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Article 20

There's No Place Like Home: Caring for the Alzheimer's Patient at Home

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Twenty-five years ago when my grandmother came to live with my husband and me, she had Alzheimer's. No one talked about the disease at the time. Most assumed she was just a 'forgetful old lady.' Several doctors mentioned "senile dementia," but the word "Alzheimer's" had yet to reach the American consciousness. Indeed, it would take us several more years to receive an accurate diagnosis, and by then, what 'it' was really didn't matter anymore. Who she was becoming and how we would care for her did.

But that wasn't the only difference in 1982. When we brought Grandmother into our home to live, we were an anomaly. No one else lived with their parents let alone their grandparents—unless they were of certain ethnic backgrounds or simply very poor. People looked at us strangely as if they couldn't quite figure out the connection. Of course, as time went by, there really was no 'connection' with Granny any more at all but that didn't matter either.

Now I don't know about you, but the thought of dying has bothered me since I was six years old. The idea that we could be here one day and then gone the next used to drive me crazy. But as the years went by, death began to worry me less and less. It was how we valued life and aging that really began to irk me from the inside out.

In 1965, my grandmother had to put her own mother in a nursing home and I went with her. If you think they're off-putting now, imagine them almost 50 years ago. The day we left Great-granny in that smelly place among complete strangers, I was bereft. The memory of her face as she stood looking at me with tears running down her face has never left me. That night, at the age of 12, I promised my grandmother, "I will never, ever put you in a nursing home. Ever. I will take care of you myself."

Now many of us have made promises in our lives that we never kept. Our excuses were many and the rationalizations endless. But I kept that one, single promise to Granny. It was probably the greatest gift to me I ever could have imagined. Not that there weren't some rough roads ahead.

When my husband of almost two years agreed to let my grandmother "stay with us for a few weeks" before her children put her in a nursing home, neither of us knew what was in store. Nor did we ever imagine that those few weeks would turn into 13 years! In hindsight, it was better that way.

At the end, I had two in diapers, put two down for naps and fed both of them mashed bananas and cereal. The only difference was that one was two years old and the other, 95. A few years after Granny died, I wrote *Kissing Tomatoes,* a non-fiction memoir that documented our 13 years together. It was picked up by The Sterling Lord Agency in New York. However, after trying to pitch it to publishers for over a year, the agent finally gave up. He was told that while "the writing is wonderful, the topic is just not of interest to the general public."

Fast forward ten years and the times have changed. Right now, there are currently 5 million people living with Alzheimer's in the U.S. It is predicted that by the year 2050, 1 million new cases will be diagnosed each year. Considering 10 million caregivers are presently caring for those with Alzheimer's, the issue at hand is both compelling and challenging (Alzheimer's Association, 2010).

Why care for someone with this disease at home? Well, cost may be a first consideration. How many families have the $70,000 per year it takes to put a loved one in a nursing home (National Center for Health Statistics., n.d.)? (That translates to $192 each day. For that price you can book a luxury room at a premier hotel!) The truth is that caring for someone with Alzheimer's, particularly in the early stages of the disease, does not require skilled nursing care. It requires the same kind of diligence one needs when caring for small children: you childproof your house and keep a close eye on them. A little love also goes a long way and you won't find *that* in a nursing home.

A second reason for bringing your loved one home with you is sharing the journey of their decline and easing the pain of their final days. It will also give you a truer understanding of the cycle of life that you will one day experience yourself. By keeping your Alzheimer patient in contact with caring family and surrounding them with their own possessions, you can not only slow the progression of the disease, but also make their transition easier. Nothing hastens decline faster than yanking someone from their home and shoving them into a sterile, foreign environment where no one really cares WHO they are or WERE.

The last and most compelling reason might be your own conscience. It was for me. Even at 29, I could put myself in her place. I knew that someday I, too, would be old, and would never want to be abandoned to the care of strangers, no matter how skilled they were! Fortunately, when Granny moved in with us, we were imbued with the naiveté that youth brings. It never really occurred to us that we couldn't handle what lay ahead.

