

Living in a Dementia Unit: A View from the Inside

Jim Vanden Bosch

Daily journal: Day 2 (Continued) and Day 3

After lunch my assistant asks if I would like to go for a walk outside. Walking outside is something that was put on my “preferences” profile before I was admitted. I had also asked my assistant earlier in the morning if I could go for a walk. I am glad this is being honored. It is very cold outside, but sunny, and the 10 minute walk is delightful; we have a pleasant talk (with me speaking in short phrases) as we walk.

One of the things I had arranged with the administration ahead of time was that I would have internet access, since there were some things I needed to work on while I was spending this time as a resident here. But there has been a glitch in getting my laptop connected to the internet, and by early afternoon this has still not been resolved. I ask the unit director (who has helped arrange my stay as a “resident”) about it and she tells me to use her computer in her office. At least I can access my emails remotely this way, and take care of some things that need tending before the end of the day. By 5:00 it is dinner time already—so different from my normal 8:00 dinner time at home. Dinner is again a huge portion of fish (I think I’ve had enough fish now) and some creamed vegetable soup.

After dinner, I stay seated and watch as the residents are assisted, one by one, out of the dining room. While sitting there, I overhear this remark from a nursing assistant who is helping a resident with eating. “No, I’m not going to help you now. You said some mean things to me; you hurt my feelings.” There was no response from the resident that I could hear. I watched as the assistant continued to ignore the resident while carrying on a long conversation with another assistant.

I have become aware of something that is very common here--a certain tone used by the staff when they talk to the residents. It has the higher pitched ring to it that is commonly used when one is talking to a baby. I keep thinking of a statement I heard recently about “the power of normal” when it comes to assisting persons who are living with dementia. The more “normal” the environment and the more normal the interactions with those who are assisting them, the healthier their lives will be. I’m thinking that the institutional setting (abnormal) together with overly solicitous staff (abnormal) combined with the well-meaning but abnormally high pitched manner of conversing with residents who are living with dementia, are all contributing to their decline. The whole set-up in traditional “dementia care” is powerfully reinforcing and augmenting a helplessness in many residents who are living with dementia.

Day 3

Now that I am aware of this “baby speak,” (also called “elder speak”) I am noticing it here *all* the time. I’m also aware that the only male staff person here on the unit does not address the residents with this tone. His approach is more direct and his tone remains level. His tone reflects an equality of personhood between himself and the resident he is speaking to. This is not to say that the female staff here who baby speak are not caring and warm. In fact, I think that this tone is a reflection of just how much they actually care about the resident. I am left wondering if the innate propensity to mothering in most women is what is coming out here. But an older adult, with or without dementia, is not a baby. This is an area that is ripe for consideration as to just how much an infantilizing tone and body language contribute to the “learned helplessness” of residents living with dementia. Dr. Kristine N. Williams has researched the negative relationship between “elder speak” and resistance to care by persons who have dementia (<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2823803/>) but I think the effects of baby speak are much broader and deeper than just resistance to care. Someone should do more research on this.

I also notice that while I am occasionally called “hon”, for the most part I am not spoken to in the baby speak tone. This is, I’m quite sure, because I present with only a mild confusion. I do not need the level of care that most of the residents here do. Therefore, I am not treated as an infant.

After some more observation and thinking on this, I am now aware that the *male* residents here in the unit are not spoken to in this way nearly as often as the female residents are. They are usually addressed in a more level tone, or if they are being resistant to care, in a more aggravated tone. So now we are squarely into gender issues here. Women caregivers speak to women residents living with dementia in baby speak tones. I heard one staff person speaking with great affection (that was filled with baby speak) to a female resident, and ended with the enthusiastically spoken phrase: “you’re just as cute as a button!”

To be continued...

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