



New York City Chapter

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Family Caregiver Guide

SPECIAL INSERT TO THE ALZHEIMER'S ASSOCIATION, NYC CHAPTER NEWSLETTER

NUMBER 1

We are pleased to offer the first of four installments of the Family Caregiver Guide (FCG), which is made possible by a generous grant from Forest Pharmaceuticals, Inc. with additional support from the Rowland & Sylvia Schaefer Family Foundation, Inc. The goals of the FCG (which will appear in the next three issues of the newsletter) are to provide caregivers unable to attend training sessions in our office with an improved understanding of the disease; effective communication strategies that improve interactions between the caregiver and the person with dementia; a deeper awareness of and ability to cope with challenging behaviors demonstrated by persons with dementia; and knowledge about safety measures and engaging activities.

We would like your feedback to determine the effectiveness of each issue of the FCG. Please log on to www.alzny.org/fcg to fill out a short survey. One lucky respondent will be randomly selected to receive dinner and theater tickets as our way of thanking you for participating.

Understanding Dementia

This segment of the Family Caregiver Guide covers topics discussed in the first of four Family Caregiver training sessions conducted by the Alzheimer's Association, New York City Chapter in its midtown offices.

Let's get started and tackle the first question, what is dementia?

Dementia is an umbrella term used to describe a group of symptoms which usually include a serious deficit in memory (created by abnormal changes in the brain) and difficulties in at least one of the following areas:

- Social functioning (confusion with time and place, which impacts functioning at home, in social situations and in the workplace)
- Changes in personality (confused, anxious, out of comfort zone, inattentive to appearance)
- Impaired abstract thinking (challenges in planning or solving problems and completing familiar tasks such as driving or paying the bills)
- Impaired judgment

Is dementia a normal part of aging?

It is a myth that dementia is part of normal aging. It is NOT! Getting older does not mean that dementia is a given. There are people 85 years of age and older who are not experiencing any

form of dementia. Although it is true that most cases of dementia are diagnosed in people who are 65 years of age and older, some people in their 30s, 40s and 50s are diagnosed with Young Onset Alzheimer's Disease (which accounts for between 5-10% of cases of AD.) As the general population lives longer — the average life span for a male is now 75 years of age, for a female 79.5 — we are hearing more about Alzheimer's disease and other dementias.

How do I differentiate between other medical conditions associated with aging and dementia? Why is an early diagnosis necessary?

There is a simple answer: If your family member is experiencing increasing difficulties with his/her memory, get a comprehensive medical and neurological evaluation and get it early! If you need information about diagnostic centers contact our 24 hour helpline at 1-800-272-3900. When seeking care, identify a physician/neurologist whom you and your family member trust, who speaks clearly to both you AND the person with the disease, who explains why tests are ordered and what results mean in an easily understood manner, is accessible by phone and/or e-mail to answer questions about medications and clinical trials, and is capable of addressing concerns in a

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sensitive manner.

- In certain circumstances, symptoms similar to dementia may be attributable to other medical conditions such as endocrine abnormalities (thyroid disease – B12 deficiency); vision or hearing loss (which results in a person feeling more withdrawn or isolated); kidney failure; depression/stress; medications or interactions with multiple medications (may lead to memory loss); and strokes or tumors. Some of these conditions MAY be reversible.
- An accurate diagnosis is critical in determining the best type of treatment. Certain types of dementia may necessitate different treatment modalities. People diagnosed with dementia live an average of between 8 and 10 years but some people can live up to 20 years.
- A diagnosis can detect subtle impairment such as Mild Cognitive Impairment (MCI). According to the Early Stage Services section of the Association's Web site www.alz.org/nyc, "MCI is a diagnosis that is used to describe people who have some problems with their memory but do not actually have dementia. It is a subtle type of memory loss that is not part of the normal aging process. With MCI you will be more forgetful than others in your age group but it does NOT interfere with your ability to participate in daily activities." (See related dementia section of our Web site.)
- A person with dementia (PWD) and his/her family need to become educated in order to learn to cope with the disease, plan for the future

(take care of legal and financial matters), and figure out how to live life fully in the moment.

What is involved in diagnosing dementia?

- A battery of neuropsychological tests
- A comprehensive physical exam
- Laboratory work
- Scans of the head (MRI, PET or CT). A PET scan may differentiate between a diagnosis of Alzheimer's disease and vascular dementia.
- Electrocardiogram
- Electroencephalogram
- Possibly a chest X-ray

What are a person's chances of being diagnosed with dementia?

Everyone has a lifetime risk of 12%.

How accurate is the diagnosis?

Approximately 90% of diagnoses are reliable, as high as being diagnosed with pneumonia.

Could anything have been done to prevent this?

Doctors strongly urge people to control blood pressure and cholesterol, give up smoking, lose those extra pounds and exercise in order to maximize heart health and minimize risk of strokes, which may result in Vascular dementia. If you are diagnosed with diabetes, physicians also recommend keeping it in check.

Research into the importance of diet in decreasing the risk of Alzheimer's disease has received a lot of attention. According to a recent study reported in Archives of Neurology, a diet rich in Omega 3's, vi-

tamin supplements (E), fruits, nuts, fish, poultry, dark leafy greens, broccoli, and cauliflower, may help reduce the risk of Alzheimer's disease in older people.

What medications are generally prescribed?

The medications most frequently prescribed to treat dementia are Aricept, Exelon, Razadyne, and Namenda. Research has indicated that medications do not work for everyone, but some people taking these medications show some improvement for some period of time.

What is the difference between dementia and Alzheimer's disease (AD)?

There are 70 different causes of dementia, Alzheimer's disease is the most common and accounts for approximately 50-75% of all dementias diagnosed. AD results in abnormalities in the brain, commonly referred to as plaques and tangles. The size of the brain significantly decreases and the plaques and tangles impact different parts of the brain which control speech, memory, learning, problem-solving, special navigation, emotions, reaction to sensory stimulation and judgment.

What are the other types of dementia?

Other types of dementia include:

- **Vascular Dementia** – Occurs suddenly after a stroke or a series of mini-strokes. People diagnosed with vascular dementia will experience periods of deterioration (following the stroke or mini-stroke) and then experience relative stability until the next episode of a stroke.
- **Mixed-Dementia** – A combination of AD and vascular dementia.

- Parkinson's Related Dementia** – Not everyone with Parkinson's disease is diagnosed with dementia. Dementia generally occurs in the late stages of the disease.
- Down's Syndrome** – People with Down's syndrome are living longer (into middle age), which results in dementia.
- Huntington's Disease** – An inherited degenerative brain disease that affects the mind and body.
- Frontotemporal Dementia (FTD)** – According to www.ftd-picks.org “FTD is a family of neurodegenerative disorders that primarily affect the anterior and temporal regions of the brain. These areas control personality and social behavior, speech, language comprehension, and executive functions involved in reasoning, decision-making and planning. FTD is not like Alzheimer's disease, although some symptoms may overlap. FTD is characterized by a gradual onset of progressive changes in personality, social behavior and language ability, rather than memory. Because of the symptoms of FTD, it is misdiagnosed as psychiatric problems or Alzheimer's disease initially.”
- Lewy Body Disease** – Shares commonalities with Alzheimer's disease as well as Parkinson's disease. Individuals diagnosed with this type of dementia MAY experience difficulties with movement, delusions and visual hallucinations as well as memory loss.
- Korsakoff Syndrome** – Caused by the lack of Vitamin B1, usually seen in people who are alcoholics.

