

In the Words of an Individual Living with Dementia
- What He Would Like You to Know -
by
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Dementia is not just a memory issue, slowed processing, problems with speech and comprehension or issues with problem-solving and decision-making. This is a whole brain disease. There are many functions the brain controls and any one of these areas may be impacted. There needs to be an understanding about what this all means in the real world.

This is not always an old person's illness. Juvenile dementia affects the young. Frontotemporal dementia affects adults in their 30s. Vascular Dementia can happen at any age. Lewy Body Dementia too has been reported to have been seen in people in their 30s and 40s and 50s. Don't discount someone because you assume they are too young to have dementia.

Don't separate a person in need from their companion. DON'T DO IT. This is a disaster in the making. Keep them together if at all possible. That person is there to help us make sense of a world that can become really confusing.

Communication is more than simply hearing that a person is angry or anxious and talking down to their level. DON'T BABY ME! And don't talk to my companion only. I am an important part of the conversation.

Acknowledge what a person is feeling, and if you don't understand, move them to the side and say gently, "I don't understand, can you share that with me again?" Now, I feel we are talking. Recognize my discomfort. Offer a chair, move me away from a crowd, offer assistance with shoes if I have to take them off, be gentle on a pat down while still being firm and doing your job. Acknowledge when I am doing 'good enough' and thank me for working with you.

Keep the things you are saying short and simple. Big words confuse me. Negative words worry me. Don't yell to everyone that "I won't do" Find other ways to work with me. Walk over to your boss and ask for guidance and solutions that will work for everyone.

I am so much easier to get along with when I am not anxious or overwhelmed. I really do appreciate a helping hand. And I will be the first person to say thank you for a job well done. We just need to get there first.

John-Richard Pagan