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Taking Care of a Loved One Who Has Alzheimer's disease

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Abstract

Alzheimer's disease is a devastating neurodegenerative disorder that currently affects millions of Americans. This means millions of Americans are providing hands-on care for their loved ones who are struggling with this illness. Caring for a loved one who has Alzheimer's disease is an extremely difficult and emotionally draining task. Ways in which caring for a loved one may affect the caregiver are discussed below, along with strategies for helping the caretaker avoid becoming emotionally and physically overwhelmed.

Keywords

Alzheimer's, disease, caregiver, care

In this article, the author has captured a glimpse of somebody's life. This is the story of a woman who was a caretaker for her mother who died of Alzheimer's disease and became ill herself while taking care of her mother. Finally, she sought psychological help. During her therapy sessions, the author kept wondering how many other people find themselves in similar situations. Is there any way to decrease the likelihood of such negative consequences for others who find themselves taking care of their parents who have Alzheimer's?

There was not one session with this woman during which the author did not find herself thinking, "I must write all of this down to help others protect themselves from getting sick while caring for a parent or other loved one who is dying." This article starts with this patient's story of her own experiences as a caretaker, followed by suggestions to minimize the stress that so many people are faced with as caretakers. By better understanding how it happens, we can minimize the dangers of becoming ill while taking care of a dying loved one.

It is important for doctors to read this information and pass it on to their patients, as they may find themselves responsible for caring for aged parents and facing similar problems. The author hopes that those who face the possibility of being a caretaker will learn how to protect themselves from becoming ill. An important part of this equation is that they must also prepare themselves for parting with a loved one who is at the end of his or her life journey.

As the prevalence of Alzheimer's disease increases, it becomes more important to learn how to avoid the kinds of problems this patient struggled with. At the end of this article, the author has included suggestions for caretakers on how to avoid stress while managing a parent's illness.

A Daughter's Story

I was an administrative assistant and a teaching assistant for professors of a well-known university. I helped them, I learned the computer, and I taught the other students how to work on the computer. I enjoyed my job, but it was a lot of stress. I then got a part-time job and worked at a hotel gift shop at night. I loved this job, although $60 a week is not enough. But I needed to be in the hotel environment, where people travel and are taking vacations. It was fun. Aside from my job, I had many hobbies that were related to arts and crafts. I used to bake candies and teach others how to make them. I used to do lots of crafts. People loved it.

When my mother started to get sick, I kept visiting her and observing her more closely than before. When I was visiting my mom, I noticed that while getting sick herself, she took care of all her neighbors. On many occasions she asked me to visit her female neighbor, saying, "She is sick and lives like a hermit, as she is not going anywhere." I would visit my mom's neighbor anytime I visited my mom. During those visits I took care of my mother's pills, refills, and other related tasks, such as talking to doctors, making appointments, and taking my mother to her appointments.

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It all fell apart as my mom started to get sick and needed more and more help. Slowly, I started to see what was going on with my mom and that it did not look like it would improve.

For most of her life my mother had an active social life with plenty of interests and hobbies, but now she was losing it slowly, bit by bit. Eventually she asked me to move in with her.

In spite of my dearly held dreams of residing somewhere with a view of the park, I moved in with my mom. Her neighbor was becoming sick and eventually she died. Shortly after, I moved in with my mom, my mother became the female neighbor herself and was eventually diagnosed with Alzheimer's disease.

She started to repeat stories, not twice but 4 times. I kept asking her, "Mom what's wrong with you, you have already told me this story. Don't you remember?" At the beginning she denied it and laughed it off, but later I saw she was surprised when I pointed it out to her. Today, years later, I regret it so much, as I had no clue she was getting sick and could not control it.

With time her symptoms of Alzheimer's got more and more obvious, but I was not aware of her illness yet. The next thing, I noticed was that she had problems writing checks. She could not write out her checks. She was frustrated about it. I would try to help her and would tell her that I had problems like this when I got upset. My explanations did not work well, so, to minimize the problem, I had to learn how to write her name well enough to sign her checks. The next thing I can remember about the progression of Alzheimer's disease was the fact that she would not be able to remember our address, so I would write that out for her too.

Her next stage of getting worse and worse was accusing me of stealing money. I was not stealing; she was hiding money and forgetting where she put it. When she decided she wanted to find her money and could not remember where she put it, she would wait for me. When I came back home from work, she would yell at me. We would search for her money, and eventually we would find it. But she would never say, "I am sorry." I felt devastated more and more, as my life become hers. Actually, she took my life bit by bit, and at that time I did not see it as a possible problem. I felt it was my responsibility, as I loved her and wanted to take care of her.