- Normal Pressure Hydrocephalus** – A rare disease caused by fluid build-up in the brain.
- AIDS Related Dementia**
- Creutzfeldt-Jacob Disease** – A rare disease that progresses quickly and sometimes results from Mad Cow disease.

My family member has been diagnosed, what now?

A flood of emotions occurs! Family members in training sessions often express a gamut of feelings ranging from: “This can't be true, my loved one seems fine most of the time” to “I don't know what to do, everything is so overwhelming” to “I need to get as much information as possible” to “Should I place my family member in a nursing home?” The personality types of family members and the nature of the relationship with the afflicted person (be it loving, difficult or dependent), coupled with the ambiguity of AD (it is a come and go disease, especially in the earlier stages), result in a unique set of reactions.

Family members as well as the afflicted person often experience feelings of denial, anger, and/or depression. “Our lives have changed, roles in the family have changed.” Adjusting to these changes is very difficult! It is a process that takes time. Sometimes caregivers think they have acclimated, but revert back to old established patterns of communication and behavior. Don't be hard on yourself, accept that this new relationship takes time and you need ongoing support. If your family members are not able or willing to be supportive, contact our 24 hour helpline to learn about support groups in your area.

Sometimes caregivers get so wrapped up in the changes in their own life that they forget what the

person who has been diagnosed with dementia is experiencing. According to Tom Kitwood, author of *Dementia Reconsidered, The Person Comes First*, the main psychological needs of people with dementia are: love, occupation, a sense of identity, inclusion, comfort and attachment. Being attentive to the PWD's psychological needs will positively impact day-to-day interactions.

What can I expect if my family member is diagnosed with Alzheimer's disease?

It is important to note that each person diagnosed with Alzheimer's disease or other forms of dementia is different and may demonstrate different symptoms. It is entirely dependent on how the brain is impacted. It is also important to remember that symptoms progress differently with each person.

EARLIER STAGES — the person with AD will experience at least some of the following:

- Memory loss
- Word loss
- Poor judgment
- Withdrawal/and or depression
- Partial disorientation to time
- Visual/spatial difficulties
- Mild apraxia (difficulty remembering which object to use for a task, such as a comb)

We often focus on loss, but it is important to build on remaining skills and abilities so the person with dementia doesn't always feel that things are being taken away from her/him (job, daily tasks, responsibilities etc). The following skills are preserved:

- Memory skills (long-ago memories, emotional memories, procedural memories, awareness of familiar vs. unfamiliar)
- Understanding skills (getting the concrete meaning, picking

out familiar or meaningful words, covering well, facial expressions that are consistent with the message being sent)

Other issues:

- Possible relationship changes
- Word loss
- Getting lost
- Unable to remember things (appointments, paying bills, medication management)
- Driving, safety issues (turning off the stove)
- Trouble getting dressed, bathing and other activities of daily life
- Repeating questions
- Losing things
- Accusations of stealing
- The possibility of overeating

MIDDLE STAGES — people with AD will experience at least some of the following:

- Short-term memory loss with some loss of long-term memory
- Slowed speech and understanding
- Complete disorientation to time
- Restlessness and/or pacing
- Irritability
- Urinary incontinence
- Perseveration (repeating words or phrases over and over again)
- Personality changes, suspiciousness, hallucinations, delusions
- Aphasia (difficulty articulating words)
- Agnosia (less able to interpret sensory input — visual, touch — such as husband or wife's face)

LATER STAGES — During later stages people with AD generally experience the following (and may require hospice care if demonstrating the last three listed symptoms):

- Individual requires assistance to walk, use of a wheelchair
- Requires a toileting schedule
- Incoherent speech creating a communications barrier
- Swallowing problems (forgets how to eat)
- Weight loss
- Repeated infections

What services are offered by the Alzheimer's Association, NYC Chapter?

The New York City Chapter of the Alzheimer's Association provides a wide range of services, all free of charge. If you would like to enroll in any of the services listed below, please call our 24 hour helpline, 1-800-272-3900:

- **Ongoing workshops:** Legal and Financial Matters; Understanding Dementia; Successfully Navigating the Healthcare System; Medicaid/ Homecare.
- **Training sessions:** Family Caregiver Education (10 hour interactive workshop) in English and Spanish; Home Health Aide Training (50 hours) in Spanish and English. (The Association will train your aide.)
- **Monthly educational meetings**
- **Support Groups:** More than a hundred and twenty-five to choose from located throughout the city. Nobody understands better than others

caring for a family member with dementia.

- **Care Consultation:** Individual care planning.
- **24 Hour Helpline:** Call for information or to ask questions ("My family member won't go to the doctor, what do I do?" "Why won't my family member leave the house?"), about behavioral issues, day programs, physician referrals or just about anything you want or need to know.
- **Early Stage Services:** Offers Memory Works and Connections, programs for people diagnosed with MCI and Early Stage Dementias. The Early Stage Services department also provides private counseling and hosts an annual forum. (See our website www.alz.org/nyc for more information.)
- **Medic Alert® + Alzheimer's Association Safe Return Program:** A 24 hour nationwide emergency response service for individuals with Alzheimer's or other dementias who wander or have a medical emergency. Enroll NOW! 6 out of 10 people with dementia will wander or get lost. In practically every workshop a family member reports that their loved one has wandered off. Save anxiety and stress.

— Amy Trommer
Dementia Care Trainer



Fill out our survey online at
www.alznyc.org/fcg

NEXT ISSUE: We will be discussing effective communication techniques which will decrease your anxiety level as well as the person with dementia's.



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NUMBER 2

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Effective Communication

My mother-in-law had dementia and my family was in denial. We continued to relate to her as if things were "normal." We simply didn't want to believe her forgetfulness was something other than temporary. After she was diagnosed, we tried to reduce her anxiety by providing love and reassurance. We tried our best to comfort the woman we loved so much, but she was overwhelmed with fear and anxiety. The way we communicated with her was based on our reality, which was factually and socially-oriented. What we did not understand at the time was that she was unable to change. We needed to change the way we communicated with her. We needed to enter her reality.

Accepting the many changes in the family unit after a person has been diagnosed with dementia is extremely difficult for everyone involved. Cary Smith Henderson, a history professor diagnosed with Alzheimer's disease, wrote a book entitled "Partial View, an Alzheimer's Journal" in 1998, where he eloquently describes his frustration related to his "loss of self" and the difficulties he experienced when trying to communicate:

"I just feel so darn useless at times. I just feel a sense of shame, in a way, for being so unable to do things, and so dense. Very simply put, we are clumsy, we are forgetful, and our caregivers, of course, understand that...We want things to be like they used to be. And we just hate that, the fact that we cannot be what we used to be. It hurts like hell. And another really crazy thing about Alzheimer's, nobody really wants to talk to you any longer. They're maybe afraid

of us...I can't really converse very well at all...The words get tangled very easily and I get frustrated...."

