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At Some Point It's just Time

By David Bull - www.caregiver4caregivers.com

Most of us can probably remember a time in our lives when we promised something to our parents and then chose to do the exact opposite or at least not think first before making a decision which in hindsight is actually what you had promised not to do. When my mother was first diagnosed with Alzheimer's I naively believed that I could handle pretty much anything that we had to do. My mother made my brothers, sisters and I promise to allow her to end her life at home.

We managed to keep her at home for almost 11 years before it became obvious that we just couldn't manage it any longer. For much of that time she was on a trial drug program which we believe now prolonged her quality of life for at least two years longer. But after being advised by the doctor and after many heart wrenching discussions and family debates, we as a family decided it was time to accept that we could no longer care for her at home. Emotionally our thoughts always seemed to go back to the idea that taking her off the test drug and placing our mother in the nursing home we were somehow signing her death away.

Circumstances change almost daily for the Alzheimer's patient, their families and their caregivers. Planning ahead is near impossible. In fact, my parents had dreams of travelling in their retirement. My mother wanted to visit Ireland, my father wanted to visit former work contacts from various places around the world.

But once the diagnosis progressed this became more difficult to do. Reality of Alzheimer's is there is no way to predict the progression of this disease. Each individual is different, different symptoms, different behaviors, and different time lapses between each. Some behaviors related to Alzheimer's have their own issues. Issues that only another caregiver could understand; "sundowners", "repetition", "obsessiveness", "want to go home." Some, Not all, Alzheimer's patients may become violent. One caregiver may find a behavior particularly hard to endure, while another caregiver may be disturbed by a totally different behavior.

Many Alzheimer's patients yearn for "home," the place of their youth that no longer exists. They'll walk and walk and walk, if unprotected by open (unlocked) doors. Much like a young child, they can be in grave danger of becoming lost or walking into traffic or accepting a ride from a dangerous passer-by. If you aren't able to keep the patient in a well-protected, locked area, you may want to look for other living facilities. Eventually, no matter how hard the family or caregiver tries, there comes a time when you realize that the Alzheimer's Patient just needs more care and may need more medical treatment than you, the caregiver, is able to provide. It's time where the best option is professional care in an Alzheimer's specific care facility.

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At Some Point It's just Time (continued)

My father began searching for the right place for our mother to go. The thought was not a happy one, we all dreaded it. We knew the search would be awful, thinking we'd never find one that met our ideal situation for our mother's care. In a way we were lucky because as a result of my father's career success, he was in a slightly better financial situation than others. He still commented on the fact that he felt like he was 'Hawking' my mother like some product for sale, trying to sell the nursing homes into 'Accepting her' as a resident rather than them wanting to help solve our issue by placing her. A situation we later expressed at numerous conferences and groups as we represented caregivers of those who were unfortunate enough to be diagnosed with Alzheimer's or any other dementia related disease and the day to day issues that are dealt with.

Eventually we found a place where my mother would end her days. Thankfully it also happened to be the place she had been too previously for day respite. A vacancy had opened and we were able to get her placed there. But then we realized that the vacancy resulted by someone else's family member had passed away and they were mourning the loss off their loved one. AND

that's why the vacancy became available. For the remaining time of my mother's life my father, brothers, sisters and I would spend numerous evenings at the nursing home trying to help the limited duty nurses with my mother and other residents. We watched her deterioration of the next six months all the time hoping her pain would end soon. Even after my mother's passing we still had the feeling there was an obligation on behalf of her for us to do whatever we can to help others through the caregiving role.

Final Note:

My parent's dream of travelling was fulfilled somewhat towards the later stages. They did travel to Ireland and then to the United States to visit friends on a final fling. But when we look at the photos of that trip in the majority of them my mother just looked lost and confused. All except in one photo. In that photo she looked like she knew exactly where she was, but in the background of that photo are the Twin Towers which only a few months later were to become a reminder world wide of a tragic and horrific event



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