Now I realize that our situation was unusual. My grandmother had been my legal guardian since I was 13 years old. Our relationship was closer than most experience with their grandparents. She was also highly educated for a woman born in 1900. Because she had raised me with both an iron hand and a loving heart, I tried to return the same as I cared for her. Her wise counsel during my teenage years was so embedded in me that I begin each chapter in *Kissing Tomatoes* with her own words in quote. I will include some here.

"If you think you can do it, try it. Then you'll know for sure."

Clearly I took this saying of hers to heart or I never would have asked my new husband if Granny could move in with us. Considering that she was clearly not her ‘self’ when we went to pick her up, the first few days were a little scary. I worried as much about my husband’s reaction to my grandmother talking to raisins and the TV set, as I did about her new and odd behavior.

Alzheimer’s is confusing enough in the mind of the patient. If you add to that a complete change of environment, you hasten the demise of the individual. I would put it tantamount to handing an inebriated person another cocktail. Their already muddled thinking gets worse. What they don’t seem to lose, at least in the beginning, is their ‘sense of place’ in the home they have lived in so long. In fact, they can fool you much better in their own environment than they can, say, at a strange doctor’s office. They know the territory even if it is simply navigated by habit: ‘That chair is meant for sitting in.’ ‘This is where I eat dinner.’ ‘Here is the cup I pour my coffee in.’ ‘There is the blue dress I wear to church.’

Granny was well into Stage I or II of the Alzheimer descent: accusing neighbors of taking her things, driving off in the car only to forget both where she was going and how to get home, and not paying her bills. She also went days without eating much (which is quite common for the elderly who live alone), and was generally confused. It was the kind of confusion that only those who know you well can discern; others often don’t even notice.

The day we drove to my uncle’s to pick up Granny, she was talking to a handful of raisins in her open palm. “Now which of you should I eat?” she asked. Considering my grandmother was a Smith college graduate, earned a masters degree in her 50s,and had worked as a high school guidance counselor, I hardly recognized this stranger before me. Apparently she also now “heard voices” from the TV that told her to leave their house at night and wander off in the darkness. My aunt and uncle, while loving and supportive, had had enough. It was difficult enough raising their own two, young children without throwing a deranged grandma into the mix. In fact, they had already put her on a waiting list for a nursing home.

My volunteering to take her with us for a few weeks before the fateful date of “the home” was as much an honoring of that promise I’d made to her years earlier as it was a rather youthful, egotistical belief that somehow I could make her ‘better.’

Of course, while we did care for her until her death, ‘she’ was not really there at all the last few years. Her ‘stand-in’ (who looked remarkably like her down to her arthritic toes) was a horrible impostor. She was the one who didn’t know that I was her granddaughter and thought I was ‘the maid’; the one who informed me there was “a cat loose in the house” whenever she heard our baby cry; and she was also the one who stood in the bathroom staring blankly at the mirror with a toothbrush in her hand wondering both what the toothbrush was for and who was that person looking and staring at her like that?

What a ride those 13 years were and what a responsibility! Even during the journey both my husband and I admitted that there was no other individual in either of our families we would have volunteered to care for. Had Granny Jo not been so ‘easy’ to live with and had her demise not been slow enough that we could keep up with her, we would have given up the first year. But we didn't. There is much to be said for youth and naiveté.

"Do your best. Then forget about it."

When we first moved Granny in with us, her disorientation was extreme. She paced the house without direction, wore odd combinations of clothing (picture naked woman wearing knee socks and a raincoat), and could not make the simplest of decisions including what to eat. Nothing in our 2-bedroom rental looked familiar to her. She wandered from room to room as if she were in the twilight zone and couldn't quite get her bearings.

So, instead of selling the furniture from her old house, we had it shipped to us. (This was fortunate as the only furniture we had purchased as newlyweds was a king bed and bookshelf). We recreated her former bedroom. Her oriental rug lay under her four-poster bed and I placed the pictures and knick-knacks on her dresser and desk as closely as I could from memory. Suddenly she knew where she was. She went right to her dresser & found the clothes she was looking for. She sat at her own desk, took out her writing paper and began to compose a letter.

