

Care For The Caregiver: 2 Views

Defusing Conflicts

By Suzanne Faith

When I first saw her, Darlene Summers related that her 78-year-old mother Joan was becoming more argumentative and agitated. Normally serene and relaxed, taking pleasure in her children and grandchildren, Joan had changed significantly since receiving a diagnosis of Alzheimer's disease four years earlier. Evenings she often would pace anxiously, mumbling about robbers hiding in the bushes, bursting into tears and shouting. No amount of reassurance seemed to help.

Worse, as Joan's challenging behavior accelerated, Darlene said her own stress was mounting. She found herself reacting with unaccustomed anger. After a particularly loud exchange where she almost raised her hand against her own mother, Darlene retreated to her room, shaking.

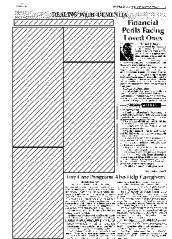
She knew she needed help.

The first step was learning about the disease progression, how to manage challenging behaviors and tips to facilitate better communication. Most importantly, she learned that being a caregiver of a loved one with this disease is one of the hardest of caregiving roles, and that reaching out for help was the best thing she could do to avoid burning out and spiraling the situation into physical aggression.

It's important to understand that many behaviors that are perceived as inappropriate by caregivers are often responses to unmet needs in those who have dementia. People with Alzheimer's exist with an undercurrent of anxiety that permeates their world. Anxiety unmanaged can rapidly change to agitation, and agitation unmanaged can turn into physical aggression and combative behavior.

Very few individuals with Alzheimer's disease are violent, but when this type of behavior occurs it's important to identify the triggers that might have caused it. Often these triggers can be an undiagnosed medical condition such as a urinary tract infection, or simply a caregiver who lacks the ability to understand how to communicate appropriately with someone with this diagnosis. It's vital for caregivers to get the support and information they need so they can relate with understanding and compassion.

Darlene learned that Joan really had no control over her disease or her behavior, and that there were



many helpful things she could do to minimize stress for them both. These included creating a regular schedule, minimizing disruptive stimuli and staying calm by not taking the aggressive behavior as an intentional attack. She realized that frustration is a natural outcome of her role as a caregiver, often arising out of trying to change an uncontrollable situation.

Here are some recommended tools for caregivers aimed at minimizing stress and preventing potential escalation:

Learn to ask for help before you're in crisis! Helpful local resources include Hope Dementia & Alzheimer's Services, Elder Services of Cape Cod & the Islands and your town's Council on Aging;

Learn to communicate appropriately. Be fully present, eliminating distraction and judgment;

Learn to listen empathically. Listen with the intent to understand the other person's frame of reference and feelings, not trying to fix or problem-solve;

Understand non-verbal components of communication. Eye contact, tone of voice and physical proximity are all critical;

Learn the triggers to behaviors and ways to minimize reaction.

Be less reactive, don't argue;

Try to keep the home more orderly and calm, and provide meals and bathing on a regular schedule.

Finally, take care of yourself!

Get the rest, healthcare and nutrition you need, as well as breaks for your own recreation. If you burn out, you'll both be less able to deal with the challenges ahead.

(Ms. Faith is senior director of Hope Dementia & Alzheimer's Services, for HopeHealth, 508-957-0200, 508-775-5656 or info@Hopedementia.org. She leads regular trainings to educate caregivers, clinicians and community service providers on how to understand the disease and respond appropriately.)

Handling Burnout

By Mary Jo French, LICSW

Being a caregiver to a loved one can be rewarding, a true labor of love. It can also be frustrating and stressful. This can mount and lead to caregiver burnout, changing a once-positive and loving caregiver into someone who is irritable and indifferent. Over time, this can result in neglect or even abuse.

Today 7.6 million Americans over 65 are caring for ill or disabled seniors. Many grandparents are primary

caregivers for grandchildren, some of whom have emotional, cognitive or physical disability. A recent study in the Journal of the American Medical Association raised concerns for caregivers who spend more than 28 hours weekly coordinating healthcare, including managing medications, for their loved ones. These caregivers are twice as likely to experience a decline in their own physical health, emotional wellbeing or finances.

A key part of my role is to educate family members on the signs of caregiver stress so they can take steps to improve the situation before burnout occurs.

Feeling irritated and short-tempered towards your loved one is an early sign. A common underlying cause is feeling stuck. Often family members vow to take care of the person who is ill and feel guilty about bringing in help, moving to assisted living, or exploring placement in a nursing home. But for patients with a degenerative disease, such as Parkinson's or MS, or people aging with a disability, the reality may be quite different after a few years. What was once possible for the caregiver to do may no longer be possible, so the caregiver feels in a no-win situation.

Finances may be another constraint. Even when the family agrees they need more help, they might not have the funds to make it happen.

Situations involving dementia or major cognitive decline complicate matters. Your loved one is there physically, but is no longer the same person. Safety becomes a tipping point if the loved one wanders, can't be alone in the kitchen, or can't attend to personal care. Sometimes the spouse or parent may become violent or paranoid or act out in inappropriate ways, putting the caregiver at risk. Then placement in an environment that can handle those needs 24/7 is in everyone's interest.

Not taking care of yourself is a red flag. Long-term caregivers may have become acclimated to a gradual decline in their loved one and not notice their own decline.

But there are simple actions to reduce the risk of burnout:

Seek possible sources of help: church and support groups, family, friends, neighbors, and online supports;

Set goals to focus and structure to your days. Take a walk, read a book. Do something just for you;

Differentiate between what's in your control and what's not. Make a plan;

Continued on page 9

Calm yourself before bed. Avoid alcohol or drugs to numb yourself out. Try progressive relaxation, sooth-

ing music. Repeat a special prayer or favorite passage.
Notice what you're grateful for, no matter how small;
And call your doctor. Many practices now have
patient advocates to identify helpful local resources,
like Elder Services, councils on aging, adult day health
centers and respite services.
(Ms. French, LICSW, is an outpatient care coordinator at Spaulding Rehabilitation Hospital Cape Cod, 508-833-4000.)