

Connecting with the Person Inside Alzheimer's

There is so much that apparently drives us apart as human beings. Yet with all our differences, we humans bond in our understanding that the one most terrifying and destructive feeling that a person can experience is isolation, in the sense of feeling locked out of the possibility of human connection.

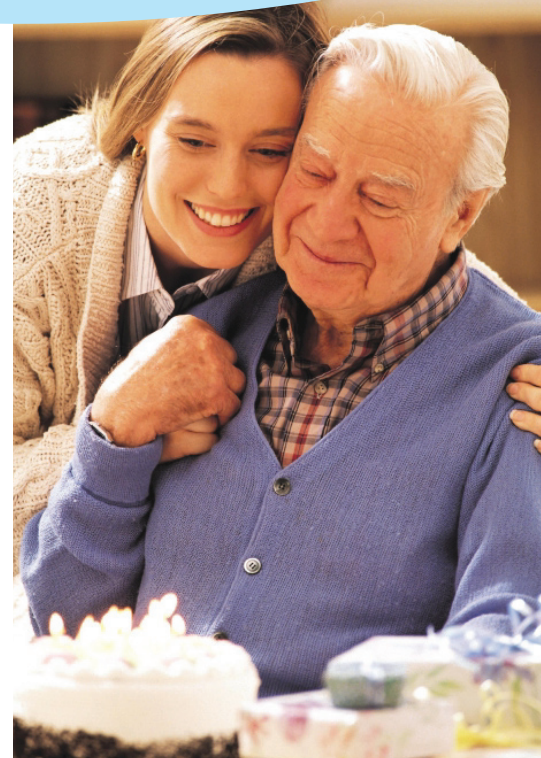
Who would more fully experience isolation and severe disconnection than a person with Alzheimer's or other dementing illness? I remember watching Ida as she sat near the nursing station during one of her more confused days. She tried over and over again to get the attention of anyone in the flurry of people rushing by her. At first she smiled and tried to establish direct eye contact. Ida was clearly a woman who spent a lifetime in social connection with others and when the smile didn't work, she leaned over and grabbed at anyone passing by. Some people pulled away and continued on. Some scolded her. Then, of course she called out in her language of many noises. When no one responded she turned up the volume. Then people did respond, telling her to stop shouting and to keep quiet. Ida eventually retreated into herself with tears. What else could she do? She was powerless over changing her situation, helpless over connecting with others, essentially invisible.

Working and being with Ida and with other persons who have dementia taught me that my function was not to figure out what actions I could take to help her. It was not about what I did or did not say; it was not about her getting anything from me, or my doing to or doing for her. As

Dr. Miller, co-author of *The Healing Connection*, writes, "it is about being in the flow of human connection rather than out of it."

Persons with dementia helped me learn that the diagnosis of dementia does not, by itself, alter a person's enjoyment of or satisfaction with being in connection with others. The disease does, however, alter a person's ability to maintain connections, which poses challenges for those of us who are not sure how to connect when the rules change. By rules, I mean the familiar or predictable learned behaviors or ways of interacting that are generally accepted as socially appropriate. We can feel lost when we try to connect with a person who is not playing by the same rules from moment to moment. How do we relate to someone who doesn't speak with the same familiar sentence structure as we do or who uses the wrong words all the time? What are we supposed to do when the person with dementia comes to the party wearing her bra over her dress? What do we say when a 94 year old woman thinks she is still raising young children that need to be picked up from school? How are we supposed to react when we have known this person our whole lives and she is not responding to us like she used to or, perhaps, does not even know us at all any more?

Connecting with the person who has dementia is challenging because she progressively forgets the rules for connecting in familiar ways. Her inability to remember the rules and her unusual behaviors are a result of a disease process. It might be structural changes in the brain and/or destruction of brain tissue but something



has occurred in the brain that has changed the person's ability to connect with others. Her memory and behavioral problems are simply beyond her control...they are not chosen, not deliberate. We cannot expect the person with dementia will be able to adapt to our standards and rules.

This, of course, means that if a connection is going to occur, it is up to us. We will need to make the adjustments necessary to bridge the gap between ourselves and the person with dementia. But how?

For over 20 years, I interacted with persons who have dementia and paid attention—looking hard at my interactions with each person with dementia for the ways in which she had been affected by me, by others, and by the world even as she progressed through the disease. Each person guided me during all of the connections and disconnections back to six basic concepts that we have been taught by religious and spiritual traditions throughout time—concepts that help us bridge personal barriers and create genuine shared relationships. I have listed the concepts not in order of importance necessarily but in a way to create the easy to remember acronym, IF LOST.

