

Family Caregiver Guide

2017
Edition

Understanding Dementia

What Is Dementia?

Dementia is an umbrella term used to describe a group of symptoms created by abnormal changes in the brain. Dementia is a state of mind and is not, in and of itself, a disease. The condition is generally progressive, meaning that it gets worse over time. Some causes of dementia, however, are treatable or reversible. In these circumstances, symptoms of dementia may be attributable to other medical conditions such as endocrine abnormalities (thyroid disease or vitamin B12 deficiency), vision or hearing loss (resulting in withdrawal or isolation), kidney failure, depression, stress, medication side effects or medication interactions, infections such as urinary tract infection (UTI), strokes, or tumors.



Dementia is NOT a normal part of the aging process, but the result of a disease or other physical damage to brain cells. **The symptoms of dementia vary from person to person, but generally involve changes severe enough to affect a person's daily life in at least some of these areas:**

- Cognition (memory, thinking, language)
- Behavior (mood, personality, social skills)
- Physical functioning (motor skills, incontinence, visual field changes)

What Is The Difference Between Dementia And Alzheimer's Disease (AD)?

There are over 75 different causes of progressive dementia. **Alzheimer's disease (AD) is the most common and accounts for approximately 70% of all dementia diagnoses.** If someone has AD, he is experiencing dementia, but if someone has dementia, the cause may or may not be AD. His symptoms could be a result of any one of those other 75 causes.

The Family Caregiver Guide (FCG) is based on the curriculum for the 10-hour Family Caregiver Workshop offered at CaringKind. The four sections of the FCG correspond with the four sessions of the Workshop:

Section 1: Understanding Dementia.....p.1
Provides information about the symptoms and stages of progressive dementia.

Section 2: Effective Communication.....p.7
Covers tools and tips for enhancing communication with people in early, middle, and late stages of dementia.

Section 3: Behaviors Have Meaning.....p.13
Introduces a problem-solving model for addressing behavioral symptoms of dementia, along with points to consider for home safety and Activities of Daily Living (ADL).

Section 4: Caring for the Caregiver.....p.19
Discusses important strategies for coping with the physical and emotional burden of caregiving.

For additional information about any of these topics, or about the Family Caregiver Workshop, please visit www.caringkindnyc.org or call our 24-hour Helpline at 646-744-2900.

What Are Some Common Types of Progressive Dementia?

Alzheimer's Disease (AD) - In AD, the brain is affected by structures referred to as plaques and tangles. As the plaques and tangles impact different parts of the brain, neurons, or nerve cells, are destroyed and the size of the brain significantly decreases. Short-term memory

loss tends to be the initial noticeable symptom of AD. People with AD live an average of eight to ten years, but some people can live 20+ years. The vast majority of people with AD are over the age of 65, but a very small percentage are in their 40s or 50s.

Vascular Dementia (VaD)

Occurs after a vascular episode such as stroke, microscopic bleeding, or blood vessel blockage. The location of the brain injury determines how symptoms manifest. People with VaD will often experience periods of deterioration followed by relative stability until the next vascular episode occurs.

Frontotemporal Dementia (FTD)

Typical initial symptoms include changes in personality and behavior or difficulty with language, rather than memory. FTDs tend to affect people in their 40s or 50s and progress more rapidly than AD.

Lewy Body Dementia (LBD)

Similar in many ways to AD, but often begins with difficulties in balance and coordination as well as delusions and vivid visual hallucinations.

Wernicke-Korsakoff Syndrome

Caused by a severe lack of Vitamin B1, usually seen in people with a history of alcoholism.

Parkinson's Related Dementia

Some people with Parkinson's disease develop dementia in the later stages of the disease.

Creutzfeldt-Jacob Disease

A rare, fatal brain disorder that progresses quickly and affects humans and certain other mammals.

Huntington's Disease

An inherited degenerative brain disease that affects the mind and body.

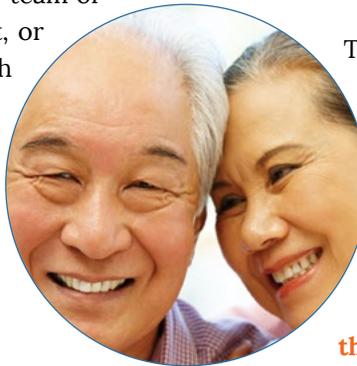
HIV-Associated Dementia

People with HIV and AIDS sometimes develop cognitive impairment, particularly in the later stages of their illness.

What Is Involved In Receiving A Diagnosis of Dementia?

If a person is experiencing symptoms that affect his daily life, a diagnostic workup is recommended to determine the cause of those symptoms. The doctor, or team of doctors including a neurologist, psychiatrist, or psychologist will perform an evaluation which may include:

- Family and medical history
- Comprehensive physical exam
- Laboratory work
- Series of neuropsychological tests, including memory, cognitive, and personality testing
- Scans of the head (MRI, PET or CT). A PET scan may differentiate between a diagnosis of AD and other dementia



The information gathered from this evaluation is then put together and analyzed. Armed with this knowledge, a skilled doctor or team of doctors can make a diagnosis of AD or another type of dementia with approximately 90% accuracy.

Why Is A Diagnosis Recommended?

The diagnostic process can rule out other conditions that may be treatable, such as the reversible causes mentioned earlier including thyroid disease, vitamin deficiency, or infection.

An accurate diagnosis is critical in determining the best type of treatment. Certain types of dementia may require different treatment modalities.

A diagnosis can detect Mild Cognitive Impairment (MCI). People with MCI experience mild changes in their memory, language and thinking abilities that are measurable, however, these changes are not severe enough to significantly affect their everyday activities. MCI does not always progress to full-blown AD, but it often does. People with MCI have an increased risk of developing AD in the future. Knowledge is power. People with dementia (PWDs) and their families can benefit from having a diagnosis because it gives a name to the difficulties PWDs are experiencing. It may help them to cope with the daily

challenges and provide a reason to make the most of each day. An early diagnosis also gives PWDs the opportunity to participate in planning for their own future in terms of legal and financial decisions and medical advance directives.

