

Wisconsin's Family Caregiver Crisis: The State's Invisible Epidemic

Family Caregiver Statements

Michele Ertl-Rosner, Slinger

My name is Michele Ertl-Rosner and I live in Slinger with my husband and three of our four children. Our oldest moved out on his own after buying a duplex earlier this year.

This is my caregiving story:

I am a caregiver for my 19-year-old daughter Julia who requires round-the-clock care. We have nursing staff in our home 10 hours a day during the week, and my husband and I cover the hours that are left and all weekends. We basically provide Julia the level of care needed for a newborn, along with a lot of medical care. We get her in and out of bed, the bathtub, take care of bathroom needs; we physically move her to every place. She gets nearly 50 doses of medications and several respiratory treatments every day. We puree all her food and feed her through a g-tube. She has daily seizures, and we do deep suctioning - she must always be in our line of sight to keep her safe and alive.

My husband and I are true partners in caring for Julia while parenting our other kids and meeting work obligations. It requires both of us working together to keep our family in balance. We're constantly working out who's taking care of Julia while the other takes care of other tasks. It's been challenging to keep our marriage strong - it's hard to find any time to spend together.

There have been a lot of sacrifices over the years. I'm pretty confident the fallout from Julia's month-long hospital stay in the ICU was big part of why I lost my corporate job of 24 years. I've turned to freelancing so I can have the work flexibility I need to meet Julia's needs.

My other kids have also made a ton of sacrifices. Julia is at great risk for respiratory infections, and COVID is a very real threat to her. Her siblings know that and decided to basically give up a year of high school to help protect their sister.

We do this because we love her. We want her to have a life filled with wonderful experiences in spite of her limitations. Just because she is medically fragile doesn't mean she should be locked away. For us, the reward is that she is still alive to spend another day with us.--

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Christine Lidbury, Madison

My name is Christine Lidbury - I am a single mom to my adult college student daughter, and I work full-time. We live in Madison. This is my caregiving story.

I'm providing support for dad, who is in 80s and has Parkinson's and dementia. He lives about an hour away.

My mother had multiple sclerosis and he cared for her for 50 years and ensured she could live at home. He wants, and I want, the same for him. Mom passed about a year ago, and now Dad has gone into steep decline. The weekend caregiver quit earlier this year, and I haven't found a replacement. I take over the weekend shift - Friday dinner to Sunday bed, - in addition to what I've always done to manage his house, finances, hire and manage caregivers, and all that medical care, I do weekend meal prep, feeding, personal care, toileting, getting him to bed, and "staff" the overnight. He is no longer able to stand independently so I learned to use a Hoyer lift. A couple weeks ago we think he had a small stroke and now can't speak to communicate what he needs or wants. It changes week by week.

I am an only child, so it's just me who can step in. I have significant health issues too. And some people ask - Is this too much for you? "Yeah, it is, but what do you do?"

I have reshuffled my job and schedule. I try to get all my work done in 3 to 4 days per week, but I can't fully focus. I'm working the entire weekend, getting back late Sunday evening, and am exhausted on Monday. I'm burning through my sick leave and vacation; I don't want to take FMLA because I may need it to manage my own health living with chronic illness. The stress is impacting my health.

All my worries are short-term right now. And that's a problem. It affects my work and what I'm able to plan for. We are basically in a holding pattern; living in intense crisis.

Why do I do it? When my dad was caring for my mom he kept saying "we don't throw people away". It's a sacred duty. And so now I need to be the caregiver, and I wouldn't be anywhere else.

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Mary Beth Freckmann, Oconomowoc

My name is Mary Beth Freckman, and I live in Oconomowoc. I am single and own my own business. This is my caregiving story.

I am the caregiver for my adult daughter with Down syndrome and my aging parents. My daughter Maddie is 28 and lives with her husband who also has Down syndrome and recently lost both of his parents. I am their main support. I check in with them

regularly about tasks they need to do. Sometimes I have to go over and help clean, give financial reminders, help with medications and grocery shopping. Maddie has had three brain surgeries in the last 7 years so it's important for me to continue to support her.

I recently moved in with my aging parents. They are 85 and 87 and I am the only one available to support them. Dad is now bedridden and has had multiple falls; mom's health has also declined, and she is recovering from a recent surgery. We have a caregiver one hour in the morning and evening - the rest of the time I'm helping with the toileting, turning, lifting. I can never sit down longer than 30 minutes without someone needing something from me.

