

Living with Alzheimer's: Communication

"Initially, Geri was still working, and I noticed cognitive challenges in maintaining her train of thought and running a meeting of her staff, uh, getting off the subway and not knowing where she was. One morning she looked in the mirror and didn't recognize her face. So that was a definite milestone for us."

"She's been diagnosed for 10 years and has had a remarkably slow decline, uh, until recently, was speaking, uh, much more fluently and, uh, intelligently than I was."

"In the last 12 months, particularly, uh, she has been encountering greater challenges, especially communication in word-find and completion of a thought. And she stops mid-sentence to search for a word. Sometimes she'll forget what the rest of that sentence was; or she'll lose her train of thought. So she's become quieter. She has been so articulate and pointing to what's happening in her mind, in her personality as the disease progresses and to lose that voice is a great loss."

"Our day to day routine has also been impacted by Geri's more recent decline. It's not just, uh, communications. It's remembering where the light switches are. It's some help in dressing and, and her clothes."

"One of the constant challenges for someone living with a disease is their self image, their self confidence. Who they are. So, for someone, could come in, especially in the early stages and to 'over care' for you, it's taking away your ability to care for yourself [Geri: "Right."] and your dignity. [Geri: "Right."] And your self-image."

"it's a hard thing because people wanna help. And it causes a lot of, 'should you do it that way, or...' And , uh, ya know, it', it's not necessarily helpful."

"So we've had the general rule that I don't help Geri with something until she asks, or, eh, until she fails."

"I think that being a caregiver really brings many opportunities that I've never had before. It's really a chance for the individual to grow."

"I think so much of it is attitude. So that's why Geri and I are trying to carry a positive attitude through this whole journey. This doesn't have to be burdensome, it doesn't have to be, uh, terrible. It can also be a joyful and a learning experience while having many aspects of it that will be challenging and difficult and even unpleasant."

"I think I do, um, show people who are in my same state that they have, case, abilities, to help others."

"Gradually we became involved in Alzheimer's national projects and had more and more, connection with people with a national stature and even have moved to the point of initiating, programs ourselves... so the concept of a new organization that we call 'MAP - Memory Advocate Peers - is to train former care partners, who've lost the person they were caring for with dementia, to become mentors, advocates, guides for newly diagnosed 'diads' - that's the person with the disease and their care partner ... with the goal of first bringing emotional support, having walked that same path."

"Secondly, over 12 months of mentorship the advocate will bring the diad information about the disease and titrate it over the 12 months so it won't be overwhelming at first but also then how to live well. So we're finding

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inspirational material and videos and opportunities that people can see, 'Well, you know – there's an alternative.'"

"And finally, we're going to try to recruit as many of our clients as possible into clinical trials and we're partnering with a number of research, uh, institutions, we'll try to get our clients into their clinical trials."

"Our advocacy has given us an opportunity to meet so many wonderful people; to, we believe, make a difference for other individuals living with the disease and their care partners, which is tremendously therapeutic, not just for Geri but for me also. There's, a fair degree of pain with any, terminal diagnosis. And, we don't deny that pain, but we try to overwhelm that pain with the positive feelings we get from helping other individuals."

"You can keep going on, and that going on is it is in, se, it, it is, um, basically all we got; and we - it's, it's a lot. And the living is a lot. We just have to take it and do the best with it."