INTEND A CONNECTION – Check to see if you are ready to connect and allow your gremlins (the inner messages and persistent thoughts that block connections)

to take a coffee break for the time you are with the person. Focus on how you present yourself. The goal is towards a respectful, open, attentive, nonjudgmental relationship.

FREE YOURSELF OF OPINIONS/JUDGMENTS/EXPECTATIONS

Try to relax your hold on personal mind-sets that create logjams in your interactions with persons with dementia. Learn how to live with not having all the answers; open to entering the other person's world. Stretch beyond your personal boundaries, pay attention and allow the person with dementia to provide guidance.

LOVE – LOVE AND ALL THAT IT

BRINGS WITH IT—respect, honor, fondness, devotion, admiration, positive treatment—is the core energy of the rhythm of human connectedness. Interacting with a focus on loving helps dissolve the games and the usual patterns of interacting. It allows you to communicate nonverbally that you honor, respect and accept the person with dementia in whatever way he or she manifests.

OPEN TO BEING LOVED – Acknowledge his or her gift and open to receive it. Allow the person with dementia to

experience the joy of being able to have a positive impact on you.

SILENCE – Allow yourself to be comfortable with inner silence and enter the other's truth. Allow the connection to unfold. Develop the art of “being with”—truly notice, listen and pay attention in the moment. When we recognize the core emotion of her story, authentically identify with some aspect of her experience and reflect that back to her, we close the gap that separates our worlds; the person with dementia is no longer alone. Each of us feels seen; each of us is more able to act and move into the present moment with the other.

THANKFULNESS – Expressing gratitude to the person with dementia for the benefits you received during your interactions can be powerful evidence to her that you received the gift of her sharing a connection. At minimum, she feels good because she was able to help you feel good.

These simple concepts help translate what the heart knows into a logical, easy-to-understand form in the real outer world. Internalizing them has empowered hundreds of caring family, friends and

professionals to emerge from challenged, frustrated and fearful interactions into real, shared connections with persons, regardless of how advanced the dementia.

I began my work as a social worker knowing that my opportunity was to be present with persons with dementia in such a way as to encourage each person to continue to participate in life. I found in the process that I also was participating in life more than ever before. This has been the beauty of connection for me—each of us was able to see the other and feel seen by the other; each of us moved beyond isolation; each of us was empowered to move forward, to grow. We have guided, encouraged, inspired and accompanied each other in connection—with ourselves, each other, the world around us and the expanded field of energy. Each of us transformed in the single moment of connection; each of us changed in the most miniscule and grand ways forever.

Nancy Pearce, MS, LISW-CP is a resident of Taylors, SC. This article was adapted from her new book entitled Inside Dementia: How to Hear and Honor Connections with a Person who has Dementia (Forrason Press). For more information on the book and upcoming presentations, please visit www.INSIDEALZHEIMERS.COM.

Keeping seniors healthy and active in valued life experiences - whether its travel, sports or the ability to visit with a granddaughter - is the driving force behind the Greenville Hospital System's newly expanded Department of Geriatrics.

The most comprehensive system-wide program in the state, it now boasts six geriatricians and a uniquely trained staff, including a regionally known geriatric best-practice expert and a licensed masters-prepared social worker. The newly expanded department will use national best-practice models to serve inpatients, outpatients and the larger community.

At GHS, we want to be the Upstate's leading geriatrics health and education resource for, not only patients, but also their caregivers, families, physicians and other service providers.

At Greenville Hospital System, we believe in total health – for body, mind and spirit, for every age, for every person. That means wanting seniors to have the best health possible so that they can enjoy a full and rewarding life.



Medical Campus.

One of the most visible components of GHS' geriatrics care program is its Center for Success in Aging, a comprehensive geriatric assessment center at GHS' Patewood

There, a team of board-certified geriatricians works with a licensed masters-prepared social worker and e-based pharmacologic unit to evaluate a patient's overall medical, physical, social and cognitive health, including a thorough review of both prescription and over-the-counter medications. The center acts as a consultation center available to area physicians and their complex older patients.

Patients are evaluated during a two-hour visit, given a comprehensive health care plan, followed up with support to connect with services and ensure issues addressed, then returned to the care of their primary physician. Because of their unique training, the geriatricians are frequently able to cut medication usage, which can have a significant impact on patient memory and overall function.