In the earlier phases of the disease, it can be tricky for family members to figure out how to effectively communicate with the person with dementia (PWD). Due to the come-and-go nature of the illness, one day (or even moment) the PWD can seem almost "normal" and the next, words and thoughts are totally jumbled. This "seesaw" effect can create a lot of anxiety for family members, so they begin questioning the PWD: "Where did you go? Who did you see? What did you eat for lunch? Do you remember Jane from work? Do you remember the name of that man standing over there?" This often results in the PWD feeling angry, frustrated, or anxious –they want to remember events, names of people, what they ate for lunch today, but are unable to do so. Family members, on the other hand, ask questions because they are trying to continually gauge how the PWD is feeling, what they can remember, how well they are able to articulate their thoughts and feelings, and whether the illness is progressing. They want to keep their own anxiety in check, to maintain control of a truly uncontrollable situation. Everyone wants things to be like they used to be, but they have changed.

As the disease progresses, the PWD is incapable of changing. It is our responsibility as a caregiver and/or family member to communicate and behave differently. The key to effective communication is retaining the PWD's sense of identity/

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personal history, including them in conversations and activities, showering them with a lot of love, comfort, and validation, and letting go of things that are unimportant.

So, where do we begin? Do you sometimes feel like you are up against a wall or banging your head against one? Do you struggle to improve your quality of life, reduce your own stress level, while concurrently trying to improve the quality of life of the PWD? If you answered yes to any of the above questions, your first step is to think about how you communicate with the PWD. You will likely find that past or even current ways of communicating are no longer working. It is time to begin accepting that new techniques need to be utilized.

Remember: this is a process, it takes time—it surely does not occur overnight. Don't be hard on yourself, it is very difficult to change the way you have been communicating with your family member for the past 30, 40, or 50 years.

Let's examine various methods of communication which may help you restore a positive relationship with the PWD.

- **Verbal Communication** This is the first and most important step in this process. Try to frame things in a positive manner. Watch your tone of voice and give verbal cues. If the PWD forgets what they were discussing, a gentle reminder MAY work well, such as "I think you were discussing the dinner we had last week at Alan's". Consider the PWD's personal history and preferences before making suggestions; do not impose your framework.

- **Written Communication** Notes sometimes work very well. Leave small notes to let the PWD know that you love them, when the doctor appointment is scheduled, or what activities are planned for the following day. Keep notes simple and to the point.

- **Facial expressions** PWDs are very astute in "reading" facial expressions. If you tend to roll your eyes, grimace, raise your eyebrows in exasperation, or look annoyed, it can result in angry or frustrated behavior from the PWD. Try your best to reduce these expressions and instead to convey genuine understanding and happiness. Learn to let it go.
- **Touch** Holding someone's hand or giving someone a hug (if they like to be touched) is often calming and reassuring. It can also help a PWD feel safe and less anxious.
- **Smell** Take a moment and think back to the time when you were young. Is there a smell(s) that you associate with a memory of a person, a meal, or a place that makes you feel happy? What smell might make the PWD happy? Did they grow up in the country? Could it be the smell of pine trees? Did they traditionally cook a special meal or dish that the family enjoyed? Did they always wear a particular perfume, lotion, or cologne? Try recreating these scents (you can also buy small scent bottles at specialty pharmacies). They may trigger a memory, and make the PWD very happy.
- **Music** Think of the type of music that the PWD enjoys and play it at home or in the car. Music often has a soothing effect and reduces anxiety. It is great to sing songs together; it doesn't matter if you don't remember all of the words, try humming the tune.
- **Art** The Studio Museum in Harlem, The MoMA, The Folk Art Museum, and the Metropolitan Museum of Art in New York City, all have programs specially designed for people with dementia (who attend with their family members and/or professional caregivers). These programs—which provide stools or wheelchairs if necessary—utilize their respective art collections to stimulate conversation and well-being. (For more information about these programs visit our website, www.alz.org/nyc.) Most museums have large parts of their collections online, which can be accessed from home, if a PWD is unable or unwilling to attend the museum programs. Try identifying paintings that evoke positive feelings and memories for the PWD (even if they were not previously an art lover). Utilizing photographs to make scrapbooks of the PWD's life, can promote wonderful conversations about the past.
- **Color** Patterns can be confusing but bright or contrasting colors are often attractive to a PWD and can affect their mood. Certain colors have inherent meaning, like yellow and red which are sometimes used to convey danger or warning (think about street signs). Blues and greens are generally calming colors and may help reduce anxiety.
- **Physical Approach** Always approach the PWD calmly from the front and speak to them at eye level. Never approach from the rear as this might frighten the person you are caring for, especially if they have vision or hearing difficulties. Try rearranging furniture at an angle which promotes conversation.
- **Listening** This is a very powerful form of communicating with a PWD. Too often, we may be distracted by the dog, the telephone, the Blackberry, the computer, the children, or the noise from the street to devote our full attention to the PWD. They may be trying their best to express a word or a thought but if we are too busy to devote our full attention, we will surely miss the gist of the conversation. Dr. Rachel Naomi Remen's book, "Kitchen Table Wisdom" (1996), includes a story that demonstrates the power of listening entitled, "Just Listen."

"I suspect that the most basic and powerful way to connect to another person is to listen. Just listen. Perhaps the most important thing we ever give each other is our attention. And especially if it is given from the heart. When people are talking, there's no need to do anything but receive them. Just take them in. Listen to what they're saying. Care about it. Most times caring about it is even more important than understanding it. Most of us don't value ourselves or our love enough to know this...We connect through listening. When we interrupt what someone is saying to let them know that we understand, we move the focus of attention to ourselves. When we listen, they know we care." Take the time to put away all the technological devices, screen out other distractions, and devote your complete attention. It will be worth it.

- **Laughter** A hearty laugh or a silly joke may help to release stress.
- **Silence** Although we are often extremely uncomfortable being silent, at times, silence can be very peaceful and powerful.

The second step requires thinking "outside the box" in order to fully understand what your family member may actually be trying to convey. Let's examine the following scenario, which is loosely based on a segment from the video "Into the Other Lane: Driving and Dementia" (Terra Nova Films, 2010)

Scenario 1

Jim was a truck driver and his whole working life was spent on the road. Two years ago he was diagnosed with vascular dementia, after having several mini-strokes. Nothing was more important to Jim than driving and when his family urged him to give up his driver's license, Jim was furious. The family consulted with his primary care physician, who agreed that Jim should have

his license suspended due to medical reasons. The physician told Jim that perhaps he might get his license back at a later date, if he got better. The physician knew that Jim would never drive again but was concerned about destroying his hope. Jim spent every waking hour talking about or going to the Department of Motor Vehicles to see if he could get a new and valid driver's license. He also stopped by his physician's office on a regular basis to convince him he was better and should have his license reinstated. Jim's family decided to park his old truck in front of the house (with a club inserted in the steering wheel), so Jim would know where his truck was, but this only made him angrier and more determined to get his license back. No matter what his family said, no matter how many times they explained that he wasn't able to drive because of his mini-strokes, he refused to listen. Everyone was incredibly frustrated and Jim said he no longer felt like a man.

