

Me and My Shadow

By Carole B. Larkin

Some people start exhibiting a behavior I call “shadowing” in the midstages of Alzheimer’s and other dementias. Those who are able to walk or roll in their wheelchairs will literally follow their loved ones or caregivers around the house trying to be as close as they physically can to the other person. After awhile this behavior becomes disconcerting and even annoying to the caregiver.

The caregiver essentially loses their own personal space and begins to feel smothered by the person with dementia and their needs. This leads to attempts to separate themselves from the person with dementia physically, which then can lead to the perception of rejection by the demented person.

If the person with dementia cannot formulate the words or thoughts to tell the other person that they feel sad or angry or upset or hurt by being rejected they will show their displeasure with “negative behaviors”. There are more negative behaviors than I can enumerate, but some examples are, shouting, cursing, hitting, or biting. It is a downward spiral leading to pain for everyone.

At the bottom of the shadowing is one of humanity’s most basic emotions -- FEAR. Fear is the constant companion of the person with a dementia. As they shadow us, fear shadows them. The world grows more and more incomprehensible, and eventually their own environment becomes scary and confusing (i.e. getting lost in the house looking for the bathroom, etc...)

They begin to not understand what others say, even their loved ones. They feel lost and alone. No wonder they look for a protector. Wouldn’t you? The one who takes care of them day in and day out is their light against the darkness of fear. It is totally understandable that they would want to stay as close as possible to the person who provides safety.

What is the caregiver to do to maintain sanity during this behavior? The answer is a two part process.

1. Address the underlying emotion of fear by constantly repeating to your loved one all day, every day, like a mantra:
 - “I love you”.
 - “You are safe.”
 - “Everything is OK” or “Everything will be OK” (if it isn’t at that moment)

Those words exactly. No more, no less. Repeat them so often that even your loved one with dementia can repeat them with you. Eventually those words will become embedded in them, and just hearing those words will flood the person with relief, and comfort.

2. Refocus (distract) your loved one with something that will make them concentrate on the thing you put in front of them instead of their fear and/or locating their protector (you!). You need to find something for you to use to redirect their attention off of their

internal fear and onto something outside themselves. Something either visual or physical is usually the best, but whatever engages the attention of your loved one for at least a short period of time will do. Examples are folding things (towels, napkins, pants), or counting things, or organizing things (putting them into containers like nuts and bolts for men), holding something like a squeeze ball or brightly colored scarf for those further along, looking at a group of favorite pictures or a favorite book, or something they can be interested in for a few minutes. You know what works with your loved one.

When you need a bathroom break, or something similar, try this: Buy or take out an egg timer. Sit your loved one at the kitchen table with something in their hands like a napkin or a book. Put the egg timer directly in front of them where they can see it, but have a little bit of difficulty reaching it. Guess about how much time you think you'll need to "take care of business" and set the clock for that amount of time, or a minute or two longer. Tell your loved one that you are going to the bathroom, and that you'll be back when the bell rings. Their job is to watch the clock. Say no more or no less. Set the timer and go! Make sure that you are back by the time the timer rings. You need to have your loved one trust you, so no dawdling! When you come back you say "See I'm here when I said I would be", or if you are early, say "See, I'm here even before I said that I'd be back".

Now, what other things can you think of to give you space and sanity for a moment?