A Poem for Loved Ones With Dementia

I Will

When you forget, I will remember for us both.
When you get lost, I will find you.
When you are sad, I will be sad with you.
When the fear comes, I will comfort you.
When you cry, I will dry your tears.
When you lash out at me, I will not be angry.
When you repeat, I will have patience.
When you forget my name, I will understand.
When you can no longer eat, I will feed you.
When your legs fail, I will carry you.
When you long for home, I will be your safe place.
When your journey is ending, I will be by your side.

I will love you for eternity.

I will…

Source: agingcare.com.
Poem by Michele DeSocio
When Your Loved One Isn’t Very Lovable

While all caregivers face some adversity, those caring for family members who, due to personality, temperament, or disease, are angry, violent, or uncooperative, face an almost impossible task. Is it possible to provide loving, quality care to a person who tries to hit, refuses medication or food, tells you he hates you, or acts as if you aren’t even there? Yes, say the experts, but it takes patience and practice, as well as recognition of your own frustration and anger.

The Root of the Problem

There are myriad reasons why a care recipient may be classified as “difficult,” says Dr. Figueroa, a psychiatrist affiliated with the Medical Illness Counseling Center in Chevy Chase, MD. It may be the disease, as is the case with Alzheimer’s which can turn kind, gentle, cautious people into swearing, violent, and paranoid strangers. It can be the prognosis, leading to feelings of anger, resentment, guilt, depression, or frustration, which the care recipient unwittingly takes out on the caregiver. Or it can be a personality trait, which loss of control magnifies. So your overbearing, stubborn, or strong willed mother becomes more so under your care, or your taciturn husband becomes snappish and sarcastic at your every comment.

For many, the loss of self-determination and the loss of freedom are the root of the difficulties. “Most of the problems I see,” says Dr. Figueroa, “stem from the fact that we forget the person’s developmental needs. We know what the medical needs are, and we try to oversee those carefully, but as the person loses autonomy, he or she may begin to act out.”

Understanding Why

Learning the cause of the difficult behavior is the first step in figuring out how to deal with it, says Dr. Peter Rabins, professor of psychiatry at Johns Hopkins University School of Medicine and the author, with Nancy Mace, of The 36-Hour Day.

Rabins says the first stop should be to the family physician to make sure there is not an unidentified problem causing the difficult behavior. “Depression is a common side effect of long-term illness or disease, and left untreated, can manifest itself in an array of difficult behaviors,” says Dr. Nathan Billig, professor of psychiatry at Georgetown University Medical Center and the director of the University’s Geriatric Psychiatry program. Given proper medications, the unwanted behaviors often disappear. “If a new medical problem is not the cause, simply knowing what is normal for a particular condition may help,” says Edie Cannon who has been a caregiver since 1994. “It helps a lot to know that my husband’s behaviors are normal for someone with Alzheimer’s.”

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When Your Loved One Isn’t Very Lovable

Gaining an intellectual understanding of why your loved one is being difficult is an important thing to do, but it doesn’t make living with him or her any easier. Hopefully, the following suggestions will help.

**Acknowledge Your Feelings**

Virginia Hoffman, a caregiver, suggests that acknowledging your feelings of frustration or anger is a necessary thing to do. “Know that it is okay to feel the way you feel,” she says. “Don’t feel guilty that it is not you who is ill. It is okay to feel as angry as the care recipient is, because even though you do not have the illness your life has been profoundly affected as well.” In some cases, it may be your anger or fears that are making the care giving effort more difficult. You need to try to step back a bit and come to terms with your own emotions.

When simply expressing your feelings is not enough, McGuire suggests removing yourself temporarily from the situation. “I’ve had people tell me that when their frustration level got really high and they were assisting their loved ones to move, they would pull harder than necessary. Recognize when you are becoming destructive to yourself or your loved one, and get out of the situation. Come back once you’ve cooled down.”

**Separate the Person from the Disease**

Reminisce and remember the good times, say the experts. “One woman I work with watches videos to remind herself of why she’s still around caring for an increasingly surly and uncooperative spouse,” says McGuire. Joyce Cannon says memories are what propel her family forward as well. “We always idolized dad, and we still do. We know it’s not his fault he acts this way. We remember that he was always there for us, and I’m sure we drove him crazy at times.”

Says McGuire, “When things are bad, remind yourself that this person is sick and the behavior is not directed at you.”

In many cases, the illness brings up unresolved familial issues, such as an overbearing mother or an unforgiving father. Even though it is a difficult thing to do, it is important that caregivers try not to allow family history and dynamics to interfere with their caregiving, says Billig. “You must remove yourself from the history with this person,” he says. “Focus on the care needs (making the house accessible, finding a home care aide, etc.), not on the personality. And keep your focus in the short-term.”