What are some of the key issues in this scenario?

- Jim's identity revolved around driving. His entire work life was spent in his truck, being on the road. He desperately wanted to drive and to return to the time when he was well.
- Jim's family was extremely frustrated with his behavior. He was "obsessed" with reinstating his license. They tried reasoning and arguing with him with no success. They related to him as if he was well.
- His physician led him to believe that someday he might be able to have his license reinstated because he wanted to give Jim hope.
- The visual cue of his truck parked outside of his house was a constant reminder that Jim could no longer drive.
- Jim expressed that he no longer felt like a man.

Effective Strategies to Consider

- Reasoning and arguing did

not work. This will always be a "head-banger" approach.

- Reassuring Jim that his truck was safe and placing it where he could see it only made things more difficult. It was a reminder that he had lost his identity.
- His physician wanted to give Jim hope, but it was false hope. He also used reason, which only served to frustrate Jim.
- Jim didn't feel like a man. He didn't have a purpose. Perhaps his family could have told Jim that they understood how difficult this was for him (validated his emotions), redirected him to talking about times on the road, removed the truck, and found some other hobby/activity that Jim would like and make him feel "manly" and useful. This response might not totally negate his desire to drive but will keep the whole family more on an even keel, provide Jim with a purpose, and help him feel understood.

Scenario 2

Susan was going to accompany her son, Joe, to a family reunion in Westchester. There were going to be 35 relatives attending the reunion. Joe decided he would be driving to the party, which would take approximately 45 minutes from their house on Long Island. They immediately ran into traffic. People were honking their horns, Jim was solely concentrating on the traffic and not speaking to his mother. Every few minutes, Susan asked Joe, "Where are we? Where are we going?" Joe's responses included "On the Cross Island Parkway," "On the Whitestone Bridge," "On the Hutchinson River Parkway," "We are going to the reunion, I just told you that." After 20-30 questions, Joe snapped and said: "Mom, can't you remember anything? Please do not ask me any more questions, we should never have gone to this reunion!" He felt bad that he snapped but Susan's perseveration (continuous repetition), was driving him crazy.

What are some of the key issues in this scenario?

- Joe wanted to bring his mother to the family reunion but her continual questioning (compounded by the traffic) was difficult to manage.
- Joe answered Susan's questions using facts.
- Joe was unable to pay attention to Susan because of the traffic.
- Susan was unable to control her questioning and was anxious.

Effective strategies to consider:

- Understand that the repetitive questioning was likely because Susan felt lost and anxious. She did not know where she was going. The confusion created by the traffic and the honking only made matters worse.
- Joe might have engaged his mother in conversation (even though he was juggling traffic) and asked her how she was feeling and validated her emotions. She may have been feeling concerned or anxious about going to a large gathering and not recognizing her relatives. Joe needed to reassure Susan and tell her he loved her.
- Joe may have tried to redirect Susan to discuss memories from long ago about growing up (which may have included stories about some of the relatives who would be attending the reunion).
- Joe might have tried bringing some CDs in the car of Susan's favorite music or singing songs with her.

These scenarios illustrate how critical it is for family members to problem solve and communicate in new and creative ways, always applying a person-centered approach.

NEXT ISSUE: We will be concentrating on some of the emotional and physical behaviors that people with dementia may be exhibiting. We will provide you with ways to manage these behaviors as well as coping strategies that may help reduce your stress and that of the PWD.

Ten Tips for More Effective Communication

- **Tip Number 1:** Try to eliminate from your vocabulary the phrase "Do you remember...?" and replace with "Let's talk about...", or "Look, there is Jane from work. Let's go over and say hi to her." If the PWD doesn't remember Jane, try reassuring the PWD that you sometimes forget the names of people too.
- **Tip Number 2:** Forget quizzing and try encouraging the PWD. Perhaps they can help you with certain tasks or chores: "Let's make lunch together." "It is a beautiful day. Let's go out for lunch." If the PWD refuses to participate, acknowledge their emotions: "I know this is difficult for you but can you try going out with me?"
- **Tip Number 3:** Slow down the conversation. PWDs live in a much slower world and sometimes have difficulty following conversation. Try to make a concerted effort to include the PWD in the conversation, even if they do not logically follow the conversation.
- **Tip Number 4:** Be clear and specific. Avoid phrases that are vague, such as "Do you see that man over there?" Be concrete. For example, "Do you see the man with the blue coat standing against the wall?"
- **Tip Number 5:** Emphasize strengths, not weaknesses. Focus on the positive as opposed to the negative. Praise the PWD, but don't be condescending. Try not to criticize or assign blame, as it will only result in angry feelings.
- **Tip Number 6:** Don't ask open-ended questions such as, "Do

you want to go outside today? When questions are phrased this way, PWDs often answer with a resounding "NO." What family members fail to understand is that the "no" response may not be a meaningful NO. Try providing people with choices and phrasing questions in this manner: "Would you rather go to the park or to the movies?" or "I know you don't feel like going out today. Let's give it a try for a few minutes. Can you do it for me?"

- **Tip Number 7:** Develop the "Art of Being Wrong". If the PWD attempts to blame you for something you didn't say or do, simply respond with "I am sorry." This may be tough, but it is worth it, it will eliminate arguments. Let things go.
- **Tip Number 8:** Get into the PWD's reality. People may make up stories about certain activities they did or places they visited. Get into their story, ask questions, and provide reassurance.
- **Tip Number 9:** Check out your environment. Certain places may provide too much noise, which will be distracting to the PWD and make communication more difficult.
- **Tip Number 10:** Limit information. If you see that the PWD looks confused during the course of a conversation, you might be providing too much information. Simplify the conversation by presenting one idea at a time.

Correction (Caregiver Guide #1, Vol. 34, Summer 2010): Down syndrome is a risk factor for Alzheimer's disease, it is not a particular type of dementia. People with Down syndrome are living longer, and at a higher risk for developing Alzheimer's disease, but not all people with Down syndrome will get Alzheimer's disease.

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Behaviors Have Meaning

Many people who attend the family caregiver workshops ask me "How do I deal with what's to come in the future?" I wish I could provide a list of effective strategies for every possible scenario but it's not that simple. Dementia is a complex disease that affects each person with dementia (PWD) differently. It often catches caregivers off-guard because they are ill-prepared to cope with the wide range of behaviors. The first thing family members need to understand is if you have met one person with dementia, you have met one person. In other words, each person with dementia is unique. Behaviors vary and come and go. Although in every workshop family members may see some commonalities exhibited by their PWD, care can never be standardized.

