

An Interview with Maggie Goonan

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James Ellison: Ms. Goonan, I've asked you to speak with me for this special issue of the DJPH in hopes that you might share your experience as a caregiver for a parent with dementia. Can you please start with a few words about yourself and your family?

Maggie Goonan: Of course – My name is Maggie Goonan. My mom was diagnosed at age 68, about nine years ago, with dementia. At first, I don't know that it changed my life too drastically. In the beginning, we were trying to keep her mind off of it since we had a lot of Alzheimer's disease in our family. She knew how this would play out. We tried to keep her mind off that and on the positives -- she still had a lot of life to live. But as the disease started to progress, my father was also sick at the same time. This was challenging for us because her moods and her personality started to change, and she was more difficult to deal with. She had a lot of anxiety, a lot of depression, and she became unpredictable. Life became a roller coaster, just trying to navigate how she was feeling and keep up with the demands of her moods. It was incredibly stressful as we tried also to care for my father. It really was a full-time job, a lot for us to juggle.

JE: Your mother was not only declining cognitively, but like so many people with dementia, she was showing changes in personality and mood and behavior.

MG: Yes, and after my father passed away, when I stepped into the sole caregiver role, I had a better appreciation for what my dad had been dealing with, 24 hours per day. I realized this would be a 24 hour a day job, and it was a bit overwhelming.

JE: What stressors did you face in particular?

MG: Well, I think the emotional roller coaster for me was the hardest part, because my mom was always such a positive and upbeat person, always very happy. Seeing her in despair was the most stressful experience for me. She had always been someone who would try to keep a positive perspective.

JE: Do you think there are special challenges for a caregiver of somebody with dementia, as compared to caring for a person with other diseases?

MG: Yes, I do. My father had cancer – his journey was completely different. With him, I could still hold a conversation, and we could still laugh and talk. Our relationship didn't change very much, it was still very much the same up until the very end, he could still give advice, and we could still reminisce. We could laugh at television shows that we watched together with my mom. But mom was different, she was no longer the same person. And she changed, too, from one day to the next. So you just never knew who you were going to be dealing with that day. And then as dementia progressed even further, we couldn't even have meaningful conversations. The dynamics of our relationship changed completely. She had always been the caregiver and now our roles flip-flopped, and I was taking care of her. Her care is all focused on "how do I best meet her needs?" every day. By necessity, our relationship is more one sided.

Also, when you are caring for someone with dementia, especially while they are still in their own home or in yours, you take on a lot of responsibility for all their day-to-day needs. For example,

you need to remember things like making appointments, picking up their prescriptions and filling the pillbox, making time to do their laundry and grocery shopping, or being the driver for anywhere they need to go. I found this difficult, because it just didn't seem like there were enough hours in the day. I still have two young children and work full-time, so at times it was quite a bit of juggling. Even now, with my Mom in a facility, I find myself lying in bed at night making notes in my phone to keep track of everything. Nowadays, it's less about running my Mom around to appointments or doing grocery shopping, and more about what new ways I can try to make this stage in her life just a little bit better and what time each day I can fit in a visit with her.

JE: So, with dementia, she became unable to realize how you were caring for her?

MG: Yes, there were times when I became the target of a lot of her frustration, aggression and fear. And so I often felt like I couldn't do anything right. But there were moments during that where she would have clarity, and she would just look at me and say, "I don't know what I would do without you." At those moments we could make that connection, and she was still in there. But for the most part, she was angry at me for what she was going through. And no matter how much I was trying to make things nice and make things right, make sure everything's taken care of, she couldn't understand my role.

JE: Such a difficult part of the burden of caregiving is loss of the former relationship. It sounds like sometimes she knew you were her ally, but not consistently?

MG: Yes. Whereas with my father, every day, he was thankful and appreciative. For me, it was an honor to take care of both of my parents, but he remained aware of what I was trying to do for him, and he was very appreciative, whereas with my mom, it she just was so upset and angry all the time, and she didn't know where to direct it, or how to make herself feel better.