What Treatments Are Available?

The FDA has approved the medications Aricept, Exelon, Razadyne, and Namenda to treat the symptoms of AD. These medications do not work for everyone, but some people show some improvement in symptoms for some period of time. Side effects are possible, so the PWD should be monitored while taking any medication. **It is important to remember that no disease-modifying medications currently exist for AD, and even if the drugs seem to help the symptoms, the disease continues to progress in the brain.**

There is also a growing body of evidence regarding non-pharmacological, or non-drug, treatments for the symptoms of dementia. These treatments can be used alone or as a complement to pharmacological treatments. The advantage of non-drug treatments is that there is no risk of adverse side effects, and they may also help increase the PWD's quality of life. Examples include music, socialization, gentle exercise, and environmental modification. Even communication modifications, such as altering the caregiver's tone of voice, can ease dementia symptoms. The second installment of this guide will address communication techniques in more detail.

Caregivers should be aware that sometimes the media reports information about nutritional supplements, dietary restrictions, and other interventions for dementia that may or may not be fully researched, effective, or safe.

Consult our website www.caringkindnyc.org or call our 24-hour Helpline at 646-744-2900 for information about available treatments.

What Are The Risk Factors For Developing Dementia?

It's important to remember that researchers have not identified anything that definitively prevents someone from developing dementia. **While we cannot currently PREVENT dementia, there are certain things that may increase or decrease our RISK of developing the condition.** It's a subtle

distinction but an important one in managing expectations of what is possible.

There are some factors that have been associated with elevated dementia risk, including:

- Age – The older a person gets, the higher the risk for developing dementia.
- Family history – A person with a first degree relative (parent or sibling) who has dementia has a higher risk.
- Genetics – Scientists are working to further understand the role of genetics in dementia. Certain genes have been associated with a higher risk of AD and other progressive dementias, but their presence does not guarantee that a person will develop a given disease. “Causal” genes, or genes that are directly responsible for a person developing AD, are extremely rare and account for about 1% of all AD cases.
- Race/ethnicity – Latinos and African Americans are at a higher risk due, in general, to their increased risk for other factors such as diabetes and hypertension.
- Head trauma – Concussions and other head injuries can increase risk.
- Heart and vascular health – Blood pressure problems, diabetes, high LDL cholesterol, and obesity, in addition to factors such as alcohol abuse and smoking cigarettes, may be associated with an increased risk of developing dementia. **This is an area where people can make lifestyle choices that lead to a healthier brain.** What is good for the heart is good for the brain, and vice versa. Exercise, a balanced diet, and smoking cessation all may play a role in decreasing risk.

How Does Dementia Affect The Brain?

The brain is an extremely complex organ which controls all aspects of how we function and interact with our world. There are specific areas of the brain responsible for different, highly specialized tasks: one part processes language, another part regulates emotion, another part is responsible for vision, for hearing, for balance, for impulse control, and so on. The **neurons**, or nerve cells, in each of these areas constantly communicate with each other via connections called **synapses** in order for us to accomplish even the most basic tasks. When the cells and synapses become damaged by disease, they can no longer do their

jobs properly. Basic tasks can become difficult, familiar environments can seem strange and disorienting, and abstract concepts can become challenging to understand. Logic and reason are no longer effective tools for communication.

The location of the brain damage, whether due to injury or disease, will indicate which symptoms appear first. Then other areas of the brain are affected as the disease progresses. In AD, the damage generally begins in an area of the brain called the hippocampus, where short-term memories are processed. However, long-term memories are stored in an entirely different area of the brain. This is why we often see a person with AD who cannot remember what he had for breakfast, but can recall events from fifty years ago with great clarity. Similarly, he may have language difficulties that result in trouble finding a specific word (“salmon”), but may be able to describe it instead (“the pink fish”).

Symptoms of dementia can fluctuate, which is why it is often described as a “come and go” disease. This can be particularly frustrating to caregivers, who may interpret the fluctuating symptoms as evidence that the person with dementia could do better if he just focused more or tried harder. In reality, the person with dementia is often doing the absolute best he can with the damaged neurons and synapses available in his brain.

We often associate dementia with memory loss, but there are many other cognitive functions that are also affected. There are changes in a person’s ability to use logic and reason, to solve problems, and to exercise good judgment. Changes in abstract thinking can make it difficult for him to understand time, dates on a calendar, or maps. Caregivers can adapt to these changes by understanding that the person with dementia is now experiencing a different reality, and adapting the way they respond accordingly. Some experts call this “the new normal,” and it is no small task for caregivers to learn how to navigate these changes. It takes time.

Grief, and even anger, over a family member’s cognitive losses are normal reactions for caregivers. Caregiver support, education, and self-care are crucial in dealing with these emotions and developing a new vision of the relationship and the future with this person.

As the saying goes, if you have seen one person with dementia, you have seen just that: one person. Everyone is

unique in terms of the rate of disease progression and the way that symptoms manifest. Each person is still a person and should be treated with dignity and respect, building on remaining strengths and making accommodations for deficits. **Throughout the progression of dementia people often retain certain abilities, including:**

- Feeling and expressing emotion
- Emotional intelligence (“reading” the emotional content of an interaction rather than relying on verbal content)
- Understanding concrete meaning (as opposed to abstract)
- Understanding and using body language
- Appreciation of art and music



What Are The First Signs of Alzheimer's Disease?

Mild forgetfulness can be a normal part of the aging process. But when memory problems begin to seriously affect daily life, they could be early signs of Alzheimer's disease or another dementia.

Here are some of the early warning signs:

- ✓ Memory loss that disrupts daily life
- ✓ Difficulty planning or solving problems
- ✓ Forgetting how to do familiar tasks
- ✓ Confusion with dates, time or place
- ✓ Trouble with spatial relationships
- ✓ New problems with words in speaking or writing
- ✓ Misplacing objects and the inability to retrace steps
- ✓ Altered decision making; poor judgment or relying on someone else, such as a spouse to make decisions or answer questions
- ✓ Withdrawal from work or social situations; difficulty initiating activities and participating in social interactions
- ✓ Mood swings and changes in personality

What Are The Stages Of Dementia?

