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The Hardest Job They've Ever Loved

Mainers find challenge and reward in caring for loved ones.

By Debra Spark
Photography by Nicole Wolf



Three generations enjoy coffee drinks at Bard in the Old Port, after some shopping.





Opposite page: Emily Ryan (right) tries to take her son, Cam Ryan, and mother, Victoria Sprague, out once every day. Here, they are making their way from a parking spot, down Congress Street in Portland to Longfellow Books, Emily's favorite bookstore.

This page: Mother and son share a sweet moment.

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hen those we love need help or struggle with health problems, we want to do everything, be everywhere, afford all. We want to address their needs by offering love and practical assistance, along with all the comforts of home. There are obvious challenges to realizing our desires, however. Time, energy, money: any one of these things can be in short supply for a caregiver, and in even shorter supply for “sandwich” generation caregivers, those individuals in their late 40s and 50s who are caring for aging parents in addition to providing for their own children. While half of the current population in their 40s or 50s have financial or practical obligations to older or younger generations, 15 percent have obligations in both directions. Of these individuals, Emily Ryan of Portland might serve as Exhibit A of a particularly challenging situation met with particular resourcefulness and charm, in no small part because the people she cares for are themselves so caring.

Emily, a recently divorced, full-time clinical social worker at Gorham High School, is mother to 23-year-old Keelia, who works in Portland, and 21-year-old Cam, who has a developmental disability due to a rare disorder called Sotos syndrome. Though he looks like a slim,

shy teenager, Cam's brain functioning is comparable to that of a five-year-old.

Last summer, when Cam turned 21, he aged out of the Portland school system's offerings for students with developmental disabilities. Before Emily had time to develop a new day plan for him, her 75-year-old mother, Victoria Sprague, was diagnosed with esophageal cancer. The doctors in Long Island, New York, where Victoria was living at the time, told her that while she might imagine friends would step up and volunteer to take her to this or that chemo or radiation appointment, people's good will would eventually dissipate. She needed a better cancer treatment plan than “I'll manage.” Victoria was used to being independent. She'd raised three children, worked in publishing, and then attended law school in her 40s. She was still working part-time as a litigator when she got sick. Even so, Victoria left New York and moved in with Emily, so Emily could direct her care.

Nothing is easy about this family situation, and though Emily's specific circumstances are unusual, nothing about them is rare. An AARP study found that, in 2013, 178,000 Mainers served as family caregivers to loved ones, many of whom

suffer from chronic health conditions like heart disease, dementia, and Alzheimer's disease. They provided care for 165 million hours, assisting with daily living and nursing tasks, arranging direct support, implementing health care plans, driving to appointments, and more. The estimated annual economic value of this unpaid effort in Maine is just over two billion dollars.

So how does Emily do it? Sheer force of personality is part of the answer. She's energetic, social, and, thanks in part to her career and in part to her research efforts, well informed about resources. She shares responsibilities for her son with her ex, but in the end, it is Cam himself who gets Emily through the challenges. “Cam is the silver lining. He is very loving,” says Emily. In the morning, when Emily is having a rough day, Cam will sometimes say, “Mom, you look so beautiful today,” and the purity of this impresses Emily. “I am not a religious person,” she says, and yet Cam expresses something spiritual for her: “He's a beautiful person, and that has helped.”

Even caregivers who aren't obligated to more than one person stress the importance of having someone who functions as a support system. The





Opposite page: Emily laughs at something Cam has said as they cook together. **This page:** Emily helps Cam with a knife.

support may be the actual person who is being cared for, as is the case with Cam and Victoria. (One of the ironies of Victoria's situation is that it allows her to be a companion to Cam, when Emily can't be.) But a support system can also be the "yeah, I've been there, too," companionship of other caregivers. For those who can't easily leave their homes, one way to view such stories is by accessing AARP's "I Heart Caregivers," an online platform for sharing caregiving experiences.

The website is sorted by state and, in 2015, caregivers from each state were honored with a painted portrait of themselves with the person for whom they were caring. Though Amy Madge lived in Massachusetts when she was a

caregiver, she was recognized in 2015 after she became a Mainer. She cared for both her parents in her childhood home, but then found she couldn't remain in it after her parents died. The memories were too painful. "I tried to rearrange things," she says, "but it was still Mom's kitchen." Her family, which at one time included six siblings, vacationed at Goose Rocks Beach in Kennebunkport when Amy was a girl, so she decided to start anew in southern Maine.

Amy now works as a patient representative at Southern Maine Health Care, but she remains committed to advocating for caregivers. "I know how hard it is," says Amy, who documented her parents' lives and her caregiving experiences in her book, *Memories of My*

Parents. "I hear from caregivers across the country who are in the same shoes. They are struggling, leaving their jobs, and exhausting their 401ks, and they need help."

Policy makers in Maine and in Washington, D.C., are beginning to address the needs of caregivers and their loved ones. Maine is one of 39 states to have passed the CARE (Caregiver Advise, Record, Enable) Act, which ensures more thorough discharge planning and information sharing with a caregiver before a loved one leaves the hospital. Maine's AccessAble Home Tax Credit can help offset home modification for those with a physical disability or hardship. Also in the works are a proposed federal tax credit of up

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to \$3,000 for working caregivers and efforts to strengthen policies involving family leave. Some of the most important support, however, can’t be legislated. “What saved me was I had really good friends and a really good church,” says Amy. “Just to get out and have a cup of coffee, that was like Christmas to me. You can’t do it alone no matter how strong you think you are. It’s the hardest job you ever loved.”

Statistically, women are more likely to be caregivers and thus more likely to take themselves out of the workplace, thereby reducing their own retirement security. Pamela Champagne, a Bangor-based microfinance consultant who used to travel to Africa and Asia for her work, is one such woman. When her partner, Warren, who also worked

overseas in Indonesia and southeast Asia, had a stroke in 2010, Pamela was 61, and Warren was 62. The stroke left Warren paralyzed on his left side, with severely impaired executive functioning. Pamela had to largely stop working to care for him and then continued to support him as she dealt with her own diagnosis and treatment for cancer. When asked how she takes care of herself while taking care of Warren, Champagne laughs, but then says she could not have helped Warren without the support of the Eastern Area Agency on Aging, which, she notes, “has a ton of resources—EZ Fix, 3D Catering, Money Minders, Senior Companions, as well as transportation—all to promote independent care rather than going into facilities.” Pamela eventually grew comfortable enough to leave Warren for the length of time

it takes her to take a dance class at the YMCA, but believes he grows uneasy when she is too far afield or even when she is talking on the phone. Pamela fears for what might happen should she predecease Warren, and that worry forms a “background of grief” that is always with her. And yet when asked how she manages the grief, she says, “I just usually give him a hug. I am glad he is in my life, I am glad I am able to care for him, and try to think of that.” As Pamela and Warren never married, people sometimes ask Pamela why she has stayed with Warren, a question that shocks her. “It’s a burden,” she says. “But it’s a burden of love.” ❧