Another reason for her initial confusion was a very poor diet. Older people who live alone not only tend to eat very little, they often simply snack on sweet or soft foods and are deficient in proteins, vitamins, minerals, and certainly vegetables! Granny started eating three meals a day with us and her cogency was immediately apparent. She talked more intelligently and was livelier. Now we could begin to play games together at night like three-handed bridge or Scrabble. The Granny I had known as a child was coming back to life before my eyes… .but not quite completely.

About three weeks after she moved in with us. I couldn't find her anywhere in the house. Frantically, I ran down the street calling her name. (This was before GPS devices were invented.) As I ran past house after house, I realized that all of the houses in our southern California development looked pretty much alike. I started down another block and there, a few houses down stood Granny. She was at the front door of some poor man's house. He had the door half-open, was bare-chested and had a towel wrapped around his waist. As I drew near I could hear her say, "But this is MY house. Let me in!" It would be only the beginning of many, many other embarrassing but just as often, funny moments.

People will tell you that caring for the elderly with Alzheimer's is a lot like bringing up children. They are absolutely, 100 percent, unequivocally wrong. Having now had two children of my own, I can tell you that it is almost EXACTLY OPPOSITE! Children learn more and more each day. They get stronger, brighter, quicker and more clever by the second. Alzheimer's patients diminish by the hour. One day they know how to use the toilet. The next day, pee is dribbling down their legs. At breakfast, they are feeding themselves. By lunch, they have no clue what to do with the spoon in their hands. While the timetable for each may differ radically, the ending is always the same something then someone is irreparably lost.

At first the loss is palpable: they can no longer drive a car. By the end, 'they' are no longer them'selves' at all. You are caring for someone you used to know but know no longer. They look the same. They may even walk and talk the same, but you are truly caring for a complete stranger; a stranger who is in fact strange to themselves.

Caring for a person with Alzheimer's is much harder for the caregiver than the patient because only one party has their faculties intact; the other is losing them as the minutes and days go by. If you can keep that in mind as you lose the person you knew, it will be much easier to deal with the person you now face.

"There is something good about everyone. Find it."

This is a bit easier to accomplish if you don't have to actually *live* with the person who is confounding you. When you find yourself caring for someone you used to love but now no longer know. When their presence becomes a burden and in fact at times you can barely tolerate them, a saying like this brings real meaning. Towards the end, my husband and I would be overjoyed if we actually got grandmother to smile once that day. He was much better at it than I was. One of his favorite things to do was tell her each day, "Granny. It's my birthday. Aren't you going to sing to me?" And, because she had no memory, she did, indeed sing "Happy Birthday to You," to him, sometimes several times a day.

What does it take to get through the day after day drudgery? Well, besides time and infinite patience, it takes an immense kind of love. What do you get? Humor, if you're willing to look for it. More importantly what do you gain? The true knowledge that you are simply doing the right thing. You are doing, indeed, what you hope someone, someday, somehow will be willing to do for you. Because if statistics are any indication, if you don't have Alzheimer's yourself by the time you are 80, you will likely be caring for someone who does or you will know someone who is.

There are many joys though and sometimes surprising upsides to taking in that 'stranger.' As newlyweds, we could only afford something very small and had few possessions. When Granny moved in with us, we gained a houseful of furniture that we otherwise wouldn't have had. Her monthly Social Security and her small retirement pension, which she received from working as a high school guidance counselor, was added to our income. This enabled us to rent a two-bedroom house instead of a one-bedroom apartment. It also increased our food budget. Given the fact that we ate like horses and Granny ate very little, we had the better end of the deal. Of course, I was cooking for one more mouth, but the difference between spaghetti for two or three is truly negligible.

We also gained company and companionship. I traveled quite a bit, which would have often left my husband alone. In my absence, they not only thrived but had fun going to the movies and out for ice cream (which I never brought into the house!). Granny and my husband became great comrades through the years. They played board games, card games, and Granny even sat for hours watching basketball on TV with him, which saved me from the chore! It was something I truly hated but that he loved… and now finally, he had someone to share it with.