Dementia is a progressive condition that worsens over time, usually with an early, middle, and late stage. It is considered to be a terminal condition because if someone lives long enough with dementia, the brain will no longer support essential body functions. It is important to note, again, that each person with dementia is unique and may demonstrate different symptoms. Symptoms progress at a different rate with each person. Persons with dementia do not suddenly become someone else. They still retain the same likes, dislikes, and many of the same personality traits that they had before the disease.

What follows is a typical progression of the stages of Alzheimer's disease, but is certainly not the only way that symptoms may progress with all dementias. Stages often overlap, and symptoms may fluctuate from day to day, week to week, or month to month. **The goal for each stage of the disease should be to maximize the person's quality of life.**

Early Stage (Mild)

- Short-term memory loss
- Getting disoriented in familiar places
- Confusion regarding time (arriving too early, too late)
- Loss of initiative
- Trouble handling money/paying bills
- Poor judgment
- Problems using language
- Difficulty learning new things
- Difficulty completing routine tasks
- **Caregiving focus is on enabling the person to remain as INDEPENDENT as possible.**

Middle Stage (Moderate)

- Short-term memory loss with some loss of long-term memory
- Slowed speech and comprehension
- Impaired ability to use logic and reason
- Disorientation to time
- Restlessness and/or pacing
- Bladder incontinence
- Hallucinations and/or delusions
- Mood swings
- Sensory changes (visual, auditory, tactile)
- Sundowning (agitation and/or disorientation increases near the end of the day)
- Making up stories to fill in gaps (confabulation)
- Loss of impulse control; disinhibition
- Fine motor skill impairment
- Wandering and getting lost – unsafe to leave alone
- Verbal repetition
- **Caregiving focus is on maintaining the person's SAFETY.**

Late Stage (Severe)

- Unable to walk independently
- Vocabulary limited or lost
- Swallowing/eating problems; weight loss
- Bladder and bowel incontinence
- Severe memory loss
- Appearing to be disconnected from environment
- Needing complete & total care
- **Caregiving focus is on providing COMFORT.**

Keep In Mind

Throughout the stages of dementia, people need help not only with basics like paying bills, remembering appointments, managing medications, and maintaining personal hygiene, but also with supporting who they are as human beings. This includes larger issues of

dignity, honoring preference, and engagement in meaningful activities. We will address strategies for meeting these needs and tools for effective communication in the next section.

Communication: A Moving Target

Changes in the brain of a person with dementia (PWD) will naturally change the way she communicates with other people and interacts with her environment. Family caregivers often express frustration with navigating these changes, not to mention coping with the emotional toll of losing the ability to communicate with their family member in the same way as before.

A PWD may not be able to articulate exactly what she wants to say, which can be frustrating and embarrassing for her. Words and thoughts may become jumbled. She may say the “wrong” thing in a social setting. She may not be able to complete familiar tasks, or learn how to use new technology. She may withdraw from activities that she used to enjoy. She may not understand what she is supposed to do in a given situation. She also may not be able to articulate pain or discomfort in words.

In dealing with other illnesses, our expectation is often to “fix” the problem. In dealing with progressive dementia, the

problem cannot be “fixed”, but the caregiver can learn to adapt in ways that enhance the caregiving relationship and the PWD’s quality of life. People with dementia are doing the best they can. **It is unrealistic to expect the PWD to change; the caregiver is the one whose behavior and communication must change.** This shift in expectations can take some time, and caregivers often need significant support in order to release attachment to previous patterns of communication and “go with the flow.”

Remember that every PWD is unique in terms of personality, personal history, and preferences, in addition to having different needs and abilities in early, middle, and late stages of the illness. There is no “one-size-fits-all” approach. The suggestions below are intended to be guidelines to help caregivers communicate more effectively, maintain the PWD’s dignity, and enhance the caregiver/PWD relationship.

Early Stage Communication

In early stage dementia, a person’s communication patterns may begin to change, but most changes may initially only be noticeable to family members, coworkers, or others who spend a lot of time with the PWD. There are some rare forms of dementia in which language is severely affected early in the illness (e.g., Primary Progressive Aphasia) but most early stage individuals are still able to articulate their needs and participate in a conversation. Some changes may include:

- Not initiating conversation as much as before
- Difficulty with word-finding (use caution before you jump in to complete a sentence for her. The PWD may merely need some extra time to find the word she wants to say)
- Becoming frustrated and stressed more easily
- Having a shorter attention span

The PWD often begins to withdraw socially and can benefit from attending a senior center or special early stage program, participating in cultural activities, or finding volunteer work that is appropriate for her level of ability. **Activities should feel as “normal” as possible, supporting the person’s self-esteem and independence.**

An early stage PWD may rely on written reminders to manage the day. Calendars and Post-it® notes can be helpful tools in remembering appointments, keeping track of medication, preparing for holidays, etc. The PWD can often travel independently by carrying a written note with the address and directions to her destination. Medication management can be simplified with pill organizers. Telephones can be easier to use if the buttons are big. Books may be easier to read if the print is large. All of these adaptations can help the early stage PWD succeed at familiar tasks.

Middle Stage Communication

What's My Cue?

Just like a politician reading a teleprompter in order to know what to say, a PWD in middle stage is constantly looking for cues in the environment in order to know what to say or do. **A cue is a hint, or reminder, that provides extra information for the PWD to help her communicate or accomplish a task.** Cues often use sensory input (sight, hearing, smell, touch, or taste) in addition to words in order to give the brain alternate ways to access the information.

Sometimes caregivers fear that if they give the PWD too much “help”, she will become dependent on that help and thus more impaired. This is not the case. Caregivers are often tempted to quiz or test the PWD: “What did you have for breakfast? What are the names of your children? Show me how you button a shirt.” If the PWD doesn’t know the answers to these questions or does not do a task correctly, she may feel she has failed. **Feelings of frustration may even show up as agitation or anger.** Accomplishing tasks, even simple tasks, can boost the PWD’s self-esteem and mood, and actually help to preserve remaining abilities.

