

Choice and control matter for those living with dementia care



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I'm sitting in an airplane, my seatback upright, tray table in its locked position, seatbelt strapped around my waist. Ready and waiting for takeoff. Each minute I sit deep in the belly of this small metal vessel, I'm reminded why I resist flying.

The engine roars, the smell of engine fumes is nauseating. In the front of the plane behind a secure locked door sits an anonymous person who will have my life in his hands for the next few hours. He's announced several times why we can't take off, but I can't understand him over the noise and poor speaker. I do, however, hear the exhausted sounding flight attendant instruct us to remain seated.

My need to feel in control is persistent, and at this moment, I'm painfully aware I'm not. I feel trapped and agitated. I close my eyes and practice focused meditation, a skill I've cultivated over the past several years to try and tame my habitual patterns of worry. After a long delay, the plane takes off, and the only choice I have occurs when I'm asked if I would like peanuts, pretzels or cookies.

What stresses many of us on a daily basis is the battle for control. Persons living with dementia are no exception. Yet, think of how many times those living with dementia are told what they can and can't do, often by people they don't know or recognize.

Think of how often they're made to feel that their options, needs and preferences don't matter — their choices taken away from them. I would imagine they feel trapped and disempowered. As a result, they may react with anger, agitation or anxiety — similar to me on an airplane.

Yet, my situation is different. I know that once I step off the plane some semblance of control will return. And since my cognitive function is (relatively) normal, I can generally temper my agitation and anxiety in social and public places.

For persons with dementia the capacity to regulate emotion may be less intact. As the disease progresses, the ability to verbally express what they need or feel declines. As a result, they're often labeled as having irrational or inappropriate behavior, when in fact they're reacting in a way that makes perfect sense given the circumstances.

When we view behaviors as a symptom of dementia, then we see them as a problem, but if we view them as a justified reaction to something that's distressing, we see an opportunity.

Most behaviors such as anxiety or agitation are triggered by factors that can be altered, including the environment, the task or our communication style. When we say or do things that threaten an individual's need for choice and control, they'll likely react with anger or agitation. Who can blame them?

I'm returning from an Alzheimer's care residence I just visited near Boston. There, they don't assume the residents are incapable of making decisions. Instead, residents are encouraged to make decisions every day from when to get up, what to eat, what music they want played at dinner to the current events they want to discuss (with the help of the New York Times and Boston Globe) at morning circle.

With accommodations most of them can read and follow written, verbal or visual instructions. With appropriate cuing they're capable of contributing to all aspects of residential life from preparing meals to participating in events that support local charities.

Residents are invited to engage in, and even lead, meaningful activities based on their preferences, interests and skills. The staff value the time spent supporting people with decision-making as much as the time spent doing other tasks.

They do more with the residents than for them. Residents are allowed and encouraged to remain independent until they no longer can.

As we land, I realize reflecting on my visit to Boston has calmed my mind and filled my heart — persons with dementia can have a good life, we can all make a difference, there's hope.

Thank you, Sharon and Sue from Hearthstone Alzheimer's Care and the residents who were so hospitable and inspiring during my visit.