Utilizing a person-centered care approach is imperative in order to accurately interpret and respond to behaviors demonstrated by the PWD. Knowing the PWD's personality, key relationships, history, routines, personal preferences and hobbies provides a window into understanding their behavior. Other factors which will provide clues include:

- What stage of the illness is the PWD in?
- Are they suffering from other medical conditions such as hearing, vision, mobility loss or other chronic illnesses?
- What physical approach is taken with the PWD?
- What is the general mood of the PWD?
- Are people talking down to or quizzing the PWD?

- Is the PWD occupied in any other ways?
- Is the environment stable and structured?
- Are people asking the PWD to do tasks that may be too complex??

Let's examine a story I was recently told by a family caregiver who was extremely stressed by her husband's behavior.

"Every morning my husband wakes up before five AM and repeatedly asks me, "Where is the laundry? I need to wash and iron the laundry." He continues to ask about the laundry and it's driving me crazy. No matter how many times I tell him the laundry is done and he can relax, he is always angry. He yells, criticizes me, and two hours later will apologize for his rage. We go through this scenario daily. It's exhausting! What should I do?"

What does her husband's repetitive behavior mean? I asked her to analyze the situation and consider the following questions: What did your husband do for a living? What was his daily routine? Did he have any hobbies? What is his current emotional status? Can you describe his personality?

After she was able to emotionally remove herself from the situation, she was better able to understand its meaning. Her husband owned a dry cleaning business for 40 years, worked six days a week, and his life revolved around his work. He supervised ten employees and was used to being in control. He sold his business shortly after being

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diagnosed with dementia. His wife learned that using facts and reasoning did not diminish his anger. She needed to adopt a new approach. One morning she asked her husband to help her with the laundry and “inspect” it as it was folded to make sure it was done correctly. They were able to reminisce about his days at the dry cleaning store and shortly thereafter she noticed his anger diminished. He needed a sense of identity—a purpose. He missed feeling useful and now she helped to fulfill his emotional needs.

Tom Kitwood, a psychologist and author of “Dementia Reconsidered: The Person Comes First” (1997) reinforces this idea. He states that the main psychological needs of people with dementia are:

- Love • Inclusion
- Occupation • Comfort
- Sense of identity • Attachment

If you think about it, these are the psychological needs of all people. If they are met, people generally feel a sense of security and well-being. The PWD experiences so many losses in addition to the inability to perform routine tasks and make complex decisions. Eventually they suffer from a profound loss of self. Wouldn't just one of these losses change your behavior? It is up to family and professional caregivers to understand what is driving the PWD and what their reactions and responses mean. This is by no means easy and requires a certain way of thinking. It also requires flexibility and creative problem-solving: If Plan A doesn't work, Plan B or even C might be required. This may seem like a full-time job (and it is) but the payoff is rewarding! Caregivers will experience reduced stress and will be able to establish and sustain a newly defined relationship with the PWD.

Before addressing specific behaviors that can be described as problematic, we must first consider our definition of a problem. Is it OK if a PWD likes to wear the same shirt

and pants everyday? What if a PWD eats with his or her hands? Is it problematic if a PWD repeats the same question 30 times a day? Is it wrong if a PWD stays up all night and sleeps all day? Should a PWD bathe everyday if they are not incontinent? Is it a problem if a PWD is constantly trying to leave the house and wander?

Answers to these questions may vary and caregivers must consider if the PWD's behavior is more a problem for the caregiver or one that might potentially place the PWD at risk? The caregiver should change their expectations of the PWD and consider what really matters. Think of it as conducting a cost-benefit analysis: Is it worth placing more strain on an already fragile relationship to argue about clothing? Perhaps you can purchase several of the same types of shirts or pants the PWD likes to wear. Thinking along the same lines, maybe you can purchase or prepare food that is easy for the PWD to handle with their hands as they may no longer be able to utilize silverware properly. Consider it might be OK if the PWD only wants to bathe twice a week. PWD's new behaviors, routines, and preferences often surprise the caregiver but it is important to realize the caregiver will need to adapt to this new way of life. People with dementia cannot change.

Let's explore some specific areas that often bring about behavioral challenges, examine the meaning of these behaviors, and provide some effective coping strategies.

It is a good idea for the caregiver or home care worker to start by keeping a journal noting what happened: where the behavior occurred, when the behavior occurred, what was said prior to the behavior occurring, and who was present at the time. Keeping a log that addresses these points, in addition to keeping in mind the personal history of the PWD, will often enable the caregiver to better understand the PWD's behaviors and effectively develop coping strategies.

Bathing

Behavioral Challenges and Considerations

- Is the bathroom too cold? Is the water the right temperature?
- Could the PWD be uncomfortable being undressed in front of a home health aide, child, or even a spouse?
- Is it too difficult for the PWD to get undressed, bathe, or wash their hair?
- Is the PWD afraid of falling while getting into the tub?
- Is the lighting in the bathroom too bright or too dim?
- Is the PWD fatigued at this time?
- Might the water be frightening to them?
- Is the shower nozzle spraying water in the PWD's face?

Coping Strategies

Make the bathroom safe. Install grab bars near the toilet and inside the shower. If you have a tub/shower, use a bathtub transfer bench or shower chair inside the bathtub facing away from the showerhead. Get a handheld showerhead to avoid water spraying in the PWD's face and place temperature controls on hot water to prevent scalding. Remove locks on bathroom doors, utilize non-skid bath mats, and cover radiators. For additional safety tips, visit www.thiscaringhome.org, which has a wealth of safety tips for all areas of the home.

Make bath time an enjoyable experience. Schedule it when the PWD is relaxed and not fatigued, give the PWD a plush bathrobe, and try aromatherapy (only if the PWD likes it) using scents the PWD enjoys. Buy a shower radio and play music the PWD appreciates.

Determine if the PWD is uncomfortable being fully exposed. If this is the case, buy a cape or cut a hole in a shower curtain and place it over the PWD. Wash them under the cape from the bottom up. Distract the PWD with an enjoyable conversation that does not focus on bathing. If the PWD seems afraid, validate their emotions and provide reassurance.

Utilize rinse-free products available from the Alzheimer's Store, which has a wide range of products and activities

for people in all phases of dementia. Visit www.alzstore.com or call 1-800-752-3238.

Display only the bath products you need as the PWD may mistake a tube of toothpaste as ointment, which could be upsetting to the PWD.

Sleeping

Behavioral Challenges and Considerations

- Does the PWD have a routine? Drink caffeinated beverages? Drink a lot of fluids prior to bedtime and therefore need to use the bathroom throughout the night? Have day-night reversal?
- Is the PWD over-medicated or experiencing pain?
- Is the PWD bored or depressed? Are they involved in any activities during the day? Might sleep issues be related to other medical conditions?

Coping Strategies

Establish a daytime routine – try having the PWD wake up at the same time each morning (according to their preference) and eat at the same time.

Eliminate caffeinated beverages and limit fluids around bedtime.