Visual Cues

Recall the old expression, “out of sight, out of mind.” Conversely, if something is in sight it is often in mind. If we want the PWD to find the bathroom in the middle of the night, we leave the light on so she can see it. If we don’t want her to eat cake, we don’t leave it out on the counter. If she has trouble remembering to eat, we leave snacks out in the middle of the table or some other place in full view.

It also can be helpful to think of visual cues provided by color and pattern. **The PWD is more likely to notice something that is a contrasting color from the background** – a white plate on a red tablecloth, for example. Pattern can become a distraction in the form of busy wallpaper or a checkered floor, or it can be a helpful indicator of where to look for an object, like a toothbrush in a brightly patterned cup.

Verbal Cues

Spoken instructions can help a PWD to complete a task, but we also need to remember to consider the effect of an impaired short-term memory. To accommodate this, caregivers should give directions one step at a time. Verbal messages should follow the three S’s:

Slow Simple Specific

Too much verbal information can actually make it harder for the person to understand and respond appropriately.

Written Cues

Depending on the PWD’s level of functioning, she still may be able to respond to written reminders and directions. For example, she may be able to use a coffee machine if the steps are written on a sign beside the coffee maker. Written cues should be simple and to the point. Choose the words carefully. **A written cue should be in large print and in a contrasting color that stands out from the background.**

By middle stage, the PWD may not be able to grasp the abstract concept of a calendar. Calendars may even create anxiety because they make the PWD anticipate an event that will happen in the future. Instead of calendars, many families have had success keeping a dry-erase board in a central location of the house that provides simple, written cues: “Today is Tuesday. Dentist appointment at 11:00. Clara will be home at 5:00. Lunch is on the table.”

Tactile (Touch) Cues

Words are not the only way to get a message across. Touch can be a powerful tool, both in accomplishing physical tasks and in conveying emotion. For example, in assisting a PWD putting on a jacket, the words “lift your right arm” may be accompanied by a light touch on the right arm. This gives extra information to the brain and may help the PWD follow the instructions better. **If the person likes to hug or hold hands, this is a pure expression of affection that needs no words to be understood.**

Environmental Cues

Our physical environment naturally provides all kinds of cues. A PWD may just need those cues to be enhanced or exaggerated in some way. She may not recognize that she is hungry until she sees people eating, or smells food cooking, or hears the clinking of a fork against a plate. She may not want to shower until she hears the water running and feels the warm steam on her skin. (The next issue of this guide will include a more in-depth discussion of bathing.) Pictures in the environment may be effective guide posts (a picture of a toilet on the bathroom door, rather than the word “restroom”). **Demonstration – showing a person what to do rather than telling her – can also be a useful tool.**

Distraction in the environment can be a barrier to effective communication. The PWD's brain can't always filter out that construction noise from the street outside, or that busy visual pattern of vines and leaves on the curtains. These things can keep her from focusing on what is being said, or even make her agitated.

Mirror, Mirror On The Wall

Caregivers have no control over the PWD's behavior and emotions, but they do have control over their own behavior and emotions. **Just like looking in a mirror, a PWD will often reflect back the emotion of an interaction.**

If the caregiver comes into a situation nervous and stressed out, it's very likely that the PWD will also be nervous and stressed out. If the caregiver can enter calmly, the PWD will often reflect that, as well.

Just because the PWD has trouble with emotional regulation and language does not mean that she cannot recognize, and send, emotional messages. She can. Some call this retained ability "emotional intelligence." Remember that tone of voice and body language can also convey emotional state, perhaps even more so than words.

Providing Choice (But Not Too Much!)

As dementia progresses, the PWD loses control over many aspects of her former life. Normal, adult responsibilities like paying bills, driving, managing medications, and decision-making are slowly taken over by the caregiver. **By providing the PWD with choice, we can give her some control over what happens to her and boost her self-esteem.**

Unlimited choice, however, can be overwhelming. For example, asking a PWD, "What do you want to wear today?" is a very complex question with many variables. Instead, offer some choice by presenting two or three different options that are appropriate for the weather outside and the type of event you are attending. If it is lunchtime, and you know the PWD did not eat breakfast and must be hungry, avoid asking, "Are you ready to have lunch?" and instead ask, "Do you want tuna or chicken for lunch?" This still

provides some choice and control, but does not leave the question of whether or not to have lunch open for debate. If a PWD has limited verbal ability, she still may be able to choose between one item and another by pointing to the preferred item.

Forget Logic

Usually by the middle stage, the ability to use logic and reason becomes noticeably impaired. This often leads to arguments between the PWD and caregiver, who may try to make the PWD understand something by using a logical explanation. Logic is the ability to reason that IF one thing is true, THEN another thing must be true: *IF there are crusts of a sandwich on a plate in front of me, THEN I must have just eaten.* The PWD may be incapable of following this line of reasoning and may be offended and angry if the caregiver contradicts her version of reality.

The PWD in middle stage may also have limited awareness of her own cognitive condition. The dementia takes away her ability to understand that she has dementia. So when a caregiver uses the argument: "Remember Mom, you have dementia! I'm trying to HELP you!" the PWD may react negatively because 1) she is not aware of her own limitations, and 2) she is not able to understand the logical consequences of those limitations.

So if we can't use logic, what can we do? We can:

- Listen and affirm emotional messages
- Validate the PWD's feelings
- Adapt the physical environment for her safety and well-being
- Distract the PWD and engage her in meaningful activity
- Use appropriate humor to dissolve tension and connect with the PWD

These techniques take practice and focused problem-solving on the part of the caregiver. The main thing to remember is that **the caregiver is the one responsible for changing or adapting the approach. The PWD is not able to change.**



To Fib Or Not To Fib?

Family caregivers are often understandably uncomfortable about “stretching the truth,” or lying to the PWD. Caregivers may think that fibbing is undignified, or disrespectful. However, **sometimes telling a fib is the MOST**

respectful and appropriate thing a caregiver

can do. For example, if the PWD continually asks about a relative who has passed away, and if every time she is informed about the death she grieves it as intensely as if it's the first time she heard the news, perhaps the most compassionate thing to do is to make up a gentle fib: “Where is Paul?” “You know, I haven't heard from him in awhile. I've always loved his beautiful baritone singing voice.”

