



Caregiving and Alzheimers

Two friends in their 50's who were discussing their parents. One person said, "I just can't go see her since she doesn't know me anymore. It's so hard to see her like that." The other person appeared to agree with her friend. It can be very overwhelming to care for those family members who are not able to communicate and participate in life as they once did. It can be very difficult to see someone's interest in others slowly fade away, no longer questioning or curious, no longer able to enjoy the birds at the feeder, the azaleas in bloom, or wonder if it is really going to rain today. The physical changes are also very sad to watch as the person begins to wither and is no longer able to dress himself, brush his teeth or even wipe his own nose. The decline in memory and ability brings a sense of loss over and over and over again to family members. These losses are what make visiting a person with Alzheimer's disease so very excruciating. **However, those losses are the very reason that visitors are so necessary!**

Nurses, aides and other nursing home staff may provide the most basic care for your loved one, but by no means can they provide the personal and tender attention that your loved one needs. Don't get lured into the idea that just because Alzheimer's has claimed someone's mind, that it has also claimed that person's emotions. The losses aren't happening to only you as a family member, but more importantly to someone you love. Everyone suffers from this cruel disease: spouses, children, friends, and most of all, the patient. While families watch the decline in functioning, the patient **experiences** the decline. Because the patient loses the ability to communicate well, there seems to be an impression that he or she isn't aware of the losses or somehow can no longer feel lonely, or scared or cold, or hungry or wet. This is absolutely not the case. You may be able to rub your loved one's shoulders when they're sitting in their wheelchair and feel him relax under your hands. They may be able to tell you that it feels good, other times, you may only be able to judge by their facial expression or the ease of the tension in his muscles. You know what your loved one enjoyed and being able to watch them still enjoy eating fresh peaches from the farmer's market requires no words- you can see it. You may also be able to do small care-taking activities that make a big difference to your loved one such as rubbing lotion on their dry skin. This type of personal care is not done by staff at a facility.

Sometimes loving someone means you are present in his/her pain even when there is nothing to be fixed or nothing to be done. You do not shy or run away from his confusion, but are there to try to soothe and comfort. You are there to put a sweater on when you think she is cold. You are there to brush her hair and put it up so she is more comfortable. You are there to cut up his meat and encourage his efforts to eat. You are there to turn on his favorite radio station. You are there to rub lotion on her arms and legs. Does it matter that your loved one doesn't know it is you? Is it enough to know she has been made more comfortable or he has eaten a little more at lunch or maybe he can sleep more easily listening to the radio? Maybe your loved one doesn't know it is you, his daughter, his son, or his best friend for the past 45 years, but he will know that love is present and that is all that really matters.

Some may say it is the duty or responsibility of staff to do those extras, and while that may be true, time or staff constraints or even apathy may hinder them getting done. Besides, a staff person cannot make that connection that goes beyond words, that goes beyond the “duty.”

So, if you have a parent or other family member with Alzheimer’s disease, figure out how to manage your own sadness and visit your loved one as often as possible. There are wonderful support groups for families of Alzheimer’s disease as well as many great books on care-giving. The end of life is often so hard. Imagine how you might feel if no one could manage seeing you....

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