Check with the PWD's primary physician or neurologist about medications and medication interactions. Could the PWD take a different dosage of medication or take it at a different time?

If a PWD is up for days and unable to sleep, consult with their physician. You need your sleep and so does the PWD. You might also consider an overnight social program that runs from the evening through the morning, such as the Hebrew Home for the Aged in Riverdale, for PWD who have different body clocks.

Also consider traditional social day programs which provide the PWD with social interaction and activities. Caregivers should do their homework and visit programs to determine if they will be a good fit for the PWD. For additional information contact the NYC Chapter's 24-hour Helpline at 1-800-272-3900.

Eating

Behavioral Challenges and Considerations

- Does the PWD have cataracts, which could impact their ability to clearly see what they are eating?
- Does the PWD have a toothache? Are dentures ill-fitting?
- Are prescription drugs making the PWD nauseous?
- Has the PWD's sense of taste been impacted by dementia?
- Is the task of eating too complex? Is the PWD experiencing difficulty utilizing utensils?
- Is the TV on during mealtime?
- Do meals look unappetizing? Does the PWD like the food being offered?
- Is the dining area cluttered or does it contain busy patterns?
- Are you eating in restaurants during peak dining hours?

Coping Strategies

- Address any other medical conditions with individual specialists.
- Try having dentures readjusted or refitted. Accompany the PWD to the dentist. Ask the dentist to keep all communication with the PWD short and simple.
- Eat out at off-hours when restaurants may be less congested.
- Be aware of your home environment. Place chairs across from each other to encourage eye contact and conversation, turn off the TV and engage in conversation.
- Keep the dining table uncluttered and simple.
- Prepare foods that are easy for the PWD to eat on their own such as chicken fingers. Maximize the existing strengths of the PWD.
- Ask the PWD to help you prepare the meal. (Say *"Let's prepare dinner together. I would love your help."*)

Incontinence

Behavioral Challenges and Considerations

- Is the bathroom easily recognizable, accessible and easy to use?
- Are medications or other medical conditions such as a urinary tract infection (UTI) resulting in

incontinence?

- Is the PWD in denial regarding his or her incontinence and unable to accept that they need undergarments?

Coping Strategies

- Paint the door of the bathroom a contrasting color from the wall color. Place a sign on the bathroom door and include a picture of a toilet. Use a toilet seat that is an opposing color to help differentiate the seat from the toilet.
- If the PWD's health takes a dramatic downward turn, contact their physician to determine if the PWD has a UTI or other medical issue.
- If the PWD becomes suddenly incontinent, contact their physician to discuss medications and possible medication interactions.
- Place a commode in the bedroom in a place which is easily accessible and not a safety hazard.
- Utilize comfortable undergarments. Some products resemble underwear, not diapers.
- Respectfully suggest the PWD use the bathroom prior to a long car ride or outing.

Delusions and Hallucinations

Delusions are false beliefs and hallucinations are distortions in a person's perception of reality. Hallucinations may be sensory experiences in which a person sees, hears, smells, tastes, or feels something that is not there.

Behavioral Challenges and Considerations

- Understand that delusions and/or hallucinations can frequently occur in people with dementia.
- Common delusions include delusions about infidelity, stealing, and facial recognition.
- Common hallucinations include a PWD seeing people who are not there or falsely hearing the doorbell ringing, or people talking.

Coping Strategies

Delusions often catch family caregivers off-guard, especially when they are the focus of the delusion ("You took my money, you stole my jewelry.") Reassure the PWD and validate their emotions. Get into their reality and acknowledge their losses. I heard a story about a woman with dementia who thought, incorrectly, her husband was having an affair. The daughter consoled her mother and acted concerned, rather than telling mom it was nonsense. Her mother felt heard and, in turn, never brought the topic up again.

Hallucinations can be very scary for the PWD as well as the caregiver. First, check the environment. Is the PWD watching TV and did the content of a show transform into their reality? Are there shadows in the room or a glare that could be misinterpreted by the PWD? Are there paintings hanging on the wall that might seem scary to a PWD? Try to modify the environment if any of these issues are present.

Reassure the PWD and try to determine if there is a reason for the hallucination. Could they have heard the doorbell ringing three hours ago and think it is still ringing? If the PWD is disturbed and anxious about the hallucinations, contact their physician.

Wandering Behavioral Challenges and Considerations

- Could the PWD be bored?
- Could the PWD need more activity?

Coping Strategies

Enroll the person in the MedicAlert® + Alzheimer's Association Safe Return® program by calling 1-800-272-3900. A Safe Return staff member can help you with strategies to encourage the PWD to wear the bracelet.

Remove visual cues that might stimulate wandering such as placing a drapery over the door. If the PWD doesn't see the door, they may not feel they want to go outside. Also remove

keys and coats from their sightline.

Create a wandering path inside the home. Change pictures, photos, and plants on a weekly basis to constantly stimulate the PWD. Take the person for a walk.

Anger

A family caregiver recently shared the following story with me. "My husband, a holocaust survivor diagnosed with Lewy body dementia, woke up in the middle of the night to go to the bathroom, tripped and fell. He broke two ribs and after a short hospital stay he was moved to a rehabilitation facility. We have no children and because of his personal history, he has a strong sense of attachment to me. The rehab facility is having difficulty dealing with him. When I arrived for a visit he was so angry that he punched me. I told him I would visit every day but it did not seem to make a difference. A few hours later he apologized for his outburst and promised it would never happen again. I have heard this before. What should I do?"

I asked the caregiver the following questions:

- What do you think is creating his anxiety? Is he receiving any medication for anxiety?
- Have you told the staff about his personal history and successful strategies you use to reduce his anxiety/anger?
- How does your husband react when it is time for you to leave?
- Is he someone who prides himself on his personal appearance?

I suspect his hospitalization and recent move to the rehab was very disorienting to him. His wife knew that her husband was anxious being there and missed her terribly. Whenever it was time for her to leave he became increasingly anxious. She would visit with him in an area near the elevator and realized her

husband was not engaged in an activity when it was time for her to leave. She also explained her husband was a "ladies man" and his appearance was critical to his sense of self-esteem and identity.

After some creative problem-solving, his wife developed the following strategies.

- Share her husband's personal history as a holocaust survivor—and the resulting need for attachment—with the staff at the rehab. Make sure all shifts on the rehab floor receive this information.
- Identify several staff members in various shifts that might be willing to give her husband a little extra TLC and pay attention to his personal appearance.
- Make sure not to leave during a shift change at the facility, which was a chaotic time at the rehab and a confusing time for her husband.
- Visit away from the elevator and notify the staff 5 minutes prior to leaving the facility so they could engage her husband in an activity or distract him in some other way.
- Speak to the physician about possibly prescribing a light dose of anti-anxiety medication.

After several days some of her strategies were working. Her husband's anxiety and anger had diminished. He was still nervous when he sensed she was leaving but with the help of the staff his mood was improved and her stress was reduced.

