

Learning to Live with a Different Me – The Hardest Relationship of All

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Relationships are an important and integral part of our life. Whether we are extroverts and love a party or introverts and have a few close friends, as humans we are made to be in relationship. I am an introvert with a few good friends. One of those friends is Lauren, a Board Certified Psychiatric Nurse. Lauren has early onset Lewy Body Dementia and has been gracious enough to assist me in writing this article on relationships. Below are her thoughts:

When I am asked about relationships I think about the one that has changed the most as a person living with Lewy Body dementia; that relationship is the one that I have with myself. I have always been independent, resourceful, and unafraid of change. I have always trusted myself to know what the next best thing was for me to do and followed my own path in life. My identity was closely tied to my vocation as a nurse and I trusted that I was both competent and dependable in this role. I was diagnosed with Lewy Body Dementia, and have subsequently experienced changes to my brain. Because of these changes, my relationship with myself has changed. Because of my brain changes, there are times when I have difficulty knowing what is real and what is not. Therefore, I can no longer trust myself and have had to turn to those around me and try to put my trust in others. I know that I am more fortunate than a lot of people living with dementia because my support system includes individuals that understand dementia and therefore understand me. While this is helpful and comforting, it does not replace the fact that I have lost my identity of being a nurse, which was once so important to me, and also that I am now unable to trust myself.



It is a very weird place to be; having to place my trust and perception of reality in the hands of others. When I think something is real, I have to ask those around me to tell me if what I see or think matches with what they see or think. For example, when I eat lunch at the day program where I go once a week, it is difficult for me to figure out where the food is. And when I am told that the food is in the cups provided for me, I usually see the food moving. There are two people that help me with this. If both people tell me the same thing independently of one

another; that the food is in the cups and that it is not moving, then I can match what they say and believe them. This is how weird my life has become. But that, at least, works for now. What is hard is when this weirdness, as I call it, has to do with my most trusted people. Then it is overwhelming and scary for me. Sometimes it is just too difficult to let go of the control of reality for me. When this happens, even when my most trusted friends try and help me, I cannot let go of what is real to me. I am sure that whoever is reading this has a trusted person in your life. But what if you had to trust that person's reality over yours? Trust aside... it is hard.

I feel as if I am one of the lucky ones to have my most trusted friends understand dementia. I know that not everyone has that. When I was first diagnosed, my two closest friends both left. One even went as far as to tell me that she regretted the amount of time that we had spent



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together because she could have spent that time with someone else. Those lost friendships are still difficult to think about. But I now have two other close friends who totally get my dementia and me. They get me and what I am going through because one has MCI and one has FTD. With these two friends I do not feel as if I have to ever hide my weirdness. With my other close friends, and even with my husband, there are still times when I feel as if I have to hide what is going on for me in my life.

I do not know what I would do without my relationships because as I am living with dementia I have become very dependent on others. I have to wait for them so I can do things. I am no longer independent in my life or make decisions about my life. I have become dependent, and for me that is the hardest thing. Living with Lewy Body Dementia has changed my brain, my relationships, and my life. I am just fortunate that my people around me are people that I can trust, that understand dementia, and know that I am always doing the best I can.