There may be times when a fib is a good tool to get the PWD to comply with decisions that affect her safety. This is called a “blame-a-third-

party” fib. Usually the third party is someone with higher authority than the caregiver: a doctor, a rabbi or priest, a lawyer, the insurance company, etc. Using this approach means the caregiver does not have to take the blame for delivering unpleasant news, such as the need to stop driving. The caregiver can say: “If it were up to me, you could drive, but the doctor said you have to stop. Here's a prescription from the doctor that says ‘stop driving.’ Don't worry – I'll still take you wherever you want to go.”

A word of caution about fibs: due to the come-and-go nature of dementia, and the fact that some parts of the brain are working better than others, **caregivers cannot rely on lies to get the PWD to comply with everything.** If the PWD refuses to go to the doctor, it's unwise to try to trick her by inviting her out to lunch and then bringing her to the doctor's office instead. This could be traumatic for the PWD, and the emotional memory of that trauma could manifest as mistrust and anger at the caregiver.

Reality Is Relative

The PWD is now living in a different reality, which may shift from hour to hour or day to day. **The disease process in the brain has affected the way the PWD sees and understands the world.** The brain is giving the wrong information, or maybe it is giving the correct information but in the wrong order. Arguing with a PWD about something that

she perceives as reality will often be a frustrating, no-win situation for both parties. The PWD's reality may be set further back in her personal past, so she may not recognize “that old person” in the mirror as herself. She may not recognize an adult grandchild because in her past-centered reality, the grandchild is still a toddler.

Some caregivers are concerned that the PWD “makes up stories” about events that are not factual. This is due to a phenomenon known as confabulation. When the brain encounters a gap in the information it is attempting to find, it may automatically, and unconsciously, try to fill in that gap with other information.

Stories from the past may get stuck together in odd ways that do not reflect the way things actually happened. It is important for the caregiver to remember that this is not purposeful or manipulative, but simply a way the brain is adapting to tasks and memories that it is unable to fully recall.

Sometimes a PWD will experience hallucinations (the PWD sees, hears, smells, tastes, or feels something that is not there) or delusions (the PWD has fixed beliefs that are not true). Neither hallucinations nor delusions can be argued or reasoned away. Instead, caregivers can find ways to validate the PWD's feelings when she is in an altered state of reality. Try to identify the underlying emotions (often fear or anxiety) rather than just the verbal message, which may seem bizarre or difficult to understand. Try responding with empathy: “I can see that this is really important to you. I'm here to listen,” or, “It seems like you're feeling really anxious. I'm so sorry you don't feel safe.”

A common delusion is a PWD's belief that the place in which she lives is not her home. Affirming the emotional message or piece of personal history at the heart of the delusion is a good way to respond. If the PWD is saying repeatedly, “I want to go home,” despite being in her home of thirty years, she may be expressing discomfort, disorientation, or fear of surroundings that do not appear familiar or comforting. She may also be referring to her childhood home. Try listening to her concerns, reassuring her that she is safe, and asking her questions about “home.”

Once the PWD is reassured, redirect her by changing the physical environment. Simply going together into a different



room can help her to change focus. Then introduce an activity, such as watering plants or making a cup of coffee.

If At First You Don't Succeed...

Try, try again! **Repeating is often necessary and effective, if it is done with patience and without condescension.** In frustrating interactions, caregivers can develop a sense of when to leave the room and come back in a few minutes later to try again. There is also much value in silence. A few minutes without talking can give the PWD's brain the opportunity to process and respond to a question or request.

Caregivers can be very hard on themselves when they are impatient with the PWD. It's only human to respond this way in frustrating situations. Let yourself off the hook and don't beat yourself up. Just take a deep breath and resolve to make a fresh start the next time.

Meaningful Activities

The art of distraction and redirection is an important one for a caregiver to master. Forgetfulness is a major symptom of dementia, so the most carefully chosen words may only have the desired effect for a few minutes. We cannot expect the PWD to remember that we just had a conversation (or ten conversations!) about going to the doctor on Thursday, so in order to get her to focus on something else we have to engage her in an activity. **The more the activity is in line with her personal preferences and appropriate to the PWD's level of functioning, the more likely it is that she will engage with it and enjoy it.** It can be as simple as reading a newspaper, listening to music, or going for a walk.

It is important not to "infantilize" a PWD, meaning to treat her like a child. The PWD may perceive an activity being offered as too childlike or simple. The caregiver can then offer the activity in a less direct way: "Look what I found," or, "Can you help me do this?" If the PWD can feel that she is helping the caregiver, it can have a positive effect on her self-esteem.

The PWD will not be likely to initiate an activity, but some gentle encouragement from the caregiver accompanied by



a simple, failure-free activity can yield a positive result. She may be drawn to creative activities like painting and collage, or even looking at works of art or photographs. A PWD in middle stage can often be successful at activities that involve stacking or sorting items, or that utilize repetitive motion. Some additional ideas for activities can be found online at the Alzheimer's Store: www.alzstore.com.

Caregivers can also explore options for activities outside the home. Social opportunities are important, as long as they are not too overwhelming for the PWD. CaringKind is partnered with multiple cultural institutions and museums throughout NYC that offer specialized programs for people with dementia and their caregivers.

Visit our website, www.caringkindnyc.org/connect2culture, or call our 24-hour Helpline at 646-744-2900 for more information.

Late Stage Communication

In the late stage of dementia, most people have limited ability to communicate with words. **Caregivers must adapt both verbal and non-verbal communication to provide the PWD with a sense of comfort and connection.** The PWD may respond to gentle touch, to music that she enjoyed as a young person, and to a warm and loving tone of voice. If the PWD was always religious, she may be comforted by hearing familiar prayers or religious songs.