My mother collected silver dollars. One day when she was unable to find them, she took a butcher's knife and threatened me, accusing me of stealing her money. I was so scared, but when I calmed down a bit, I asked her to let me look for them and found them. She would lose other objects too, and sometimes I found them in very odd places.

Since I felt nervous and wanted to avoid any confrontation, any time I saw her money, I would put it on the counter so she could see it. Then she would take it, hide it somewhere, and accuse me again of stealing it.

At that time, I felt hurt, as I knew in her eyes I was such a horrible person. My siblings were her favorites, as they were not stealing from her and doing all the things I supposedly did. She picked on me because I was the caretaker. She perceived me as not being a good child but my siblings were glorified, as they came to visit and went home, whereas I was the one who was with her 24/7.

Caregivers are the objects of abuse and accusations from those they take care of. My mother would accuse only me, not my brother or sister, of stealing her money when I was alone with her. When my brother came to visit, she was very nice to him and would tell him she loved him, whereas she would not say, "I love you" to me. I remember trying to talk to my mom and hoping for her "I love you," without any success. This is around that time, I started reading about Alzheimer's disease, I was able to understand her illness better, but I never could handle my jealousy of the fact that she could tell my siblings she loved them, but she could not say those words to me.

One of my mother's hobbies was sewing. She had hundreds of patterns. She made clothes for Barbie dolls for all the girls in the family and friends. When she started getting worse she would try to do her sewing, make mistakes, and then try to undo her work and start over. Eventually she was unable to manage the sewing anymore and told me she had decided to give it up.

At times, my mother became very angry and frustrated with herself when she could not remember things. She would then take her anger and frustration out on me. When that happened, I shut myself in the bathroom and cried. Then, I tried to hide it from her so she wouldn't see I was sad and had been crying. I felt sad all the time, with no relief.

The Alzheimer's progressed slowly at first, but then my mother started going downhill fast. I would have to help my mother go to the washroom or give her an enema, because she could no longer manage these tasks herself. Instead of getting up and going to the bathroom, she would make mistakes and I would be there for her, to help clean her up.

I was helping my mother and I was ruining my own life. Both of us were getting worse and worse.

Over time, my body became hers. She needed my hands, my legs, and even my mind, with nothing left for me. I served it all to her without missing a beat, never thinking of the consequences for myself.

One night I heard her calling me. We had a monitor with a pretty loud speaker installed in her room, but she was so loud I could hear her through the door. She was screaming, and it took me a half hour to calm her down and find out what was wrong. I did not want to turn on the light so she would wake up completely, so I tripped in the dark and hurt my toe on her special hospital bed. The pain was so severe that I had a hard time making it to my own bed.

The next day, I could not walk or get out of bed. I called the doctor and he ordered an x-ray. Since I did not want to leave my mom, I had the x-ray done at home. I found out I had a fractured toe. At this point, I was on my own. I was still taking care of all my mom's needs and my 2 siblings never seemed to care. I was homebound with my fractured toe for 6 weeks. I remember being with my mother 24/7, sitting on the chair right next to her bed and wondering what I would have to do to get my mom back. I prayed, cried, and pleaded with myself that I did not want to live without her. I loved her more every day, but at the same time I knew I was waiting for the end.

I cared for my mother and kept her company for years, cooking for her, feeding her, and cleaning her every day. After she died, my brother and sister kept saying, "You did not do anything for our mother, because she had caregivers." I knew I had been there 24/7, and I felt like no one could understand me except other people who would do the same thing for a loved one. I keep remembering that it was me who fed her and helped her with all the tasks of daily living, such as dressing, eating, and hygiene. I felt proud of myself that I was able to care for my mother, and I wanted my siblings to understand that the caretaker was there for a few hours a day and that I did all the rest. I never told them that when the nurse left, I became the nurse. The difference was that I had no training for the job and was not qualified. I wanted to scream at my brother and sister that I was my mother's child, just like them.

While taking care of my mom and watching her illness pulling her farther and farther away, I was scared of everything. I was afraid of losing her, afraid of getting sick myself, and I could not stop asking myself if I would someday get Alzheimer's disease and change in the same ways my mom had.

I was so afraid of being sick like my mom that when I was doing my own health-related paperwork, I asked my siblings to sign a do not resuscitate order for me, and they refused. I thought to myself, if they knew what it meant to lie in bed and be incapacitated, unable to say their ABCs, do simple math, or even understand what was going on around them, they would understand what I was asking for.

