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Dealing With Resistance to Care

By Luciana Cramer, Educator and Care Specialist.

Patients living with dementia may have a general notion that their cognitive levels have declined, but they are often unaware of exactly how dementia affects their ability to live independently. It is said that they lack of insight. Although they may notice that it is getting harder to keep track of their bills, they will not notice sending blank checks on the mail. They may realize that attending social events is becoming uncomfortable, but they may not notice introducing themselves to the same person multiple times. They may even be convinced that they are able to care for themselves and for the household, but they will not notice the expired food in the refrigerator or the piles of clothing waiting to be laundered.

Inexperienced caregivers will take upon themselves the task of pointing out these shortcomings to their loved ones with dementia. They will quickly learn that doing so not only fails to solve the problem, but aggravates it, when the reaction they get is one of shame, humiliation, denial, confabulation or just plain stubbornness. And everybody gets upset. And the bills remain unpaid. And the dirty laundry still lies in piles.

Lack of insight often results in resistance to care, a failure to admit they need assistance and refusal to accept it. Most caregivers for dementia patients will encounter the problem of resistance to care at some point, typically in the early and middle stages of the disease.

RESISTANCE IN EARLY-STAGES

In the early-stages of dementia resistance to care is most likely related to the desire to remain in control. It is scary to



contemplate relinquishing control over your finances, giving up driving, quitting social gatherings, having to rely on others to organize your calendar and household. Some patients at this stage will do everything they can to hold on to their independence and make their own decisions. And their decisions are not always the most sound.

If they do not have a care-partner to assist them and verify that their activities are safe and effective, they may not even notice when trouble starts to happen. A long-term care insurance policy may get cancelled for lack of payment. The pet dog may become ill for lack of appropriate diet. The automobile may blow a gasket for lack of oil change.

RESISTANCE IN MID-STAGES

In the mid-stages of dementia resistance to care turns into a more personal note. Having already relinquished control over major executive decisions, patients now cling to control over their individual everyday choices. What to wear, what and

when to eat or drink, bathing, where to go and what to do with their free time. The more cognitively impaired they are the poorest their personal choices will be. And again, if they do not have a caregiver assisting them, problems start to happen. They may wander and get lost; they may neglect drinking water and develop urinary tract infections; they may confine themselves into a single room in the home and never leave.

Dementia patients require assistance. Whether they admit it or not, this is the nature of the condition. They need help. But how does a caregiver assist a person who adamantly refuses to be assisted, refuses care?

Caregivers in general need to develop skills in communication and understanding dementia. When encountering resistance to care, caregivers must also develop strategies to provide care without confronting, offending or overwhelming the patient. Here are some strategies that may be useful:

- ◆ **Do not argue.** This is not about being right, this is about helping a person with a serious disability. They will not be able to follow logical reasoning, so do not try to convince them, or explain the reasons why they should accept help.
- ◆ **Make a thorough assessment** on the conditions surrounding the refusal of care. Is it based on old habits, or events that happened during your loved ones younger years? People say that old habits die hard, but in dementia rather, *old habits resurface*. You really need to know who the person is and their personal history, when addressing the reasons why they are resistant.
- ◆ **Consider the possibility of physical limitations**, such as arthritic pain or poor hearing or eye sight. Remember that the person with dementia may not be able to tell you what is bothering them.
- ◆ **Pick your battles.** Is it a matter of safety or rather personal preferences? Is it really necessary that they bathe every day, or would a sponge bath suffice in between baths? Can you make some adaptations to make the activity more enjoyable for them?
- ◆ **Select a time when your loved one is more likely to be relaxed.** In general, brains affected by dementia work better in the morning, right after a few hours of deep sleep, than in the evening, after a whole day of straining to make sense of everything. Do not wait until they are really tired to bring up an activity.
- ◆ **Make your loved one feel included in the decision making process.** They may not be able to select which outfit to wear today, but they may be able to answer to “Do you want the red or the blue shirt?”
- ◆ **Use visual cues rather than verbal ones.** A note from the doctor stating “No driving” may be far more effective than you telling them not to drive.
- ◆ **Be subtle and use finesse.** They do not always have to know they are being helped. The laundry can be done when they are out to lunch, mail can be presorted before they get to it, a caregiver can be hired under the pretenses of having a cleaning lady, prescribed pills can be taken as if they were vitamins.
- ◆ **Use fiblets, or make up a story to help them relax.** If he does not want to go to the doctor, you may say that changes in social security now require it. If he wants to drive the car you can say that it is broken and suggest waiting until the store brings the part.
- ◆ **Use the help of professionals.** The advice from a lawyer, doctor or law enforcement agent may carry more weight.
- ◆ **Put in place systems to help coping with the loss of independence.** Connect with transportation services, GPS tracking systems, friends and family members who can assist your loved one stay active and maintain social relationships. Contact the Alzheimer’s Association to learn about resources and strategies.
- ◆ **Don’t give up.** You can always try again later or another day.

Resistance to care is more uncommon in the late stages of dementia, when it is more likely a matter of adjusting the caregivers’ approach and expectations to the patient’s limitations and personal habits. Studies report that only 9% of patients residing in nursing homes exhibit resistance to care.

For extreme cases of continuous resistance to care, please consult your neurologist. There are safe and effective medications that can help alleviate the anxiety caused by dementia and reduce the petulance related to refusal of care.

And above all, make sure YOU get plenty of rest and meaningful, enjoyable activities. Caring for a loved one with dementia is a long arduous process, with many ups and downs. You need to take good care of yourself first and be a caregiver second.