It is critical to remember that caregivers must creatively respond to behaviors—reality and facts will not work. Changing your way of thinking is something that doesn't happen overnight. It is a trial-and-error process that takes time. If you can remember to utilize (in the midst of a very emotional time) some of the techniques discussed in this guide, hopefully your stress will be diminished.

Amy Trommer, MSW; Dementia Care Trainer, Alzheimer's Association, NYC Chapter



Family Caregiver Guide

SPECIAL INSERT TO THE ALZHEIMER'S ASSOCIATION, NYC CHAPTER NEWSLETTER

NUMBER 4

We are pleased to offer the final of four installments of the Family Caregiver Guide (FCG), which is made possible by a generous grant from Forest Laboratories, Inc. with additional support from the Rowland & Sylvia Schaefer Family Foundation, Inc. The goals of the FCG are to provide caregivers unable to attend training sessions in our office with an improved understanding of the disease; effective communication strategies that improve interactions between the caregiver and the person with dementia; a deeper awareness of and ability to cope with challenging behaviors demonstrated by persons with dementia; and knowledge about safety measures and engaging activities.

We would like your feedback to determine the effectiveness of each issue of the FCG. Please log on to www.alznyc.org/fcg to complete a short survey and enter to win \$250!



Caring for the Caregiver

A family member attending the Family Caregiver Workshop at the Chapter recently remarked, "There is no roadmap for this disease, I wish there was a "how-to guide." Another agonized over every decision she had to make regarding her husband's care, fearing she would make the wrong choices. She eventually became mired in research, unable to accomplish any task or place a plan of action in gear. A third caregiver reluctantly confided, "I wish my husband had any other disease, even cancer. At least there might be some chance he would go into remission and I could gauge how he was doing day-to-day. A diagnosis of dementia does not afford me that possibility."

Caregivers of persons with dementia (PWD) often feel their lives are spinning out of control. It is no wonder! According to the National Institutes of Health, caregivers, especially those caring for a PWD, are thirty times more likely to experience depression than non-caregivers. What factors contribute to the emotional roller coaster ride so many caregivers experience? Could it be...

- The innate unpredictability of the disease? Never knowing what symptom or new and unusual behavior will surface from one day to the next.
- Fear? Wondering whether you will have the energy or strength to face the increasing

decline of the PWD.

- The constant shifting? Of your relationship with the PWD, of daily responsibilities and roles (i.e., paying bills, food shopping, scheduling doctor's appointments, taking care of legal matters, arranging for repairs around the home, etc.), or of your own emotions.
- Complicated feelings? The future is not what you anticipated, family members you thought would help shoulder some responsibilities are not as helpful or not helpful at all. Perhaps you miss the relationship you used to have with the PWD, the intellectual stimulation, the companionship, the security.
- Loneliness/Depression? As the PWD's condition deteriorates, friends and family often withdraw. People are sometimes scared to see the PWD, unsure of how to communicate, and often retreat, leaving the caregivers to fend for themselves.

Given the enormity of the task of caring for a PWD and the emotional toll exacted, is it possible to reduce the caregiver's burden? No simple answer exists for this question, but a good place to start is with yourself.

Know yourself. Step back for a moment and think about your

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personality. What kind of caregiver are you and what impact might this have on the way you provide care?

- **The Caregiver in Denial —** Do you adopt the attitude everything is fine until a crisis forces you to confront the reality of the situation?
- **The Expert Researcher —** Always needing to master each new issue you face. Gathering tons of information about dementia, medications, home health care vs. nursing home placement, etc., constantly weighing pros and cons.
- **The “It is all about me” Caregiver —** Unable to make decisions because you are so focused on how the disease is impacting you and not the PWD.
- **The “I am in Charge” Caregiver —** All family members need to follow your lead, including the PWD. You must always be “in control.”
- **The Self Sacrificing Caregiver —** The caregiver who is unable to hold a job or maintain friendships or relationships because your entire life (24/7) is devoted to caregiving. Unable to set boundaries.
- **The Paralyzed Caregiver —** Unable to reach decisions in a timely basis.
- **The Reluctant Caregiver —** Trying to reconcile long-standing feelings of guilt or anger.
- **The Hero/Heroine —** You can handle all of this by yourself and refuse to get any help.
- **The Mother —** Perpetual caregiver.
- **The “I am in the here and now” Caregiver —** Able to accept the situation as it is.

Most caregivers can identify

with at least one of these ‘types’. It is important to step back and examine who you are: how your personality impacts your caregiving, your sense of burden, your ability to solve problems, and your own health. Knowing yourself — your unique caregiver perspective — will enable you to get in your own way less often.

Know your boundaries. It is not only okay to draw lines—what you will and will not do, can and cannot do—but having appropriate boundaries is essential to ensuring your own well being throughout your caregiving journey.

Know your hot buttons. Understand what sets you off. Caring for someone with dementia can be very frustrating. Being able to catch yourself before you reach the end of your rope should help in reducing your burden and improve both your quality of life and that of the PWD for whom you care.

Joan Griffiths Vega, a local instructor in Mindfulness Based Stress Reduction (MBSR), a program developed by Dr. Jon Kabat-Zinn and faculty at the Center for Mindfulness at the University of Massachusetts Medical School, suggests caregivers use the following MBSR acronym to ease stress and improve mood:

S (Stop)
T (Take a breath)
O (Observe)
P (Proceed)

In other words, try not to immediately react to a situation. Hold your breath or curb your tongue, and observe what is going on before proceeding. If you can just slow your words and actions down a bit, anger will likely dimin-

ish. This can be very difficult, and as with any new skill it will require time and practice, but if you are capable of making some progress, even a little bit, you will feel your sense of burden begin to ease.

Give yourself permission to care for yourself. You may experience grief, anger, sadness, frustration, and many other feelings. These are all normal. You are not alone. Keep reading to learn about additional ways to support yourself.

1. Educate yourself and others. Learn new techniques and strategies to help improve your quality of life and help sustain your relationship with the PWD throughout the course of the disease. Learn about the education programs offered by the Alzheimer’s Association, NYC Chapter, enroll in the Family Caregiver Workshop, attend our monthly education meetings.

Visit the Chapter’s website — www.alz.org/nyc — for information about the latest research studies, advocacy efforts, support groups, arts and cultural programs, MedicAlert® + Alzheimer’s Association Safe Return® program, Care Consultation, Early Stage Services, medication trials, residential care options, pharmacy discount programs, the NYC Chapter’s quarterly newsletters, special events, community resources, and volumes of information about Alzheimer’s disease and related dementias.

For more information, call our 24-hour Helpline at 800-272-3900. These and all of our programs and services are available free of charge.

Subscribe to the Alzheimer’s Daily News online, a publication of the Ageless Design Research Foundation, by visiting www.agelessdesign.com.

2. Develop creative problem-solving skills to address challenging behaviors demonstrated by the PWD. When caring for a PWD it is important to consider what is truly important and let the other things go. Avoid arguing with the PWD — you probably will not win. Develop the art of being wrong — saying you are sorry often ends any argument. Begin trying to accept the situation, diminish negative self-talk, and release any anger you may be feeling. Step into the PWD's reality, understand their underlying emotional needs (inclusion, a sense of identity, attachment, love, comfort, and occupation [Kitwood]), and provide validation. Think outside the box and avoid reverting to reality and facts.

