

Relationship with Our Families

The sandwich generation

Raising children and caring for ailing parents isn't easy, but there is support

By Laurie Kaiser

Maggi Debus' alarm clock recently rang at 2:40 a.m. She climbed out of bed to wake her 5-year-old son whom she was training to use the toilet at night. A few hours later, she was up again when her 86-year-old mother needed help getting back to bed.

This was no unusual night of wakefulness for Debus, who lives in the same Buffalo Victorian home where she grew up. Rather, it's a typical scene in the life of the 44-year-old mother of three and primary caregiver to her mother, who suffers from high blood pressure, stomach ulcers, and a numbing condition in her feet that makes it difficult to walk.



Photo by Michael Mejewski

Maggi Debus, the mother of three young children (pictured), also provides live-in care to her 86-year-old mother, a practice that defines the "sandwich" generation.

The push-pull of children and aging parents is an increasingly common story for millions of adults who find themselves stuck in the "sandwich generation." And they are one rest-deprived lot.

According to a 2011 report from

the Pew Research Center, 30 million Americans are unpaid caregivers for their aging parents, and many of them are also raising children or supporting an adult child who has moved back home. The numbers are high in Erie County, where

“My parents helped me when my marriage was falling apart, now it’s turned full circle.”

— Maggie Debus

15.8 percent of the population is over 65 years old, compared with 13.7 percent in the state.

“People who end up as caregivers often put their own needs on the back burner,” said Miriam Callahan, project coordinator for the Erie County Department of Senior Services Caregiver Resource Center. “They make sure their loved one gets to the doctor, but not themselves.”

The youngest of nine children, Debus spends a fair amount of time taking her mother to medical appointments and ensuring she takes her medication, along with juggling her kids’ activities and maintaining their 4,000-square-foot house. Debus admits she rarely has time for herself. Even fitting in a regular walk is difficult.

Despite the challenges, Debus, an upbeat and seemingly unflappable woman, doesn’t view her role as a burden. Debus moved in with her parents nine years ago when her first husband left. At the time, she had a 3-year-old son and

3-month-old daughter, and her parents were relatively healthy.

“My parents helped me when my marriage was falling apart,” Debus said from her bright yellow and green kitchen as her younger children, Grace and Teddy, buzz in asking for help getting a game set up. Meanwhile her mother calls Debus on a cell phone from her bedroom, explaining the pains she is experiencing. “Now it’s turned full circle.”

Debus’ beloved father passed away in 2011, a year after suffering a heart attack. Watching his decline took a psychological toll.

“He was a big, strong man who always took care of us,” she said. “Then I had to be the strong one.”

Now, Debus must remain strong yet flexible —preparing bland meals her mother requests and sticking close to home. While she’d like to be able to camp overnight with her family and go to a Bills game, she said, “I wouldn’t trade this for anything.”

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When more care is needed

New senior communities come in all styles and sizes

When it comes time to find a new living arrangement for Mom or Dad, the process of sifting through the options can be daunting. Independent living? Assisted living? Nursing home? Most retirement communities described as “independent living,” mean that residents take care of their daily needs, but meals are provided. Other services such as laundry, cleaning and transportation may be offered as well. “Assisted living” offers a medical presence and helps with personal care tasks like bathing and dressing, along with medication reminders. Skilled nursing provides a higher level of care, which can include feeding and around-the-clock medical supervision.

Western New York has a plethora of choices for seniors who require all levels of aid – including no help at all – and many communities offer luxuries and amenities that completely discredit the old nursing home stigma.

At Amberleigh, an independent retirement community in Williamsville, residents live in their own apartments, although some hire aides to come in and help with showering or other tasks. Three meals are served in a restaurant-like setting each day. Amberleigh also offers respite care after a fall or surgery. “Everyone is mentally capable of taking care of themselves,” said Beth Hulbert, director of sales and marketing for Amberleigh. “A lot of people have walkers or motorized scooters, but they are very full of life.” Peregrine’s Landing in Cheektowaga offers enriched assisted living, as well as

a memory care unit.

“Residents can bring in their own furniture; they can come and go as they please,” said Peregrine’s Landing Administrator and Registered Nurse Charlene Brosius. “We want to provide a homelike setting where residents don’t feel like they are losing their independence.”

Fox Run in Orchard Park provides a continuum of care with a mix of independent living apartments, assisted living suites, and skilled nursing units, including some memory care units. When residents move in, they’re typically fairly independent and then transition to assisted living or skilled nursing as the need for more help arises, said Fox Run Executive Director Michael Maloney.

