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Why do people have such a hard time talking about Alzheimer's Disease?

alzadv Posted: 03 September 2008 04:39 PM [Ignore]

Newbie

 Total Posts: 5
 Joined: 2008-09-03

Based on the fact that some of the topics in the Alzheimer's forum have received over 400 views, yet there are only a few messages in each topic, I have to assume that people have a hard time talking about this topic, even though there are evidently a ton of people out there who find the information useful.

So I'd like to talk about the following:

Why is there such a stigma against Alzheimer's Disease and other forms of dementia, and

What can we do about it?

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Kathleen, MSW Posted: 18 September 2008 06:16 PM [Ignore] [# 1]

Newbie

 Total Posts: 12
 Joined: 2008-06-04

I think that this is a very interesting topic. Why do people have such a hard time talk about Alzhei Disease. For me, the daughter of a father with Alzhei Disease the reason I find it so difficult is not the stigma that may come with certain diagnosis but the actual emotional affect that this disease has on myself, my father and my family.

I can not talk about the difficulty of watching my father who I love begin to lose the ability to function day to day, forget simple things like where he went that day or what he ate for dinner 5 minutes ago without crying or becoming intensely cognicent of the fact that things will never be the way they used to be. My father is the smartest man I know, but he no longer gets pleasure from reading books or discussing the news or other current events, this is a man who went to law school, not to practice law but to enhance is education and work in another field. It is surreal to see someone who still looks like the person you once knew in the physical sense but you begin to realize that they are almost of "shell" of themselves.

I beleive that Alzheimers is a very cruel disease, it is one that can not be necessarily identified in the physical sense right away, there is no cure and only 1 main medication that can be perscribed, although it can slow progression it will not stop the overall symptoms. I think in some ways people who have loved one's with this disease don't always understand it b/c there is no immediate physical identification and having someone "mentally" change, sometimes, very quickly can be overwhelming. I also beleive that some families may have feelings of embarassement due to their loved one's behavior, etc.

It is my hope that discussions like this one and more education about the disease will help everyone understand Alzheimer's a little better and that this disease can and does affect anyone. Ultimately, providing more dialogue may ease the difficulty of talking about this disease and the social stigmas.

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STOA Posted: 25 September 2008 01:12 PM [Ignore] [# 2]

Newbie

 Total Posts: 2

It's hard to talk about because we are living it day to day. It takes so much mental energy to remain upbeat and positive around those we are providing care for that while it seems like it would help to share and talk to others in the same situation, it just ends up bringing you down.

There is no upside to this disease and I believe the harsh reality and ugly finality of its' progression is almost unbearable for most people when the person involved is your own loved one.

I almost try to avoid the topic with friends on how my mom is doing because I can never give a 'good' report. The look on their faces when I tell them that she is losing her language capability and she can't remember how to cut her food is haunting.

Joined 2008-06-06

It's an unpleasant club we all belong to as caregivers for Alzheimer's victims. Yes, we come and read this information and it helps us to know that we are not alone... but by just responding to this post, it will take me a while to move past the gut wrenching sadness of this awful disease and loss of my beautiful, brilliant mother – my best friend.

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alzadv

Posted: 25 September 2008 03:26 PM

[Ignore] [# 3]

Newbie

Total Posts: 5

Joined 2008-09-03

I want to respond to both posts to this discussion about why it's so hard to talk about Alzheimer's disease.

First a bit of background. My mother had vascular dementia and passed away in June 2008. I did not have the experience of caring for her on a day-to-day basis as I live a few thousand miles away; however, I live now with my own demons such as the "why didn't I do more?" demon and others... I got home every few months or so and spent some concentrated time, but always felt as if I was blowing and then out again. Fortunately my mother never quite forgot who I was, although at the end she had to be given some hints! Our family watched her for 8 years as she declined. Her short term memory went, and she would not talk about it. She decided by herself to give up driving but didn't discuss it with anyone. She gave up needlework, sewing, cooking and reading as she started to lose confidence in her abilities in these areas, and still she did not talk about it. No one really talked about it in the family, and so at one point, about four years ago, I decided that I had better start to say goodbye to her, to the mother that I knew, and do it on my own without anyone knowing what I was doing.

I am glad that you both wrote down your thoughts. People, families need to talk about dementia before it happens, or at the beginning when signs of possible dementia are first detected, so hopefully opening up will help other people to open up as well, even if it's very painful.

Secondly, I wanted to know if it's possible for you to see your parent as still being your parent, or a person, or perhaps a different person but still a person... I can't reference your post while I write this, but quite often families will use terms like "losing my mother" or "he's gone." I even said up above that I had to say "goodbye" to my mother! I don't like sounding naive, or sounding like I don't understand your situation (which I don't because no two situations are identical), but your loved one is still there. Enjoy them. Find activities that you can share. Challenge their brain. They can learn and do. Even though it's awful to watch your loved one deteriorate or be destroyed, try and find the joyful moments, because if you look hard enough, they do exist.

