, she was already at mid-range Alzheimer’s (way past mild symptoms) and her primary doctor should have tested her earlier. You need a specialist who can intervene before conditions worsen.”
- **Monitor Medications.** “We should have recognized earlier that mom wasn’t taking her medications,” says Joel. “She was fighting my dad on taking her pills, which exacerbated her other medical issues. Get help to ensure this is being managed.”
- **Get involved with financial management.** “This is a hard discussion to have, but don’t wait until you’re in a desperate situation,” says Joel. “If competency is a problem, you need to be an advocate for your parents, no matter how hard that discussion is.”

Changing Policy

“We need more advocates to support this fragile community,” says Joel. “Families are facing a crisis and need better support to navigate the system. Legislators need to hear the facts and see what people are actually facing.” He suggests this community will continue to need policy change. “Realistically people are living longer and we’re prolonging life,” says Joel. “More attention needs to be given to support the families that are living with this disease every day.”

“We also need to look at the wages of the staff who care for our parents,” says Joel. “These people are not making livable wages and need to get paid for the invaluable services they provide.”

Get Involved

Joel is a volunteer with the Alzheimer’s Association. He is on the Alzheimer’s Impact Movement (AIM) Committee and serves as the AIM Chair for the Walk to End Alzheimer’s in Milwaukee. His role is to keep the Walk community aware and engaged in issues the Association is advocating for on a state and federal level. “I enjoy using facts to bring light to the issues that face this fragile community,” says Joel.

For Alzheimer’s & Brain Awareness Month we salute the strength and perseverance of caregivers like Joel. We need to create more awareness for the changing needs of those impacted by Alzheimer’s and other dementia.