Consider joining a support group to explore your feelings and form connections with others caring for a PWD. The NYC Chapter has more than 130 groups (with trained and experienced group leaders), which meet during the day as well as in the evening. Held throughout the NYC metropolitan area, we offer groups for many different types of situations including groups for spouses, adult children, daughters, caregivers of a PWD in the late stage, caregivers of PWD with Frontal Temporal dementia (FTD), LGBT caregivers, etc.

You might also consider meeting individually with Chapter staff for Care Consultation services, or seeking individual counseling. For more information about these options and more, visit the Chapter's website at www.alz.org/nyc or contact our 24-hour Helpline.

3. Consider your relationship with the PWD. Has it historically been loving or contentious? Do they push your buttons? Do you

have a strong attachment to your partner, parent, or other relative? All relationships are complicated and dementia further complicates things in the way it impacts not only the person with the disease but everyone involved.

Dr. Roberta Satow, in her book *Doing the Right Thing — Taking Care of Your Elderly Parents Even If They Didn't Care for You* (Jeremy P. Tarcher/Penguin, New York 2005), writes: "There is no one day after which we no longer have to contend with the compulsion to repeat old patterns that keep us stuck and unhappy... old patterns and conflicts that remain either unresolved or incompletely resolved reemerge throughout our lives — especially during stressful times such as caregiving. If we do not resolve them, the best we can do is reach a point where we are more conscious of the telltale signs that presage their reemergence. We can get to a point at which we can realize the meaning of what we just said or did and not let our lives or our selves get out of control. Or we can do even better than that. We can resolve the underlying conflicts that cause us to repeat painful experiences."

4. Understand there are no perfect solutions. The following passage from Pauline Boss's book, *Ambiguous Loss — Learning to Live with Unresolved Grief* (Harvard University Press, 1999), is especially poignant for caregivers of people with dementia. It perfectly describes the universal dilemma faced by many caregivers of a PWD — the desire to master a situation, where mastery is impossible:

"If we are to turn the corner and cope with uncertain losses, we must first temper our hunger for mastery. This is the paradox. To regain

a sense of mastery when there is ambiguity about a loved one's absence or presence, we must give up trying to find the perfect solution. We must redefine our relationship to the missing person. Most important, we must realize that the confusion we are experiencing is attributable to the ambiguity rather than to something we did — or neglected to do. Once we know the source of our helplessness, we are free to begin the coping process. We assess the situation, begin revising our perceptions of who is in the family and on what basis, and gradually reconstruct family roles, rules, and rituals. We feel even more in charge even though the ambiguity persists."

5. Be three steps ahead of a crisis instead of responding to one. While it is not always possible to avoid crises, taking certain steps can help keep them at bay.

- Take care of legal and financial matters. Complete a living will, Health Care Proxy and Power of Attorney. Attend one of our Legal and Financial Seminars to learn more about transferring assets, supplemental needs trusts, Medicaid, and Medicare.
- Remove environmental hazards from the home that could result in harm to the PWD (falls, burns, etc.). Visit www.thiscaringhome.org for a list of tools and tips for safety, or contact our 24-hour Helpline for guidance.
- Remove anything that could be used as a weapon.
- Remove valuables from the home. If you do not want jewelry, important papers such as birth certificates, or family heirlooms to disappear, place them somewhere safe. Give

the PWD a laminated copy of a birth certificate, social security card, insurance card, etc. or a less expensive, less sentimental piece of jewelry to wear.

- If your family member is responding to telephone calls requesting money or donating money to charities, remove the credit card and checkbooks from the home, place a block on the phone or stop telemarketers from calling by registering with the National Do Not Call Registry. Consider having mail sent to a forwarding address or P.O. Box. Call our 24-hour Helpline for specific strategies that can reduce the PWD's anger (i.e., giving them something else to do to refocus their attention and keep them busy).

6. Get help in the home or consider nursing home placement. If the PWD refuses help but needs it, get it anyway. Our 24-hour Helpline can provide you with information about agencies and how to successfully introduce help in the home. It is a transition for both the caregiver and the PWD, but it is worth it. Ask Helpline staff for a copy of "Making Home Care Work For You," a valuable guide that addresses a wide array of relevant topics.

Realize that sometimes nursing home placement is the best option for the PWD and also for the caregiver. Get past the negative connotation and at least obtain good information about all options, even if you are not actively considering them or are ambivalent. The Chapter's Residential Care Specialist can be reached through our 24-hour Helpline.

7. Connect to your community and its resources. Find out about programs in your area including overnight respite programs, day programs, programs at local museums to explore art and art making with the PWD, ballroom dancing for caregivers and the PWD, music and singing events for caregivers and people with dementia, meal delivery programs, bill payer programs, visiting nurse services, and visiting doctors of a variety of disciplines.

8. Give yourself permission to take time off and enjoy life. You deserve it! You need to take care of yourself first and then you will be able to better care for the PWD. If you are happier, the PWD will also surely benefit. What makes you feel good? When was the last time you had a good hearty laugh? Take time to:

- Take your dog for a walk
- Meet a friend for lunch
- Sing songs (at the top of your lungs!)
- Go to a movie
- Take a class
- Visit a museum
- Go on a vacation
- Garden
- Cook
- Read a book
- Sit quietly by yourself
- Meditate
- Exercise
- Attend a support group

Don't let guilt stop you. Guilt is an emotion that is real but can have severe negative consequences. Talk with someone to help you reconcile your feelings. Schedule time each day or each week to

enjoy yourself. Allow yourself to feel guilty but don't let it interfere with your taking time for yourself. If you feel this is impossible, have the PWD join you in an activity so you can do it together. Even if the PWD is confined to a wheelchair or is nonverbal, they will appreciate being out and about and in the presence of others.

9. Strike a healthy balance. While you may have been thrust into the role of caregiver, not everyone has the ability or desire to be a caregiver. Olivia Eames Hovlitzelle, author of *Ten Thousand Joys & Ten Thousand Sorrows: A Couple's Journey Through Alzheimer's*, (Jeremy P. Tarcher/Penguin, 2010), who will be speaking at the Chapter's Monday night education meeting on May 23rd, quotes a Tibetan Nun who is discussing balance:

"Maybe you're already aware of this," she replied, "but in Buddhism we talk about the principle of the two benefits. The idea is very simple. For anything to be of benefit to another person, it must also be balanced with benefit to oneself. We can get all trapped into giving too much of ourselves and lose the balance in relationships. That's where this idea of two benefits can be a helpful reminder."

10. Take advantage of the New York City Chapter's programs and services, all of which are offered free of charge. Our 24-hour Helpline is available around the clock, 365 days a year, and is the best place to start. **Call us anytime at 800-272-3900.**

All four segments of the Family Caregiver Guide were written by Amy Trommer, MSW, Dementia Care Trainer.