JE: What did you find helpful when you were trying to cope with her anger?

MG: Lots of times, I just had to step away from it. It would just get to be too much. And I would call my brother and say, "Hey, can you go and spend some time with mom today?" I wasn't sure how much longer I would be able to do it. Leaning on other people was helpful just to give me a little bit of a break. I was very cognizant of the fact that she could not help how she was feeling or behaving so I constantly reminded myself of that. I was very careful not to react or respond to her with any frustration or anger because I did not want to have any regrets when all was said and done. Also, at one point during the height of her disruptive behaviors, someone reminded me that this was a phase that would not last forever. They reminded me that a phase would come when she no longer knew me or could speak to me. And I knew when that time came, I'd wish for the days when she still called me by my name, even if it was in anger. That helped me have some perspective. I've spoken to so many others who are in the thick of it right now and at their wits end and I try to remind them of those things too.

JE: How did your parents' friends react to their illnesses? Was it different with your mother's dementia?

MG: Yes. With my father, help was coming from every direction, we had a lot of friends and family who were popping in with meals, and offering to come and spend a couple hours with him so I could run to the grocery store or pick up his prescriptions, whereas with my mom dementia makes people uncomfortable. With dementia, a person is not themselves anymore, or they can't carry on a normal conversation. So it's a lot harder for people to step in and lend a hand, I don't

think they're as comfortable with it. That made it more difficult because the help was less available. I had seen that earlier when my mother's brothers developed Alzheimer's. When we would visit them in the long-term care facilities, they couldn't really talk or carry on a conversation, or they would get aggressive. Mom never shied away from that, you know, she leaned into that, and watching her deal with that and find ways to redirect them, or just to bring a smile to their faces, even if they couldn't talk, you know, that was a big thing. Sometimes she would come with a little boombox with music that she knew they liked. And when she put that on, it kind of changed their whole demeanor, or she'd bring them ice cream, which they both loved. Watching her with them. I learned a lot about how to try to relate to someone in this situation.

JE: Were there particular safety or physical challenges in caring for your mother at home as her disease progressed?

MG: Yes. She initially wanted to stay in her home after my father had passed, and she wasn't happy about our hiring some in-home caregivers. When that didn't work out, I brought her to my home, but that was difficult. She would wake up in the middle of night, disoriented, not being familiar because she wasn't in her home, and risked falling down a set of stairs or making her way out the front door in the middle of the night. Even trying to get her into the car to drive anywhere was a challenge. She started to comfort herself with alcohol, and we had to monitor that. There were just so many possibilities for things to go horribly wrong in that setting, so I realized fairly early on that this was not safe for her.

JE: It must have been stressful for you to find alternatives. How did you go about deciding to move your mother into a long-term care facility?

MG: Well, when the risks of having her in the home outweighed the benefits, we needed to make that decision. There was still a great deal of guilt despite knowing we were doing the right thing for her. We started to visit some of the facilities. My cousin, who had been through this, said to me, "Maggie, the problems are not going to go away, it is just going to be different once she moves. You have to set your expectations appropriately." So, I kept that in mind. I looked for a facility that would be nice enough for her, and where the people seemed really nice. We found one we thought was suitable and visited on Valentine's Day. It really appealed to mom because she was feeling very lonely at home, even in my home. And things got better for a little bit after she moved there, but we soon saw that the facility wasn't well equipped to deal with her when she became disruptive and combative.

JE: When her behavior became challenging for the facility, how did you handle that challenge?

MG: Soon, we were referred to another place that was known to be able to deal with difficult behaviors. Around this time, too, my mother was evaluated by the Swank Center. My mother's medications had gotten sort of screwed up and the Swank Center got them squared away, which helped her disruptive behavior enough that could live in a facility with other residents and not be a risk to herself or to anyone else. Finding a skilled dementia specialist made a huge difference. Delaware is greatly in need of more dementia specialist neurologists and geriatric psychiatrists.

