Listen to Alzheimer's disease patients and their family caregivers and you sense the urgencies of their fears.

For the family, fear comes from the unpredictable course and symptoms. How long will this last? How long can the patient safely stay alone? If the phone rings at night, is it Dad saying Mother is lost? Fear is generated from not knowing when a beloved spouse might misinterpret an action and strike out, or wander off to fall prey to the elements or exploitation. It is fear of the future. Who will be there for me, the caregiver, as the patient gradually becomes unaware of my needs? It's wondering if the money will last through what can be a long-term illness. It's wondering, if you are the spouse, if you're up to the task after 49 years of depending on a very competent husband. Late in the illness, it's the fear that you might not have done enough or made the "right" decisions for the patient and the family.

For the Alzheimer's disease patient, early in the development of symptoms it's the fear of failure, the fear of being overwhelmed in front of respected coworkers and beloved family, the fear of losing an important job and family responsibilities that are vital to the self worth and adult identity. Many early-stage AD patients fear they are losing their minds or going "insane." Others find it more difficult to believe that they are changing. These patients assume that those around them must be changing. Their friends and bosses are plotting against them; their families are stealing from them; people are talking about them.

As the disease progresses, AD patients lose a sense of time. A five minute errand may seem like five hours or five days to an AD patient alone in a home environment that no longer looks familiar. Without a recent memory, events and their consequences lose connectedness. The patient cannot learn from experience that his wife always returns if he has no memory of her previous trips out and back. A sense of time is vital to make sense of how you got to where you are and what will happen if you behave in a certain way. AD patients can't learn from recent experience. Everything that counts is in the present.

If an AD patient cannot make sense of where he is and what's supposed to happen, then his "protector" or caregiver is his key to security and well-being. Experienced caregivers learn that AD patients fear being left or abandoned above all else. Those patients who wander off are generally not "running away"; they are searching for something familiar and more secure. Most of our earliest memories of security and protection come from our parents, and many AD patients repeatedly ask for their parents. An AD patient may search for his spouse even when the spouse is away only for a short time. The spouse is the AD patient's interpreter of the world. The spouse makes sense of what appears to be random dangers lurking elsewhere, and to be without that spouse, even briefly, is to experience great fear.

To live with AD must be something like always entering in the middle of a movie in progress. The police siren could be coming for you, since you have no memory of your previous actions. People may be after you at night for something you have done or something you have forgotten to do. If you forget how a furnace or fireplace works, no amount of reassurance will convince
you that it isn't a potential threat. Rational explanations are lost along with the capacity to organize facts to form logical conclusions. Many AD patients think their spouses or even their parents are "lost" in a web of confusing events and fear. Leaving notes doesn't reassure a man who won't know where to look for the note or what a concept like "back at noon" might mean. AD patient's worlds are out of control and the uncertainty is a constant threat. They need repeated reassurance in the moment: I am here for you. I can find you. I will make sure you look nice for our guests.

AD patients respond to comforting and reassurance much better than they respond to teasing or logical explanations. To provide this consistent reassurance takes its toll on families. Caregivers should make sure they take care of themselves. Explore creative outlets. Exercise regularly. Take time off for friends. Caregivers can better meet patient needs to the extent their own needs are met for reassurance, comfort, and esteem building.

**SOME THOUGHTS FROM THE ALZHEIMER'S PATIENT'S PERSPECTIVE**

Exerts from an article by W.B. Bolton

Please do not startle me . . . with your voice . . . by adjusting my clothing ... by brushing my hair ... by interrupting my actions. Don't expect snap decisions . . . ask me what I want . . . change plans without prior consultation . . . expect the same level of intellectual capability as before . . . belittle me . . . treat me as being stupid (maybe demented, but not stupid) ... hurry me or crowd me. I need time to think and space to move (I'm slow and clumsy).

Do understand that I'm OK if things go as I expected and that it takes all my mental ability just to exist at an acceptable level. Be patient and considerate . . . Speak logically, slowly and one thing at a time . . . Be specific in requests--using descriptive adjectives . . . Give or let me do something each day--and quietly finish it if I do not . . . Accept the fact that I move and think slowly and may be untidy . . . Give me a large napkin at the table--and a dinner plate, even for toast . . . Show me that you still love me—affectionately touching me --Try and find a passive social outlet for me . . . Make sure I don't tax myself . . . Realize that I may be around for five to 15 years and that I am not a stick or piece of furniture to be hidden away.