When approaching someone with late stage dementia, caregivers should speak slowly and clearly, use the PWD's name, and identify themselves by name as well. Remember to approach the PWD from the front so as not to startle her, use eye contact, smile, and go slow. Sensory stimulation such as smell, color, and textures may help her connect with the environment. Give her safe and soothing objects to touch and manipulate. If she is in a wheelchair or on a bed, get down on her level, either by kneeling or sitting in a chair. Hold her hand, if she likes it.

We never know how much language the PWD understands, so try to assume that she does understand what is being said. **Avoid talking about the PWD in front of the PWD. Try talking to her instead.** Tell her about your day, reminisce about the old days, even if the conversation

is one-sided. Read to her. If you need to have a conversation with a doctor, family member, or professional caregiver about something that might upset or embarrass the PWD, then take the time to leave the room for a moment to preserve her dignity and avoid agitation.

No One Can Do This Alone

As dementia progresses, caregivers will need to rely on a network of family, friends, and professionals for support.

Caregivers need to be able to communicate their own needs and to ask for help when needed.

The fourth section of this guide will discuss caregiver support in more detail and provide ideas for self-care. As always, CaringKind's free, 24-hour Helpline is available to provide caregivers with information and support at 646-744-2900.

For further reading

If this guide has been helpful to you, you may be interested in learning more about the work of experts in this field. The names below can be typed into an Internet search engine, or your local library may be a resource for related books and publications. In addition, a list of recommended reading can be obtained by calling the 24-hour at Helpline 646-744-2900.

- Teepa Snow (communication)
- Naomi Feil (validation therapy)
- John Zeisel & ARTZ (arts & cultural activities)
- Cameron Camp (Montessori-based activities)
- Michelle Bourgeois (memory books and cues)



Behaviors Have Meaning

What Is A "Behavior"?

Professionals in the dementia care field use the term "behavior" to describe things that a person with dementia (PWD) does and says which may be unpredictable, bizarre, or perhaps even dangerous. Dementia-related behaviors may be different from how the person behaved in the past, or they may be an exaggeration of past behaviors or personality traits. They may be externally focused (agitation or anger) or internally focused (apathy or depression). They may be normal behaviors (getting undressed) in an abnormal context (getting undressed in a public place due to disorientation). The important message for caregivers is that regardless of dementia, all behavior is essentially human behavior.

There is nearly always some kernel of emotional truth or normalcy that can help the caregiver understand why the behavior may be occurring, and then develop an appropriate intervention if necessary. This takes practice, and plenty of trial and error. The caregiver becomes a behavior detective, with the ultimate goal of alleviating the PWD's emotional and physical distress and enhancing his quality of life. This is often accomplished through the caregiver's flexibility, creativity, and ability to engage the PWD in a safe and meaningful activity. Behaviors tend to be most pronounced in the middle stage of dementia, but some people exhibit

behavioral symptoms early. Not every PWD develops extreme behavioral disturbances. There is no way to tell what lies ahead for each individual. As the saying goes, if you have seen one person with dementia, you have seen just that: one person. There is no "one size fits all" approach.

Because each PWD and situation is unique, caregivers should learn how to problem-solve behaviors as they arise. Five steps of effective problem-solving are:

1. Describe the behavior.
2. Identify potential causes.
3. Determine if intervention is necessary.
4. Identify and implement interventions or strategies to alter the behavior.
5. Afterwards, evaluate what worked and what did not. This problem-solving model is loosely based on the excellent work of Teepa Snow, an occupational therapist and dementia care expert.

Learn more at www.teepasnow.com.

Step 1: Describe The Behavior In Objective Terms.

Behavior has meaning, and it is the caregiver's job to figure out that meaning and respond appropriately. Often, behavior is the PWD's attempt to communicate an unmet need. Some dementia-related behaviors can include:

- Hallucinations
- Delusions/paranoia
- Insomnia
- Wandering
- Hoarding/collecting
- Repetitive questions
- Agitation or aggression
- Sundowning (agitation or confusion that gets worse in the late afternoon/early evening)

It is helpful for the caregiver to keep a journal of the PWD's daily behavior in order to look for patterns. **Make a note of WHAT happens, WHEN it happens, and WHO is present when it happens.** Also note if anything happens before the behavior occurs, as this may be a behavioral "trigger" to be avoided.

It's important to be objective about the details and not jump to subjective conclusions, as in: "He takes forever to get dressed because he wants me to be late for work." The PWD's slowness in getting dressed is likely due to a variety of internal and external factors, none of which is an intention to manipulate or spite the caregiver. Caregivers should try not to take behaviors personally.

Step 2: Brainstorm Potential Causes Of The Behavior.

Internal (physiological or emotional) causes could include:

- Pain/discomfort
- Dehydration or constipation
- Hunger or thirst
- Fatigue
- Medication side effects
- Caffeine side effects – can contribute to sleep problems
- Infections – urinary tract infections (UTIs) are a common cause of cognitive symptoms
- Depression
- Anxiety/fear
- Embarrassment
- Boredom
- Frustration

External (environmental or task-related) causes could include:

- Temperature – too hot or too cold
- Lighting
- Noise
- Clutter
- Overstimulation
- Unfamiliar surroundings
- Size of the space – too big or too small
- Time of day
- Mirrors – the PWD may not recognize his own reflection and think a stranger is watching him
- Difficulty with sequencing of tasks
- Personal care tasks being forced by a caregiver

Step 3: Is Intervention Necessary?

SO WHAT? ←————→ SAFETY RISK

Not every dementia-related behavior needs to be changed. Sometimes intervention is not worth the caregiver's time and energy. Each situation is unique. Use your best judgment to determine whether an intervention is needed, and develop a "trial and error" mindset.

It's helpful to think of behaviors as falling along a spectrum. At one end of the spectrum are what Teepa Snow calls "so what?" behaviors (e.g., wearing mismatched socks), and at the other end are immediate safety risk behaviors (e.g., touching a hot stove). Most behaviors tend to fall somewhere in between these two extremes.

Identifying "so what?" behaviors can help caregivers to let go of the need to control or change all of the PWD's behavioral changes. Some refer to this as "knowing when to pick your battles," or "not sweating the small stuff." Caregivers who have learned to let things go often report a decrease in stress levels and an increase in positive interactions with the PWD. "So what?" behaviors may seem bizarre, or mildly annoying, but they ultimately do not put anyone's safety or quality of life at risk.