JE: So, the medication changes helped and in addition your mother was now in a facility that was more accommodating for people with behavioral difficulties. What were their special skills? How were they more successful?

MG: The director of nursing in that facility had a really, really good handle on how this disease affects people and what you can expect with it, and that overmedicating was not the way to go. She tried to avoid sending residents out to inpatient psychiatric facilities. She said she wanted to know who the person was in the disease and that was more difficult when they were overmedicated. She encouraged her staff to work through disruptive behavior episodes without over-relying on sedation. Their behavioral approach involved “containing” my mom during agitated times, making sure she was away from others, diverting her attention. They took enough time with me to know who she was, and what her triggers were, and what kind of things made her happy. When she was being difficult, they knew what they could say to her, to distract her or to get her mind on something else, which would bring it down a notch.

JE: Like you, it seems, this facility was able to remain in touch with your mother's individual needs and personality and keep a connection with her as a person.

MG: Yes, they were managing her disease without losing track of who she was as a person. I am grateful to the staff, and I recognize that these facilities, doing this difficult work, need more staff and that their workers need to be better compensated. I often feel that there aren't enough staff to attend to the needs of all the residents that are there. I think it's just really important that they are able to pay some individual attention to some of these folks, so that they're not just ignored. And communication between the facilities and hospitals, too, is so important. My experience with the ACE [Acute Care for the Elderly] unit at Wilmington Hospital, for example, has been outstanding – but in other hospitals my experience hasn't always been so positive. I think it's really helpful when a person with dementia can be cared for by nurses and doctors familiar with the special needs of persons with dementia. Another concern I had with my mother was when she would arrive at a hospital with bruises or dehydration, and there didn't seem to be enough interest in how she got that way. Sometimes these bruises aren't just, you know, part of being older. Fall risk or other problems that could be addressed should be recognized. I feel like falls are too common. In assisted living facilities, some of the regulations seem unprotective – In nursing homes, a hospital bed or a bed rail can prevent falls, but they're not allowed in Delaware's Assisted Living Facilities. My mom fell out of her bed in the facility several times and suffered back fractures. If we could have just been allowed to put a bed rail on her bed, maybe we could have prevented those things. She's also taken many, many falls out of her wheelchair forward because she fell asleep in the wheelchair and hit her head. If seatbelts were allowed, that might be avoided. I understand they are trying to avoid restraints, but maybe there should be more flexibility, to evaluate the need for that kind of protective restraint on a case by case basis. It's one thing to restrain someone still able to walk around freely, but it's another thing when someone is wheelchair bound, can't get up, but still wants to lean forward and could fall. I feel like some of these regulations are well-intended but increase safety risk for some residents.

JE: Yes, this seems another dimension of what you said earlier, how important it is for facilities to know their residents individually. As we wrap up this interview, I want to thank you for sharing so many helpful observations and ideas about your journey and that of your family. Are there any final comments that you want to make?

MG: My last comment is for other caregivers – to emphasize how important it is to care for yourself first! You need to take time for yourself and to ask others for help. There are people who want to help, and sometimes they don't know how to offer or how to help, so you may need to be specific about what you need from them. And I wish we had more guidance in Delaware regarding which facilities are most helpful and what their particular strengths are. Our choices

for where to find help for a person with dementia and difficult behaviors is limited. I'd like health care professionals to know more about how to choose the right facility for a loved one, what to look out for, and where to go first. And finally, if your loved one is having problems that are not responding to treatment from a primary care clinician or a facility, seek out a specialized consultation from a memory center, and use the resources that Delaware provides, including the Alzheimer's Association. All of these resources help you realize you are not alone in this.

JE: Thank you for your suggestions – and for letting others know about what you have learned in caring for your mother.

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