This has all been so difficult we agreed to look for a nursing home placement for Dad, which was not as easy as it sounds. I made countless phone calls over weeks with a series of dead ends and frustrating answers. We did finally find a nursing home placement last Thursday for my dad in Cedarburg (after more than 2 months of searching)...much further away from where we had hoped, further from my mom and an hour drive for my oldest brother and I.

I recently became a realtor, and I am still building my business. I have no FMLA, or other source of income. If I don't work, I don't get paid.

My life is not my life right now, and I feel guilty saying that. I can't take time to see my sons or friends or meet clients. I've spent years building this business but it's now on hold.

There is no way to plan for the future right now.

What would help? If I had money to support me through this intense caregiving time, so I would not have to financially worry about what caregiving is doing to my personal finances, it would relieve half of my stress. I would be able to be more present with my parents.

Even though this has been incredibly hard, I have felt grateful for this time with them because I know I really don't have a lot of time with them. Comfort is a gift I can give them right now.

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Denise Roman, Waupaca County

My name is Denise Roman, and I am the caregiver coordinator for Waupaca County as well as a caregiver myself. This is my caregiving story.

I am right now caring for my Mom - and before that I cared for my husband who was diagnosed with terminal cancer, and my father, who both passed away in 2016.

For my husband it was really hands on. Lots of palliative care. I flushed lines, managed medication. I took a leave of absence from work. We started hospice the last 6 months of his life, which was really for me. When my husband was dying, I lost so much time with my daughter, missed her high school years. COVID allowed me a year with my daughter and mom under the same roof and it was such a great opportunity.

My father suffered a massive stroke at 80 and passed away at 90. We provided respite care for mom, and she provided all the care for him. On the weekends I took care of bathing him, getting him in bed, and spending time with him so mom could decompress.

Now I'm living with my mom who is 85 and caring for her. She is physically well but declining. We are in a rural community and I wish my mom would have more support other than just me. Folks like her who need a little support have nowhere to go, no agency to support them, and that can be the difference between staying at home and heading to a nursing home.

I've been a caregiver for so long, for 15 years. What happens when I don't have anyone to care for? When death occurs, there is a relief and guilt. It's so hard to plan for the future when I don't know what it will be. My husband passed quickly, and my father had a long decline. Will mom be here a year or ten? What will my future be after?

I have three brothers, and I'm the only girl. My three brothers do not have the same expectations or responsibilities with it comes to caregiving. I moved from another area and uprooted a career to provide care, I don't resent my brothers, but the changes in my life have been profound. I have taken on the additional responsibilities and a disproportional amount of work. The impact of those decisions gets all the positives but there is also this thought about what might have been.

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Deatrice Ash, Milwaukee

My name is Deatrice Ash and I live in Milwaukee. I am a single mother and have been a caregiver for my 19-year-old daughter Dartrice since her birth.

This is my caregiving story:

I do everything for my daughter on a daily basis. From the time I get up at 5:30 to the time she goes to bed to about 9, 9:30, unless she's in school. She is nonverbal and she can't walk without assistance. I help her with medications, her personal care needs,

toileting, showering. She can feed herself some finger foods, but otherwise everything is fed to her. She cannot be left alone because of her seizures.

I have a little help but it's not reliable. I am supposed to have someone here to help every day. But people don't want to work for 9 to 10 an hour - it's hard to find people to work for those wages. Mostly I am the night help and the weekend care. I pick up the pieces.

I am thankful my two jobs are flexible, and they try to work with me because my help for my daughter is so unreliable. I basically don't have a social life. I have to care for my daughter and whatever I do she's with me.

I worry about the future. After she is done with school at age 21, there really is no place for her to go after 3 and most work hours last until 4:30. I may have to leave the workforce and I'm already struggling to make ends meet.

I've also been supporting my mother who is 88. She needs help getting to doctor's appointments and I worry about her. I also have my own medical issues. I'm supposed to be in aquatic therapy from my back. I have extreme back pain and arthritis, but I keep on going, I keep on going.

It's been a struggle for me. A lot of the times I feel like we've been abandoned. We all deserve proper care, regardless if we're disabled or elderly. Everybody deserves that right. It gets rough some days, but I'm just thankful to still be alive to do what I need to do for my daughter and my mother.