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Dee Mayfield, CDP

Posted: 08 October 2008 11:23 PM

[Ignore] [# 4]

Newbie

Total Posts: 1

Joined 2008-10-08

Sometimes, people who care for an Alzheimer's loved one avoid talking about it with others because they are overwhelmed with feelings. "If I express them at all, I might lose it again." Sometimes throught do us in—"I wish this weren't happening to her." "I wish this wasn't happening to me!" "Now I feel guilty thinking about myself," "This is so awful." etc. Those feelings and thoughts don't go away, however we can learn to handle them. Talking with others helps in the long run, even though we cry in the short run.

My Mother passed away in February from Alzheimer's disease. I was her long-distance caregiver/helper for a few years before she was diagnosed. She then lived with me 4.5 years and in a nursing home 4.5 years (where I worked part-time for the last 6 months of her life so I could be close to her).

As devastating as the disease is, there can be moments of joy, fun, humor, and much love. Look for them, write them down, cherish them. In 2002, the autumn leaves in Illinois were stupendous! I brought home 20 leaves, ironed them in wax paper to preserve them awhile, and laid them on the dining room table on a white table cloth. Mom moved them around on the table, sorting them by colors, putting them in piles, cooing over them, asking me to look at them, etc. They were a joy to her and they entertained her, which was a great time for me to take a break.

I was travelling at night with just Mom and me in the car. She didn't talk much and I was all sung out from the 4-5 tapes I'd been singing to her. It was quiet. No sound for miles, just the hum of the motor. When suddenly she SCREAMED! "OH MY GOODNESS!" It scared me so much I almost wet my pants! I said "Mom, What is wrong?" (That was when I could still call her Mom, later I called her by her first name which was fine.) To my question she asked, "Did you see that beautiful moon?" hahaha - Scared me half to death—but you just can't be aggravated - she just wanted to share a beautiful sight.

During the time my Mom needed verbal cues to help her do her, we'd invited friends over for dinner. I would say, "Mom, pick up your fork." "Put some food on the fork." "Mom, put the fork in your mouth, eat." It usually worked, but this evening it did not. My mother stared at the man across from her at the table. I assumed that it was because she didn't recognize him/remember him. I introduced him and said, he was my friend, then went back to the verbal cues. She still stared. I mentioned, "Mom, you're staring at Bob. Put the food in your mouth." She still stared. No amount of convincing would get her to stop staring and start eating. Instead of just letting her sit there for a little bit, I said "Bert, why are you staring at him?" To which she informed all of us, "I want to see if that PIG is going to eat everything on his plate!" hahaha Fortunately, our guest laughed too. It's easy to say that "this" or "that" is because of the Alzheimer's/Dementia. However, if I delved deeper and gave it some thought, many of the things my mother did were a combination of who she has always been and the disease (who she was now). INSIGHT-- When she grew up in the Great Depression - a person only put 1 Table spoon of each food on their plate, ate it, then took another. If as a child, I took too much on my plate, she'd explain that putting a lot on your plate made you pig-ish. Only take a serving - then if you'd like more, you get that after you've finished what you have. (Perhaps you had a mother similar to mine.)—Soooo - it really was only normal for her to think our guest was 'a pig' since he had PILED his food quite high. It's just that that the Alzheimer's disease took away some of the controls of 'polite behavior' and allowed her to say what was on her mind. Now, wouldn't we like that privilege sometime? hmmm...

One more incident, because I know I'm chatting on... and I do so in hopes that you will look at the GOOD moments or the FUNNY moments...and know that there are many more. One time, I'd picked my Mother up from the nursing home to take her to the doctors (I liked that better than having her go to the home while I wasn't there - at least till Mom couldn't move around as easily). After the appointment, I brought her back to my house for lunch. I was feeling quite bad - I sat close to her, just wanting to 'feel her essence' - hear her voice, feel her touch. And I looked into her eyes and suddenly missed her so very much... I missed having MY MOMMY... someone who could take care of me, instead of me having to take care of her. So - I started to cry. And that dear woman, who couldn't remember how I was related to her, sometimes didn't know my name, she held me close to her and while I cried on her shoulder, she patted my back and said, "Awww... aww.... It's okay."

We all change. You and I have been changing from the day we were born. So I figured if my Mom could put up with all the changes I've been through and still love me, then I could give her love and acceptance back for who she is and who she is becoming... ESPECIALLY because she has no choice.

Because of my mother and her horrible disease, I have learned more tolerance, patience to wait while someone thinks of an answer, the ability to state things more than one way without catching an attitude. And as my cousin puts it, "Dee, you never would have become a certified dementia practitioner and trainer or learned to help others, if your mom hadn't had Alzheimers."

Keep looking for joy, and take time for yourself. Dee Mayfiel

- Image Attachments



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