By evaluating how close the behavior is to an immediate safety risk, you can get a sense of how important it is to do something to change it. Just because the behavior isn't

harmful doesn't mean that you shouldn't intervene, but the sense of urgency is different. For example, repetitive questions are not a safety risk but can certainly affect the caregiver's quality of life, and might convey some kind of anxiety or other emotional need on the part of the PWD.

The context of the behavior should also be taken into account when determining if intervention is necessary. For example, if the PWD has a hallucination of seeing his mother and he relates it as a pleasant experience, then intervention is not needed. If he has the same

hallucination and becomes agitated or angry, or begins to throw objects at the person who is not there, then an intervention should be considered. **Remember, both hallucinations and delusions represent the PWD's version of reality and cannot be altered by arguing or using logic and reason. In other words, telling him that there's no one there is not going to help the hallucination go away, and may result in even more agitation.**

Step 4: What Interventions Or Strategies Might Work?

If you have determined that an intervention is necessary to address the behavior, the next step is to figure out which strategies to try. Notice that the words of choice here are "interventions" and "strategies," NOT "solutions." There is no way to completely avoid behaviors, which are a normal part of the progression of dementia. There are only ways for the caregiver to adapt that may make the behavior less dangerous or disruptive. The caregiver only has control over her own behavior and (to some extent) the physical environment. There is no control over the disease process occurring in the PWD's brain and the resulting communication and behavior changes.

Here are some possible strategies to try:

- Identify and avoid triggers.
- Slow down (speech and actions).
- Increase use of cues (visual, verbal, tactile, written, and/or environmental).
- Decrease distractions and noise in the environment.
- Anticipate and address physical needs (pain, hunger, thirst).
- Affirm emotional messages (fear, anxiety).
- Reassure and provide comfort.
- Listen and convey sincere empathy.
- Provide choice when possible.
- Establish a routine.
- Distract and redirect.
- Engage the PWD in meaningful activities.

- Increase pleasant experiences (eating chocolate, petting an animal, listening to music, massage, looking at art, making art, looking at family photos, etc.).
- Use relaxation techniques.
- Adapt tasks to the PWD's level of ability.

It is important for caregivers to know the PWD's history, including family, employment, and personal preferences. Was the PWD always a "night owl?" Did he prefer to take a bath or a shower? Was he in the military? Who are the people important to him? Family members usually have the advantage of knowing these things already, and they can and should share this information with professional caregivers. Do not assume that nurses or home health aides have been informed ahead of time about the PWD's history. Provide a brief, written synopsis for them so they in turn can provide personalized care for the PWD that honors his history and preferences.

If multiple strategies to alter a behavior have been implemented but the behavior persists, AND if the behavior puts the PWD or someone else at risk of harm, then prescription medications to alter the behavior may be appropriate. Physicians can prescribe psychotropic drugs to treat behavioral symptoms of dementia. Caregivers should always discuss treatment with the physician in detail, and carefully weigh the potential benefits of taking the medication against the risk of harmful side effects. **ALWAYS explore non-pharmacological interventions first (music, changes to the environment, etc.) before pharmacological (drug) interventions.**

Step 5: Evaluation

Caregivers often ask, “What is the *right* way to do this?” and “Did I do this *wrong* by doing it this way?” The answer lies in the outcome: if the PWD becomes more agitated or withdrawn, then try a different intervention the next time. If the PWD is more content and engaged with his environment, or if a task is accomplished more successfully, then make a note to try that intervention again. It can be helpful to keep a behavior journal to keep track of effective (and ineffective) interventions.

Due to the nature of dementia as a progressive and ever-changing illness, what “works” one day may not work the next, and vice versa. **The more tools the caregiver has on-hand to deal with behaviors as they arise, the better.**

Activities Of Daily Living (ADL)

As mentioned previously, even simple daily activities may become difficult for a PWD to safely and effectively accomplish on his own. The PWD will eventually need help with his Activities of Daily Living (ADLs), which can result in challenging behavior. **Sometimes the PWD does not understand the help being provided, or may not think that he needs help at all.** What follows are some ADLs that may become more challenging as dementia progresses, and some strategies for coping with the changes.

Bathing

Questions to Consider

- 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 undress himself, bathe, or wash his own 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 particular time of day?
- Is the sound of the water frightening to him?
- Is the shower nozzle spraying water in the PWD’s face?
- If the PWD is still capable of washing himself, does he know which products to use in the shower for which task (e.g., shampoo, shaving cream, mouthwash)? Does he know how to set the water to an appropriate temperature?

Coping Strategies

- Install grab bars inside the shower.
- Use a bathtub transfer bench or shower chair inside the bathtub.
- Use a handheld shower head to avoid water spraying in the PWD’s face.
- Place temperature controls on the hot water valve to prevent scalding.
- Remove locks on bathroom doors.
- Utilize non-skid bath mats, and cover the radiators.
- Make bath time an enjoyable experience. Give the PWD a plush bathrobe, and try aromatherapy using scents he enjoys. Play music the PWD appreciates.
- Schedule bathing when the PWD is relaxed and not fatigued.
- If the PWD is uncomfortable being fully exposed, buy a cape or cut a hole in a shower curtain and place it over the PWD. Wash him 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 his emotions and provide reassurance.
- Wash the least frightening parts of the body first (hands and feet).
- Save hair washing for last so the person does not get cold.
- Try no-rinse soap and shampoo.
- If the PWD is still able to bathe himself, start the shower water running or draw the bath for him. Put out only the bath products he will need, right where he can see them. Cover the knobs with a washcloth to decrease the chance that he will adjust the water temperature and make it too hot or too cold.

Eating

Questions to Consider

- Does the PWD have cataracts, which could affect his ability to clearly see what he is 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 affected by dementia?
- Is the task of eating too complex? Is there difficulty using utensils?
- Is the PWD eating with others or alone?
- Is the TV on during mealtime?
- Does the PWD like the food being offered? Do meals look appetizing?
- Is the dining area cluttered? Do the dishes have busy patterns on them?
- If you are eating in a restaurant, are there too many options on the menu? Are you eating there during peak dining hours?



