



## **Understanding Alzheimer's: 8 Common Myths Debunked**

Published in Huffington Post on March 13, 2011

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It is so easy to think that there is no one there anymore when the person in front of you does not talk, or when she makes unintelligible sounds, or says things that don't seem to make sense, or doesn't remember what happened from one minute to the next. This is a normal reaction, but one that commonly leads to a whole set of unintentionally harmful behaviors towards the person: talking as if the person was not there, or addressing her as one would a child, or not giving her the opportunity to make decisions she is still capable of, or assuming that our interactions with her don't matter.

The person whose essential needs for dignity, connection and autonomy are not being met is left with a host of raw emotions (anger, grief, shame, depression) that she is unable to express adequately because of her cognitive limitations. Out of desperation, the person shuts down or acts out, becoming aggressive, pacing, wandering, calling out and crying. We drove the person to madness, and now we blame her for it. This is insane. What is called for is a better understanding of what it's like to live with Alzheimer's.

Here are eight truths to change the way we relate to persons with Alzheimer's or forgetfulness -- a kinder word than dementia:

### **#1 The fact that the person doesn't speak does not mean that she doesn't hear or understand.**

No matter how withdrawn or irresponsive the person may appear, one should act and speak as if she were completely cognizant. This precludes talking about the person in front of her, or ignoring her presence, or using language that is disrespectful. We treat the person as we would want to be treated, only using simpler language and talking slow so as to maximize the chances of being understood.

### **#2 Not recalling facts does not mean that the heart does not know or does not remember.**

To the contrary, persons with forgetfulness are extremely attuned to the quality of their relationships, and carry with them the emotional imprint of prior interactions, whether positive or negative. My mother may not remember that I called her earlier, but the positive effect of our phone conversation will linger for hours afterwards.

### **#3 The loss of abilities, no matter how severe, does not mean that all abilities are lost.**

Research shows that the following abilities remain, even into advanced stages of forgetfulness: experiencing pride, maintaining dignity, experiencing shame and embarrassment, feeling concerns for others, communicating feelings with assistance, maintaining self-esteem and manifesting spiritual awareness. That's a far cry from what we usually think.

**#4 What appears as nonsensical behavior actually makes a lot of sense from the person's perspective.**

Making sounds can be a desperate way of soothing oneself in the face of extreme alienation. Pacing is a way to channel one's anxiety or boredom. Wandering can be viewed as a search for something missing, like one's old home, or a lost sense of connection. Crying out is a plea for help. Aggressive gestures are expression of anger from one's needs not being met adequately, or from one's frustrations with the many losses attached with the Alzheimer's experience. We see all these behaviors as attempts to cope with very real distress.

**#5 The person is not a child or a baby, although some of her behaviors may cause us to treat her that way.**

The person may need assistance with basic activities such as eating, getting dressed, taking a shower, grooming, etc., or she may engage in pre-verbal modes of communication -- behaviors that we normally associate with very young children. But she is not a child. She is an adult, with years of experience and accumulated wisdom, much of it stored in her heart and her spirit. No matter how well intentioned, infantilizing the person will only cause her to feel worse.

**#6 It is not all downhill from here, at least not always.**

The journey through forgetfulness is nonlinear, with some remarkable breakthroughs here and there, often precipitated by the right context. Stories abound of persons who start speaking or smiling again, after they are moved to a different environment, one where they feel safe, engaged and loved.

**#7 The fact that the person struggles with initiating tasks does not mean that she is incapable of making any decisions.**

When in doubt, err on the side of exploring the person's range of abilities. Preserving the ability to make choices, no matter how small, is especially crucial. Many times, I have witnessed care partners take over all aspects of a person's life, unwillingly depriving that person from the opportunity to make even such a simple decision as which clothes to wear in the morning. Which dress, the blue or the red one? We all want to feel that we are still in control somehow.

**#8 Asking what to do with the person can be the wrong question.**

We are part of a doing culture. Sometimes, all that is required of us is to simply be with a person -- as in sharing moments sitting, walking, listening to music, watching a sunset or gently touching the person's hand -- after we have asked for her permission. This is an experience not unlike meditation.

**The more we understand, the easier it will be on us and the person in our care.**