Abridged from Take Care! Summer 1997 (Vol. 6, No. 3) by Marla Gold with permission of the National Family Caregivers Association, Kensington, MD, the nation’s only organization for all family caregivers. 1-800-896-3650; www.thefamilycaregiver.org.
### Dealing with Wandering

#### Wandering May Be OK…Sometimes

Many people with brain impairment wander or pace. This is OK as long as the person wanders or paces in the daytime and is in a safe, supervised environment.

Wandering can help relieve anxiety and restlessness. It can also be a good source of exercise. Problems may occur, however, if the person wanders away from home or wanders at night.

Excerpted with permission from the booklet *Caring For A Person with Memory Loss and Confusion, An Easy Guide for Caregivers*, 2002 Journeyworks Publishing. All rights reserved.

The following includes some helpful tips to prevent wandering out of the home, and to be prepared if it does occur:

- **Place locks out of the line of sight.** Install either high or low on exterior doors, and consider placing slide bolts at the top or bottom.

- **Use devices that signal when a door or window is opened.** This can be as simple as a bell placed above a door or as sophisticated as an electronic home alarm.

- **Provide supervision.** Do not leave someone with dementia unsupervised in new or changed surroundings. Never lock a person in at home or leave him or her in a car alone.

- **Keep car keys out of sight.** Remove access to car keys.

- **Keep a list of people to call on for help.** Have telephone numbers easily accessible.

- **Ask neighbors, friends and family to call if they see the person alone.**

- **Keep a recent photo and updated medical information on hand to give to police.**

- **Know your neighborhood.** Pinpoint dangerous areas near the home, such as bodies of water, open stairwells, dense foliage, tunnels, bus stops and roads with heavy traffic.

- **Is the person right or left-handed?** Wandering may follow the direction of the dominant hand.

- **Keep a list of places where the person may wander.** This could include past jobs, former homes, places of worship or a restaurant.

- **Consider enrolling the person living with dementia in a wandering response service.** The contact for Safe Return is 800-432-5378, medicalert.org/alz.

- **If the person does wander, search the immediate area for no more than 15 minutes.** If the person is not found within 15 minutes, call 911 to file a missing person’s report. Inform the authorities that the person has dementia.

Adapted from https://www.alz.org/help-support/caregiving/stages-behaviors/wandering.
Tips for the Month of February

♥ Caregivers often ask if their loved one should be told they have Alzheimer’s. There are no absolutes. It may depend on how early it is diagnosed and on your individual circumstances. Do what is comfortable for you. If your loved one asks what is wrong with him you may wish to merely say, “You have a memory problem.”

♥ If you find there are a lot of things you want to get done this week, write them down in order of priority. Do priority one first - at your loved one’s pace - then two, three, etc. If everything doesn’t get done by the end of the week - so what? At least the priorities at the top of your list will probably get done and anxiety levels can be kept at a minimum for all concerned.

♥ Your loved one may need help with bathing. Tub baths can be difficult and dangerous. Shower water on top of her head might frighten her. Hand-held shower nozzles, rubber non-slip strips on the shower floor, and sturdy, well placed grab bars help to ease an often precarious task.

♥ If there is a job your loved one enjoys doing like making beds or setting the table, let her do it. Keeping busy and active is good. Tasks should not be taken away just because they aren’t done the way they used to or at the speed they used to. Helping can be a very rewarding and calming activity for her as long as it is at her pace. (While she is occupied with a task, you’ll have time to do other things.)

♥ Fatigue usually brings out the worst in us. Whatever areas we are weak in seem to manifest themselves when we are overtired. If you are not getting enough rest, try to find a way to insure that you do. If your loved one is not sleeping well at night, talk to his doctor. Mild medication carefully prescribed by his physician, or more daytime activity for your loved one may be in order.

♥ Clothing that goes over your loved one’s head may become a source of fear and agitation for her. Clothes with full front openings are better. If she cannot dress herself but is constantly undoing the front openings, try clothing with zippers or buttons on the back.

Adapted from: Lyn Roche, Coping with Caring, Elder Books, 1996.
**Who Would Take Care of Your Loved One If Something Happened to You?**

It is important to have a plan in place in case of your own illness, disability or death.