I hold on to all my memories of this time, and it still feels as if it were yesterday. I can still remember her schedule, with all her regular appointment times, as well as her daily routines. One routine I remember specifically is her shower and hygiene appointments. My mom had a shower appointment once a week with a caregiver who visited her on a regular basis. I had to leave my mom's apartment and go to my friend and upstairs neighbor's apartment during these baths, because it was too hard for me to watch. My mother had a hard time managing her pain when her body had to be moved and jostled.

With time, my mom became very ill. I promised her that I would die with her. I did not want to be alone without her, so I knew then that I would not be able to handle losing her. I could see her getting sicker, but I did not see what was going on with me or where I was heading.

Shortly before my mother's last days, I was hospitalized. The doctors locked me up in the psychiatric unit and loaded me up with medications. The doctor said I was "struck by stress." During my hospitalization, my mom passed away.

Since I was hospitalized, the standard of care is to follow-up with a psychiatrist and psychologist to monitor my condition. In addition to their help, I have been listening to religious radio and have learned that suicide is a sin. I am suicidal at all times and I am afraid to follow through, as I fear that if I ended my life, I would find myself in a similar hell to the one I am in right now. I am also scared that if I make a failed attempt to kill myself, I may become disabled like my mother. I do not want to become disabled and I do not want to be alive, lonely, and without my mother.

While I struggle to process my mother's death and get better, I try to function as normally as possible. I try to make myself visit my siblings, go to church, and keep my neighbors company. When I visit my siblings, it seems to me that they do not miss our mom and that they are not grieving. It seems to me as if my mother never existed for them. They are happy and cheerful, with no signs or symptoms of grief.

I am going through constant turmoil. Since I lived with my mother, I am still at her condominium. This situation poses many problems for me. Since the economy is not that good and there are a few condominiums for sale in my building, my siblings demanded their share of the condo as money. Since my mother owned the condo and I had no strength to oppose my siblings, I paid them off. In the process of settling on the condo, I paid for all the lawyers. I am not even sure if I was supposed to pay for all of this myself.

There is not 1 day that I do not ask God if I am now paying for something I did wrong. My feelings about this seem to relate to the fact that I did not die with my mom, that I am in her apartment where everything reminds me of her, and I am extremely lonely.

I cannot help comparing my life at present to the one I had years ago. I took over my mom's life, picking her clothes and her food, and she was totally dependent on me. I think my mom lived her life in my body, so that I had no life of my own. Today she is gone, and I pray just to be able to go to the store. I am not used to doing anything for myself. It takes so much out of me to do anything or go anywhere, because I am constantly nervous. Five years ago, I could still go to the store with my mom and feel happy.

I do have people around me but none of them are my mother. I feel like I have no support from others, as some of my friends say I am selfish and my siblings are busy and seem not to care. Most of all, none of them seem to understand how I feel and that I miss my mom so badly that being alive is a chore.

Being alone is so tiring and hard. I wish I could live life to its fullest, but I just exist. I am physically and mentally uncomfortable. I am scared to do anything, afraid to go out and be with others. Most of all, I was a sickly person, so I am surprised I outlived my mother, who was healthy all her life.

Taking care of my mom took everything out of me. I would get up and make sure she was well taken care of, always putting her needs before mine. I would kiss and hug her, showing her lots of affection. I always did her nails and toenails. She was such a good patient and never complained during the last days of her life.

It is hard to take care of your dying parent and it is just as hard to live without her. When I got sick and wound up in the hospital, my brother and sister had to take care of my mother for just a couple of days. They were not able to handle taking care of my mom. They kept complaining that it was not convenient, and finally she was transferred to the nursing home. After a couple of days there, she was gone. It has not been very long since that happened, and I keep thinking if I had not gotten sick myself, my mother would have lived longer.

Suggestions on How to Protect One's Own Health While Caring for a Loved One

The author wishes to thank the daughter for sharing her story, letting the author take notes, and allowing her life story to be published for the benefit of other people. Most of all, the author is grateful the daughter felt comfortable enough to let the author into her deepest secrets and painful feelings.

It is worth asking what we have learned from one daughter's difficult struggle about how caretakers should take care of themselves. Good self-care is just as important as good other-care, not only to avoid compassion fatigue but also to avoid anxiety, depression, and possible hospitalization.

It is most important to remember that if we want to help others, we really need to be in good physical and emotional shape ourselves. What this means is that we need to think in terms of providing enough nourishment for both the sick person and the caretaker. For simplicity's sake, the author refers to the person who takes care of a parent as a child. In this case a child is not an underaged person but the adult caretaker. In other words, when the child cooks a meal for the parent, she should also prepare a proper meal for herself. If the parent eats pureed food, the child should eat the solid version. The child should also not get into the habit of finishing the parent's food without thinking about it, because gaining too much weight can lead to health problems that make it more difficult to be an effective caretaker.

