The Rules of Engagement

Those of us caring for a loved one with dementia know that it is more art than science. What works one day does not the next. There are some basic rules of engagement, but most of the time it seems we must be flexible and creative in dealing with a person who is in a frequent state of change.

The basic rules of engagement involve approach, voice, and touch. We must be mindful of the basic sensory deficits in a person living with dementia. We must remember that their vision has changed; they have reduced peripheral vision and possibly a loss of depth perception. We must remember that their auditory perception has changed as well. They may be experiencing a constant distraction of white noise, they may hear loud and confusing phantom noises, and they will have lost their ability to immediately identify the direction from which a sound is coming.

In addition to their loss of sensory abilities, they will have lost the ability to process information as quickly as you can. What we grasp in an instant may take them several seconds to process. When we speak at a normal rate, they may completely lose some of the words in the sentence we have spoken. When we try to be as clear as we can, it may not make sense to them.

We must remember the sensory and cognitive deficits when we approach a person with dementia. The basic rules are: Approach at eye level. Pause more than three feet away to get their attention. Smile, speak slowly, lower your tone of voice, and use simple sentences that contain only one thought or instruction.

Do not approach closer until you have eye contact and an indication that they are ready to receive you. This welcoming indication may be their outstretched hand or a smile. Only then can you approach closer and make physical contact by gently but firmly grasping their dominant hand, which is the hand they might hit with if an improper approach has frightened them.

Never approach quickly or from the side or behind, which will be out of their range of vision. Always use a soothing voice, smile, compliment them, and address them by name. Tell them how good they look today or how happy you are to see them. Remember that even when they understand every word you say, they will process the information at a much slower rate. Pause between sentences and never hurry them.

Once you have mastered the skills of approach, voice, and touch, you need to be mindful that their reality may not be the same as yours. Often, a person with dementia may move within their mind to an earlier time in their life. I know a man whose mother started calling him the name of her brother; his uncle who had died years ago. This upset him at first, but soon he realized that his mother had moved to a different reality, and he began to work with her within that reality. When she called him by his uncle's name, he responded to it and asked her to talk about the thing they liked to do together. The woman happily described events of decades before, which seemed to make her very happy and put her at ease.

The first time a loved one with dementia does not recognize you or calls you by someone else's name, it really hurts. You must not take it personally; they are not trying to hurt you. You must try to remember that they are not giving you a hard time; they are having a hard time.

The cardinal rule of dementia care is to validate what your loved one believes and says. Never contradict and never argue. You will never be successful in dragging them back into your reality; rather, it is your job to try to understand their reality and validate – not challenge or contradict – their beliefs.

As I said at the outset of this column, effectively engaging your loved one with dementia is an art, not a science. Beyond the basic rules of approach, voice, and touch, you are often in unknown territory. What worked one day may not the next. But if you find ways to validate what they do and say, care-giving will become much easier.

Keep in mind that individuals living with dementia do not live in a world of logic or real time. They live in a world of feelings. They react to how others make them feel. As a caregiver, a big part of your job is to make them feel validated and useful. Don't treat them like a task. Treat them like a person of value who may see the world differently than you do, and who is certainly struggling to cope within the world in which you live.

It is never easy, but often when we think they are making it hard on us, it is because we have unintentionally made it hard on them by not understanding and practicing the basic rules of engagement.

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