In a way, we also had our own, private, live-in therapist! If *w*e were upset with each other, we could go to Granny and tell her everything. In the beginning, she actually gave us both good counsel. As the years went by, we still continued to tell her everything even though she had no clue as to what we were talking about. It was nice to simply have someone to confide in that you knew couldn't remember long enough to share it with anyone else!

And we had laughter. Lots of it. Buckets full and you never knew just when or where it would happen… like in church one morning. We had taken Granny with us to listen to a new minister deliver a sermon. Frankly, he was terrible and boring, but we were polite. That is my husband and I were polite. Finally, after about 15 minutes of his painfully boring sermon, Granny stood right up in the congregation and said in a very loud and decisive voice: "He is just awful. Let's get out of here!"

Then there was the time we were well, let's just say, in our bedroom with the door closed. Suddenly, the door flew open and Granny's face loomed just beyond John's raised, naked buttocks. She looked straight at him and said, "Helen, dear, I'm all out of hangers do you have any extras in your closet?" Did I mention that her eyesight had also failed inexorably?

And at the very end, when our daughter was two, Granny walked into the kitchen, took one look at our little girl and said for the zillionth time: "Do you know there's a baby in here?"

"Yes, Granny, I do," I said also for the zillionth time.

"Well, where did it come from?" she queried again.

So, instead of telling her as I did at least 5 or 6 times a day, "from my tummy." I replied instead, "I found her in the mailbox."

"Oh, well, should we keep her?" Granny asked with sincerity.

"Yes," I told her, "I think we can because it was OUR mailbox."

"Okay," she said, satisfied, and left the room.

"Always leave a place while you're still having a good time."

This was one of Granny's mottos that I was unable to keep for her at the very end. You cannot control the pace of Alzheimer's anymore than you can keep the second hand from moving around the clock. It simply does what it does.

But the good times were many: taking Granny with us to the pool hall where she showed off her 'behind-the-back' shot in a room full of bikers; riding the bumper cars at Disneyland; watching her laugh as her white hair blew wildly and wouldn't 'hold still' in the front seat of my VW convertible; watching the faces of the other shoppers as my grandmother kissed tomatoes in the produce section; seeing the reaction of a NYC patrolman when Granny politely asked him if he was her "chauffeur" and would he "please take (her) home now"; explaining to the ambulance driver (which our neighbor had called in a panic) that "Granny often likes to lay down in the ditch and nap after she gets the mail from our mailbox."

Now don't get me wrong. Dead lifting a naked, wet 5' 9" woman from a bathtub full of water because she's had a stroke is not easy. (I enlisted the help of our pool man). And getting a grown woman to wear a diaper because she can't figure out how to get to the toilet is also not easy. She may just take it off in Macy's when you're not looking. And, forcing a grownup to brush her teeth when she doesn't want to is another challenge particularly if you don't want to get bitten. (I learned to wear rubber gloves for the task.) And, ultimately, cleaning up the mess when someone has defecated in their bed is not pleasant no matter who you are. But it happens and somewhere, right now, it is happening to someone else.

Most of us are really not up to the task, especially at the end. We finally called hospice for what would turn out to be the last week of Granny's life. We didn't know it at the time. And, until the women from hospice came, we also did not realize just how much we had been doing with and for Granny for a full 13 years. Amazing what you can do if you don't stop and think about it.

Would I do it again? Yes, but only for my husband. Considering what he went through with my grandmother, it's the least I could do. How many women have a husband who would hold your grandmother upright in the shower while you bathed her? Or help you diaper and wipe her? Or take her shoe shopping and lace up her shoes? Or patiently lead her step by step to her seat at a baseball game or the beach? Or help her brush her teeth and feed her by hand when she no longer can do it for herself? I'm guessing it's not a long list.