Regardless of what level of care a senior requires, one thing is constant along the continuum – the need for socialization.

If Mom is living alone and her only human interaction is when the postman delivers the mail, she isn’t getting adequate social stimulation, Brosius said, adding that mental acuity can actually decline just sitting in front of the TV all day.

“Most of our (independent living) residents could stay at home. But the social connections aren’t there,” Maloney said. Fox Run not only provides residents with peers to discuss politics with, but also a number of onsite activities, such as lectures, art lessons, and fitness classes. Similar enrichment programs take place at Peregrine’s Landing and Amberleigh.

The most common comment that Hulbert said she



hears from residents is: “Why didn’t I do this sooner?”

“They no longer have to worry about their roof or paying their taxes,” she said. “We do all the work, and they can pretty much do whatever they want. It’s very simplified.”

At the onset, however, the decision to move into a care facility can be freighted with anxiety and denial.

“A lot of families may think Mom is doing well at home, taking her medications and eating well, but she isn’t,” Brosius said. “We want to listen to Mom or Dad. After all, they always gave us advice. But as they get older, they may not be the best judgment-makers.”

Maloney recommends that people take their time to research what communities are available to meet their loved one’s unique needs.

“Do the research and planning early on – before reaching a crisis point,” he said.

— Laurie Kaiser

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Not all adult children with aging parents are in this place physically or emotionally, however. Since Leah Hughes started WNY In-Home Care and Senior Services last June, she has been inundated with calls.

“We have clients whose children live in Texas, California, New York City, along with Western New York,” Hughes said. “They call saying, ‘Please help me. And can you go to my mom’s house tomorrow?’”

Her staff of 11 caregivers provides a range of services, from spending a few hours a day cooking meals and handling medication to providing round-the-clock care.

“Most people want to stay at home longer and avoid the dreaded nursing home,” Hughes said. “Our goal is to allow for aging in place to occur naturally.”

Along with private homecare, help is available from the Erie County Department of Senior Services. They offer a six-week class called Powerful Tools for Caregivers that provides information on

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everything from safety-proofing your home when your parent has Alzheimer's disease to dealing with difficult emotions. It costs \$25 for the whole session and includes a handbook.

"The comment I hear most from people is, 'I didn't know there was help out there. I thought I was alone,'" Callahan said.

And that feeling of isolation can lead to unbelievable stress. An elder law attorney relayed to Callahan the amazing number of estates he ends up handling for the caregiver first because he or she dies before the patient.

"They burn out emotionally and physically," Callahan said.

Cindy Moore, 43, an Amherst mother of 10- and 14-year-old sons, felt some amount of burnout after three years of caring for her ill mother, Phyllis Nice, who passed away in August.

"My mother was very strong-willed. Like any mother-daughter relationship, it was strained at times," said Moore, a working mom and Cub Scout leader with an easy smile. Moore moved her mother in with her family in 2009. "She was very reluctant to let me take care of her."

Nice went from being a fiercely independent career woman to one with a circulation disorder that resulted in having a leg amputated. A year ago, doctors found cancer in her lungs; it then moved to her bladder.

For Moore, an only child, her mother's care became a series of doctor's appointments, radiation treatments and crisis management. After Nice fell and broke her hip, she went to a rehabilitation center. When she returned, her mental faculties had declined and she had become incontinent. In the end, Moore said it felt like caring for an infant again.

If she hadn't had such an understanding employer and supportive husband, she said she couldn't have provided the level of care she did.

Debus, too, credits her husband of two years for incredible support. Three sisters who live out of town pitch in when they can. She admits she would like more help.

Hughes said often she hears from stressed out adult children who complain their siblings aren't pulling their weight.

"We are caring not just for the clients but for the entire

family," she said. "I realize I'm not only running a business, but also playing therapist in some ways."

As her mother grew sicker, Moore turned to an adult daycare center to provide respite care while she and her husband worked. If she had to leave during the evening, close friends stepped in to help.

"No one can do this without support," she said.

As challenging as the last few years were, Moore said she's proud that her children got to see her providing the bulk of care for her mother.

"They saw it's not always easy to do the right thing." ■■

For more information and help, visit these websites:

<http://www2.erie.gov/seniorservices/>

<http://wnyinhomecare.com/#/home>

Laurie Kaiser is a freelance writer from Amherst.

"No one can do this without support."

— Cindy Moore



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