

Covid Has Not Stopped Savvy from Supporting Family Caregivers



The Covid-19 pandemic has upended all our lives in ways big and small. And yet it is a testament to human resilience that with barely missing a beat, we meet the challenges that quarantines and social distancing present and find ways to carry on. In last month's blog I reported on steps the Elder Services of the Merrimack Valley and North Shore's (ESMV) Healthy Living Center of Excellence has taken to keep their Evidence-Based wellness programs running virtually and how funders like the National Council on Aging, the Administration for Community Living, and Harvard Pilgrim Health Care Foundation are supporting that effort.

One of the programs that has migrated to an online platform is the Savvy Caregiver program, which supports caregivers of family members with dementia. Although the need to stem the Covid-19 pandemic is a public health priority, the mental and physical toll that caregiving takes on families has not gone away. They still need educational and emotional support to cope with their responsibilities as caregivers while taking care of themselves.

The first class to take part in the Savvy Caregiver program online under the tutelage of Crystal Polizzotti, CDP, Healthy Aging Program Manager with Elder Services of the Merrimack Valley and the North Shore, recently completed the course. I spoke to one of the graduates.

Janine's Story

Janine cares for her mother who has dementia. She talks about her experience in terms that are not only descriptive, but also intimate and heart-felt. Much of what follows is in her own words.

Janine became her mom's primary caregiver by default because, for the most part, she and her mom have always lived in the same building. Even though she was close by, her life was pretty much her own until her mom's behavior changed to the point where she and her siblings realized she needed support to stay safe. She was showing signs of dementia, and they had to figure out how to manage what was happening.

"I'm the only immediate family member in close proximity to my mom," says Janine. "My siblings all have kids, work outside the home, and are managing busy and complicated lives. It's not easy for them to pull away. We've managed to set up some kind of a schedule, and although it's far from optimal it's working for now. For the most part everyone is doing what they can as best as they can."

And, although the pain that many families have suffered with the loss of loved-ones to Covid-19 can't be overstated, Janine describes the pandemic as a blessing in disguise for her and her mom.

"I couldn't be more thankful for Covid right now," she says. "I'm very grateful that I can work from home. I would be reliant on someone else to care for my mom if I couldn't be here."

When the Caregiver Needs Care

“I didn’t recognize the signs of my mom’s cognitive decline until they became blatantly obvious. Not that I wasn’t educated enough to have recognized the signs much earlier. There were a lot of arguments, a lot of disagreements, a lot of just silliness when I think back on it. But I just wasn’t aware of what to look for.”

Janine recalls, “We noticed changes in my mom about four years ago. Although, it eventually became obvious that she needed care, my siblings and I were weighing the need to provide help against allowing her to maintain her independence. We knew we had to provide her with support, but without completely interfering and taking over. I think what changed in the past year or so is that I found that my responsibilities for her care, safety, and general wellbeing were continuing to increase.

I had a meltdown is the only way I can put it. I had to sit down and talk to family about the fact that I needed more help from them as I found myself doing more and more for our mom.”

With advice from family and workplace colleagues, Janine sought resources to help her cope with the demands of her career coupled with the pressures of family caregiving. She began with one-on-one therapy, and although it allowed her to vent, it only went so far in providing practical solutions to managing the day-to-day challenges she faced as her mom’s primary caregiver.

Janine shares a stark memory that brought her to discover the Savvy Caregiver program.

“I’m a crisis counselor. You never see people when they’re having a good day. It’s February. It’s Friday before a long weekend. It’s 3:00 p.m. in the afternoon, and I have a family sleeping in their car. That’s a lot of pressure, and it became clear that I needed support myself if I was going to do my job, as well as take care of my mom.

So, the first thing that I did was go online, and the Savvy program came up at the top of a Google search. And it just so happened that it started the following week. So, I didn’t have to wait a month to get involved with it.”

Janine’s Online Savvy Caregiver Experience

“It was incredibly helpful to listen to other people, hear their experiences and get feedback about my own experience,” says Janine. “I think the one thing that I wanted from the Savvy Caregiver program was to hear how other people are managing their situation. How are other people dealing with a family member who no longer recognizes really basic things?

I wasn’t hired to do this. This is my mom, and I think that relationship all by itself is what makes caring for her really hard. I had always looked to my mom to help me make decisions in my life, even mundane things like buying a car. I miss that.”

Janine goes on to say, “Savvy gave me the confidence to make more care decisions independently. Before Savvy I was always second guessing myself. Savvy gave me the courage to make a decision, stick with it, follow it through, and see what happens. Like yesterday I noticed that my mom was unusually lethargic and uncommunicative. I must have watched her a good 20 minutes to half an hour trying to figure out what might be going on. Was she like this because she hadn’t eaten, or because it was a very hot summer day?

Despite her objections, I finally decided to turn on the air conditioning. I thought to myself, she doesn't want me to turn on the AC, but you know what, I don't care right now. I need to figure out what's going on, and try something, because I don't want to go to the emergency room only to find out that she's fine. Turning on the air conditioning seemed to solve the problem and was an easy decision to make."

A Ringing Endorsement

"I would absolutely recommend Savvy," says Janine. "You have nothing to lose by hearing about other people's experiences. Their stories allowed me to put a lot of what I'm going through in perspective. It's hard when you're responsible for the care of someone you love, and you don't know what to look out for.

I really appreciate the education that Savvy provided. The films, as heart-breaking as they were, helped me recognize where my mom might be on the spectrum of cognitive decline and what I can expect as her dementia progresses. I'm constantly monitoring her for changes, which is why any little shift in her routine makes me think "holy cow" what are we in for now.

I'm very fortunate that her condition has been stable for several months now. But the other shoe is going to drop. Decline is inevitable, and when it happens, I will have to adjust my role so that I will be able to manage my caregiving responsibilities and also be able to manage my life."

And her thoughts on participating in the Savvy Caregiver program online?

"In truth, it's a lot easier because I didn't have to leave the house," says Janine. "I didn't have to dress up. I didn't have to get directions. I didn't have to download anything onto my phone. I was in my house and feeling pretty comfortable with the conversation. I think it worked well."