Our 13 years with Granny Jo were 1983-1995; a time before cell phones & the Internet. No one had an email. Texting was a dream of the future. 'Chat rooms' were real chats with real people in our own living room. We took pictures that we had to wait for weeks to develop and the world was a much bigger place. Now we have friends who 'skype' their parents living far away. But as small as we've made our world with technology, we are truly further apart from each other than we've ever been in history and that is our great loss.

None of us are here forever. Life, no matter how long or short, is always a brief visit. So we do what we must—we do what we can—we do what our conscience calls us to-- and then we move on. But there are things in between we must question: Why do we treat birth and babies with celebration and cuddles but death and our dying with only dead flowers and distance? Why do we spend more time picking out a shower gift than we do in researching a nursing home? Why is a baby that has nothing to offer but helplessness and a blank past more worthy than an old person who has given life and contributed to the world? Why did the ancients value the old for their wisdom? What did they know and value that we have yet to discover as a nation? Why do the 'poor' countries live in extended families and save the best morsels at their table for the elders?

Because they know where richness and treasure lie: in the eyes that have seen and searched and shared and shed tears. In the hearts that have loved and lost and kept loving. In the arms that once held us but can no longer hold anything or anyone at all. In the people we loved and we lost even as they stood in front of us, and yet never stopped loving.

People often ask me, "How could you do it?" My only reply is, "How could I not?"

References

Alzheimer's Association. (2010). *2010 Alzheimer's Disease facts and figures*. Retrieved from http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf

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Handout 1.

Suggestions for Caregivers

1.Try and keep your loved one in their own surroundings as long as possible. Change confuses them.

2.When they can no longer care for themselves safely, move them in with you. Try and recreate the bedroom they knew. The more familiar you can keep their environment, the less confused they will be.

3. Watch their diet closely being sure they get small amounts of protein throughout the day. Many elderly people gravitate towards soft, sweet foods that are easy to consume but not always healthy.

4. Have them participate in some kind of exercise daily, even if it is simply walking to the mailbox. It will set the tone for both their physical stamina and their mental outlook.

5. Remember that people with Alzheimer's grow more helpless as time passes. Treat them as the person they are NOW, not the one you remember.

6. Just as you would not park a child in front of the TV all day, do not let your elderly do so either. They will soon become part of the furniture and have little to offer.

7. Take them everywhere you go as often as you can for as long as you can. Even if they have no clue as to where they are going it keeps them connected to both you and the world. I would add that it is also good for others to see our elderly included not excluded.

8. Engage them in conversation. Encourage them to talk and express themselves even if you have to hear the same story over and over, every day for years. It is *their* story.

9. Sing with them often. There's nothing wrong with a chorus of "Jingle Bells" in July. Surprisingly, many Alzheimer patients who can't tell you their own names, can still sing entire verses from songs they learned as children.

10. Keep their lives simple but organized. Even their clothing should be easy to put on and take off.

11. Give them chores to do that they can handle at each stage. In the beginning, Granny had to fold the laundry and get the mail from the mailbox. At the end, she had only to get out of bed and dress—with help of course.

12. If at anytime they become more than you can handle, get help. Every Alzheimer's patient, like every person, is different. They can run the gamut from docile to violent.

13. There is no shame in asking for help. Most people like to be needed but you will have to ask! Over the years, I enlisted teenage baby sitters, our next-door neighbors, the pool man, the mailman, our minister, and complete and total strangers.

14. There will be a time, though, when you will need real, professional help. Whether it is a live-in facility or a hospice, there will be a time you need it. Fortunately, today with the Internet, there are countless organizations at your fingertips. Some of them include: The Alzheimer Association, AARP, Alzheimer Foundation of America, The National Family Caregivers Assoc., The National Respite Locator Service, The Family Caregiver Alliance, Eldercare Advocates, Caregiving.com, and Aging with Dignity: 5

Wishes. These are only a very few, and by the time this is published there will be many, many more.

15. Keep them warm because there will come a time when they don't even know they are cold. Even if they do and a blanket is nearby, they will not make the connection and cover themselves.

16. Love them often. Hugs and kisses are better medicine than anything you will ever buy in a bottle.