While taking care of the parent, the child makes sure the parent takes his or her medications and makes it to all doctors' appointments. Well, the child has his or her own appointments, and they also have to be met. It is important to buy a big double-appointment calendar that has 1 day on each page, with room for 2 schedules: 1 for the parent and 1 for the child. In this way, both schedules are easily visible at a glance and are assigned equal importance.

It is essential for the child to keep regular appointments with primary care physicians. If possible, it makes sense for the child to have the same doctor as the parent. This way both appointments can be made together, they will be more convenient, and the child will be less likely to forget her own appointment. In most cases, the primary care physician is well qualified to understand the conditions that caretakers live with and can tell whether the child needs psychological care or support. This support can either be provided in a group setting led by a professional or layperson or in a clinical setting where psychotherapy is provided by a licensed clinician.

While performing the demanding role of a caretaker, each person should have regular appointments with a clinical psychologist regardless of whether or not their doctor has suggested it. Supports such as these can help to monitor the emotional health of the child and provide a safe space to express difficult emotions and let off steam. The frequency of the appointments can range from once a week to as little as once a month, depending upon the child's condition and financial situation. When it is just a support, those appointments can be once a month. However, when the care becomes more difficult and the child needs more attention and help to manage, he or she should decrease the time between appointments.

It would be unfair to not mention very important care that is available in situations when the sadness, crying, and anxiety symptoms become more severe. When and if the child needs medications to control his or her symptoms, he or she should schedule a psychiatry consult. In general, it is much better to recognize the condition faster and help it with psychotherapy and medications rather than to let the symptoms go untreated and eventually become too severe to manage in an outpatient setting.

While we are discussing hospitalization, it is worth noting that the author of this article was once asked to give a presentation at a college on the topic of being a caretaker. At that time, most of the attendees were people who took care of persons who had vascular problems and hence needed a lot of help. While addressing sleep problems some of the attendees were crying. After the presentation was completed the evaluations were very positive but they mostly asked for more presentations like this one, as well as support groups.

Looking more closely at sleep hygiene, it is crucial to remember that the child needs to sleep also. Often the child keeps a radio-monitor in his or her bedroom to hear the parent if he or she needs something. People with Alzheimer's disease frequently mix up day and night and, therefore, wake up in the middle of the night, travel around, leave home, or wake up their child. If possible, an alarm system should be in place to keep the parent from getting out without the child's knowledge. If frequent nights are sleepless, the child should arrange to switch off with someone else for a couple of days within a week. If no family member is available, it may be possible to hire someone to give the child a break and a decent night's sleep. If the parent already has a nurse or nurse's aide, he or she may know someone who can help.

One of the important daily routines for the caretaker is to maintain a social life and see other people besides the parent. Whether the child goes out or has visitors over, interacting with other people and getting outside will provide stimulation and a more balanced life. Assuming the parent is well enough, he or she can also socialize at home when family or friends come over.

The child should also organize his or her time to leave home for such activities as shopping, going to the movies, or working out at a health club. The caretaker should not feel guilty about leaving to engage in such activities when other family members come over, because this is an important part of self-care. If no family member is available for a few hours a week, it is almost necessary for the child to find some paid help so she can get out of the house, meet other people, and keep abreast of everything that she was doing before she became a caretaker.

The child needs to have breaks from being a caretaker. No one should be required to work 24/7, and being with someone every day, helping someone manage the most basic daily tasks, and "loaning them your hands, legs, and heads" is a very hard job. It is not only hard physically, as the child has to be on his or her toes all the time but it is also emotionally draining.

It is extremely hard to witness somebody slipping away. It is even harder when that person is your beloved parent. Watching a loved one change into an unrecognizable person requires extreme will and strength, therefore, the support is crucial.

When the time comes and when the parent needs skilled help, the child will need a lot of professional help to let go and allow the parent to be cared for by other people. The difficult process of letting go can be supported and helped by a psychologist. Ideally the psychological care should be scheduled before the parent is moved to a nursing home or hospice, as the child will have a great deal of adjusting to do. Not only will the child experience major environmental changes with the parent gone but the child's coping strategies will also need adjustment. When the parent moves out, sometimes the child may have too much time on his or her hands, with no idea how to fill up the time. To avoid unnecessary loneliness and make plans for what the child will do when the parent is no longer there, it makes sense to consider these issues before the parent moves to the next level of care.

Last but not least, the author's message to those who cannot let go is that you must find some way to ask for help. No one wants you to forget about your parent. The author wishes that each caretaker would take at least as good care of himself or herself as they do of their beloved parents. After all, it is what their parents would want them to do.

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