

Reflections of a Non-Expert Care Giver

By Carol Allen

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Regarding caretaking for a person with Alzheimer's, my specialty, my area of expertise, is being the non-expert. I had no training. I had no tools in my toolbox. The only qualification I had was the willingness to do it, the willingness to take care of my parents, at home, for the remainder of their days as per their request.

In May of 2005 I came home to take care of my mom who had been diagnosed with Alzheimer's five years earlier. My father was eighty-nine, my mom eighty-eight. Fuller had never been handy in any way domestic and Peg was now more of a hazard than a help around the house. Shortly after coming home my father's health rapidly declined. I was soon caring for him around the clock. It was only a few days before he died that we had Hospice Care. I knew very little about the scope of Hospice's services and my father's decline, being so rapid, pulled me into 24-hour caregiving like being drawn into an eddy.

Now I am much better prepared. I have Caregivers' Respite Program as well as Hospice help for my mom and I take advantage of their help without taking advantage of their kindness. Mainly what they provide for me is the tremendous relief of knowing I am not doing this alone. They are my 'higher power' that I can call on at my time of greatest need. It is one of the great lessons I have learned as a caregiver: "They also serve who only stand and wait." Knowing that help is there, a phone call away, gives me a continuous sense of relief. It keeps me healthy and sane throughout this whole journey. It enables me to thoroughly enjoy my mom, the act of caregiving and my life.

When I said that I didn't have any tools in my box I was being a little dramatic. Other than the ability to cook simple nourishing meals—a topic for another talk another time—I said I have, 'willingness'. This is actually vitally important. Willingness is openness with direction, with energy. If one doesn't have willingness then the breaks are on and any action will be draining, exhausting, damaging. I didn't start out with a full-blown case of willingness. I was scared and distraught when this whole thing began. I didn't believe at first that Peg really had Alzheimer's. And the decision to 'leave my life' and move

back with my parents was not without its measure of anxiety. But just a little willingness opens us up to tremendous support. Look around here. Here is support through the Office of the Aging who can help you in so many ways. They know the path we are on and can see ahead to the challenges that await us and they can direct us to the services that meet those challenges. But also in a subtle silent way help can come in when we provide the opening for it.

How does one 'open'? What is the technique? Openness is a kind of 'stepping aside'. It is getting out of the way and allowing the world to unfold without the individual placing his expectations on how exactly that unfolding should go.

I am a person of faith, in that I have faith in faith. That is what I am talking about. I want the best for my mom, for my self, but how that is to come about and what exactly 'the best' is I don't know. But I have faith that a higher more universal Intelligence does. And faith is the connection to that intelligence and willingness the primed pump that provides the flow. If I set aside my expectations then that force has room to move into my life, my world. So surprisingly, from my level of understanding anyway, faith is saying: 'I don't know' or in other words, 'Thy will be done.' This is openness, willingness. It might seem like a big step but you don't have to be open. Just be open to being open.

Here is a little story: About a year ago Peg was being taken on a walk by Mary (a caregiver respite provider) while I was upstairs. Mary opened the door and called to me with urgency in her voice. I rushed down and together we set Peg in a chair. Her eyes were opened but glazed, vacant. We called 911 and Hospice and I held her and told her I loved her. This happened so fast yet time seemed protracted. After Peg had been like this for 5 or 10 minutes, I silently prayed. And no sooner then I had the intention to pray she looked around and became animated. If that was just a coincidence then it was a cosmic coincidence. I thought. 'Whoa! I will never again doubt the efficacy of prayer!' It doesn't have to be long, pleading or repeating. When the ambulance came they administered oxygen and she suffered no ill effects. So I thought the next time that happens I will, one, pray and, two, administer oxygen. I had the opportunity to do that some months later. Again she was fine after the episode.

Let me tell you about Peg, my partner in this great adventure. She is sweetness incarnate. It is as if the Alzheimer's is removing the covering of intellect and ego and her inner purer spirit is shining forth more brightly. It is this inner

person that is all I have left to relate to. Communication is more non-verbal. I still talk to her and she can often respond simply with a few words. But more important than what I say is how I say it.

I have learned so much from these last four years. One very simple thing I learned was from a friend, also a Margaret, just a few months before I came home. She had helped her dad take care of her mom when she got Alzheimer's. Her mom, throughout her decline, insisted on wearing her pantyhose everyday. As many of you know it's an art to put those things on. Now imagine you're a man whom, presumably having never put them on your self, now must put them on your wife. It was a daily struggle. Well, Margaret went into the room one morning and emerged promptly, task completed. Her dad asked, 'How did you do that so fast?' And she said she sang to her as she did it.

I am not much of a singer, but I have a little repertoire of ditties that I sing to Peg. They're particularly useful while we were doing all the things that might be considered awkward, like having your daughter attend to you in the bathroom washing your privates. Singing makes it light and fun and is a distraction. Maybe Peg is thinking, 'If Carol's okay with it then I can be too.'

My mother is 92. She is nearing the end of her life span. You see cartoons of people wearing sandwich boards declaring, 'The End is Near!' Well it's kind of like people (not me) who think the glass is half empty, because if the end is near then a new beginning is soon after. So a new beginning is awaiting my mom. Of course, I don't know what that is exactly, but I believe this time of her life is a preparation for it. And I am here to help her in whatever way I can. Children are learning all sorts of skills for their new life. My mom is somehow preparing for hers. My job is to comfort her and make her life sweet and easy. My job is to be a witness and learn what I can. It is a learning of something subtler and more precious than skills. I am seeing what remains when those skills are gone; seeing her in her purity, to seeing Life itself, Love itself.

So you hear of people 'losing someone they love to Alzheimer's'. And certainly they are going, going, going, never to return. But it gives us, the caregiver, the time needed to shift our attention from the outer expression of life to its inner reality. We are not our bodies. There is a whole human being in front of us still desiring the same thing we all desire: to be loved for who we are right now. This is a wonderful opportunity to pour out our love and express it in ways that we never expressed it before. Giving my mom a bath is totally precious, as is

spoon-feeding her the food I have prepared. I think of all the times she did that for me! I am sure she enjoyed doing that way back then! Peg had five children, four boys then me, her only girl. She deserves to round off her life with a little babying. Her mom used to say to her when she was little that her mind never stopped; mentally, she was always busy, busy, busy. Her brain deserves a vacation. So I don't see her Alzheimer's as a great tragedy anymore. She is comfortable and happy. This is her path and I wish to honor and support her on it.