- Consult a lawyer regarding a living trust, durable power of attorney for health care and finances, and other estate planning tools.
- Consult with family and close friends to decide who will take responsibility for the person with dementia. You also may want to seek information about your local public guardian’s office, mental health conservator’s office, adult protective services, or other case management services. These organizations may have programs to assist the person with dementia in your absence. To ask about available programs in Memphis, contact the Aging Commission of the Mid-South at (901) 222-4111.
- Maintain a notebook for the responsible person who will be assuming caregiving. Such a notebook should contain the following information:
  1. Emergency numbers.
  2. Current problem behaviors and possible solutions.
  3. Ways to calm the person with dementia.
  4. Assistance needed with toileting, feeding, or grooming.
  5. Daily routine.
  6. Favorite activities or foods.
  7. A current list of medications for both of you.
  8. Allergies.
- Preview resource boards, and long-term care facilities, in your community and select a few possibilities. If the person with dementia is no longer able to live at home, the responsible person will be better able to carry out your wishes for long-term care.

Adapted from: www.nia.nih.gov/health/alzheimers-caregiving-caring-yourself

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**Tips from ADS: In Case Something Happens to YOU, the Caregiver**

- **Keep a note in your wallet** with an emergency phone contact number in case something happens to you. Include a statement that you are a caregiver for ________ (person’s name), who has dementia and **cannot be left ALONE**. (Laminate the note if possible.)

- **Keep a current list of medications** for you and your loved one in your wallet, and on your refrigerator, for emergency personnel.

- **Program your phone** to include emergency contacts and medical information. (Go to www.pcmag.com, “How to Add an Emergency Contact to Your Phone’s Lock Screen,” to find out how to make information accessible to others on your phone.)

- **Caregiver ID jewelry** can be purchased through the MedicAlert+SafeReturn service. If something happens to you, others will be alerted that you are a caregiver for someone in need of supervision. Contact: 888-572-8566, or go to www.medicalert.org/safereturn.
“Friends” enjoyed the January Football parties, and talking about different sports teams. January was also a special time for reminiscing about Martin Luther King and Black History. February will be filled with varied crafts, games and activities related to Valentine’s Day. Love is in the air at ADS! May warm memories, moments of joy and love fill everyone’s hearts!

People With Alzheimer’s Have Taught Me About Love

People with Alzheimer’s typically love:

Art  Music  Children  Animals

Sometimes one of these activities can reach people with Alzheimer’s on a level we cannot. Try handing a paintbrush and some water paint to a person with dementia as a therapeutic activity. Playing a person’s favorite music can totally change their demeanor. If real children aren’t available to interact, a baby doll can be very comforting for someone to hold and cuddle. Interaction with dogs and cats, and sometimes other pets, can often greatly improve someone’s mood. Of course, people with dementia love other people. They may remember past love and also experience love in the present —even if they don’t talk anymore and even during the last days of their lives; simply hold their hand and talk to them softly.

*People living with Alzheimer’s taught me about the never-ending and unconditional power of love. They’ve taught me that love matters.*

Adapted from article by Marie Marley, alzheimersreadingroom.com

Alzheimer’s Foundation of America’s

VIRTUAL EVENTS
For Caregivers and Loved Ones:
Music, Art, Fitness, Meditation and more!

Go to alzfdn.org/events to view the calendar and find details.
Caregivers dealing with people with dementia need to be aware of both verbal and non-verbal communication. It is essential for caregivers to understand the importance of non-verbal communication. According to research, people with dementia receive over 93% of their information about the world through non-verbal gestures. Often it’s not what you say but what your body language says.

Below are some tips for communicating with a person with dementia:

**Verbal**

- Say the individual’s name and identify yourself.
- Refer to people by their names.
- Speak clearly and slowly.
- Speak with warmth and positivity.
- Simplify the words and make statements instead of asking questions.
- Talk to the individual as an adult, not a child.
- Answer questions in a calm and reassuring manner.
- Encourage the person when they are having trouble expressing themselves.
- Move at the pace of the person according to their time and place.

**Non-verbal**

- Maintain eye contact while having a conversation.
- Observe the actions of the person and listen to the words carefully.
- Use visual cues: Point, touch or hand the person the item you want them to use. For example, if you want someone to drink water, point to the glass or put it close by or pick it up and hand it to him/her.
- Do not stand directly over the top of the person; bend down to their level so that they do not have difficulty looking up.
- Avoid body language which conveys frustration, anger or being in a rush.
- Sit with your palms up, and not with your arms crossed, to convey positive feelings to the person, showing that you like him/her and may want to hold his/her hand.
- Physical touch, a hug or a handshake, is very important.
- Have a pleasant look on your face and smile often.

Effective communication can make a difference and give your loved ones the much needed assurance and ensure their overall wellbeing. Afterall, it is not the person but the disease which is difficult.

Adapted from articles from: samvednacare.com, blog posted August 26, 2016; and alzheimersreadingroom.com, article by Marlo Solitto