- Eat meals together so that you can show the PWD how to eat by example. If he says he isn't hungry, prepare something for yourself that smells good, and give him half "so it won't go to waste."
- If the PWD responds well to sweet tastes, try putting cinnamon or a sweetener on savory foods. Prepare meals he usually enjoys, or foods that remind him positively of his childhood.
- Ask the PWD to help you prepare the meal. Give him a simple task at which he can succeed, like tearing up lettuce for a salad or chopping vegetables, if he can safely use a knife. Show him what to do instead of telling him.
- Eat out at off-hours when restaurants may be less congested. Provide suggestions from the menu or a choice of two items: "You usually like either the chicken or the ravioli."

Sleeping

Questions to Consider

- Does the PWD have a routine?
- Does the PWD drink caffeinated beverages?
- Does the PWD drink a lot of fluids prior to bedtime and therefore need to use the bathroom throughout the night? Is he on medications that cause him to urinate more, or that make him sleepy during the day?
- Does the PWD have day-night reversal?
- Is the PWD experiencing pain?
- Is the PWD bored or depressed?
- Is the PWD involved in any activities during the day?
- Could 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 his preference) and eat at the same time.
- Eliminate caffeinated beverages and limit fluids around bedtime.

Coping Strategies

- Address any other medical conditions with a doctor.
- Have a dental evaluation and readjust or refit dentures as needed.
- Be aware of your home environment. Place chairs across from each other to encourage eye contact, 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 his own. Provide finger foods if necessary.
- Thick, heavy cutlery may accommodate for impaired fine motor skills. A plate with a high lip on it can prevent food from spilling off the plate onto the table.
- Present one type of food at a time (first the salad, then the chicken, then the potatoes).

- Check with the PWD's doctor about medications and medication interactions. Could the PWD take a different dosage of medication or take it at a different time of day?
- If a PWD is awake for days and unable to sleep, consult the doctor. You need your sleep and so does he.
- Consider an overnight social program that runs from the evening through the morning, or hire a home health aide who will stay awake for the overnight hours.
- Keeping the person active and engaged during the day may help him to sleep better at night. Traditional social day programs provide the PWD with social interaction and activities.
- Place a commode in the bedroom in a place that is easily accessible and not a safety hazard.
- Utilize comfortable incontinence undergarments. Some products resemble underwear, not diapers. Place the incontinence undergarments in the underwear drawer as if they were regular underwear.
- Purchase protective mattress pads.
- Respectfully suggest the PWD use the bathroom prior to a long car ride or outing.
- Implement a toileting schedule, prompting the PWD to go to the bathroom every couple of hours.
- Choose clothing that is easy to pull down quickly and safely: elastic waistbands, no buttons, no pantyhose.

Incontinence

Questions to Consider

- 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 incontinence and unable to accept that he needs protective undergarments?
- Is the PWD not recognizing the urge to go to the bathroom?
- Is the PWD recognizing the urge to go but not able to get there in time?
- Are impaired fine motor skills making belts, zippers, or buttons more difficult to manage?

Coping Strategies

- Use visual cues: 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 a contrasting color from the rest of the bathroom or use a product that turns the toilet water blue so it is more visible.
- If the PWD's health takes a dramatic downward turn, contact his physician to determine if there is a UTI or other medical issue.
- If the PWD becomes suddenly incontinent, contact his physician to discuss possible medications side effects and interactions.

Other Safety Considerations

The PWD's living environment should be structured as much as possible with safety in mind. Small area rugs on the floor and low tables in the middle of a room may put the PWD at risk for falls. Stacks of newspapers or books on the floor are also a hazard. If the PWD tries to use the stove and is unable to do so safely, consider disabling the stove or removing the knobs. Even small appliances like coffee pots, microwaves, or toaster ovens can start fires if used incorrectly. Make sure that all prescription and over-the-counter medications are kept out of reach to avoid accidental overdose.

Wandering can be extremely dangerous for a PWD. Sixty percent of people with dementia will wander, and we don't know to whom or when it will happen. As a preventative safety measure, enroll the PWD in the MedicAlert® NYC Wanderer's Safety Program by calling 646-744-2900, or on our website at www.caringkindnyc.org/wandersafety. CaringKind staff can help you with strategies to encourage the PWD to wear the bracelet.

If the PWD has a history of wandering, remove visual cues that might stimulate the urge to go outside. Try placing a drapery over the door, or painting the door the same color as the walls around it. If the PWD doesn't notice the door, he may not feel the need to leave. Also remove "going-out" items like keys and coats from his sightline. Provide a safe wandering path inside the home, and take the PWD for regular walks outdoors. Consider that the PWD may be bored and may need more structured activity to keep him engaged.

Do not lock the person in from the outside, as this would prevent him from leaving during an emergency. Consider installing a bell that rings when the door opens to alert the caregiver that the PWD is trying to leave. When going out in public together, the caregiver should carry a recent picture of the PWD, in case he becomes lost. Dressing the PWD in a brightly colored shirt or hat may also help him to stand out in a crowd.



For further reading

For additional tips and a variety of suggestions for home safety products and activities, call our free, 24-hour Helpline at 646-744-2900. You can also visit these excellent websites:

- This Caring Home:
www.thiscaringhome.org
- The Alzheimer's Store:
www.alzstore.com or 1-800-752-3238

Caring for the Caregiver

Participants in the Family Caregiver Workshop are all caring for family members with dementia, but there is a wide variety of experience. People are dealing with different stages, symptoms, and disease processes. Relationships are varied: a son whose mother with dementia lives in another state; a retired spouse who cares for her husband 24/7; a grandchild who has put her career and personal life on hold to be the primary caregiver for her grandmother. Many are coping with a great deal of added responsibility, frustration, fatigue, and worry. But as actress and singer Lena Horne once said: **“It’s not the load that breaks you down, it’s the way you carry it.”**

While we can’t change the nature of the “load,” or the stresses of dementia caregiving, we can help caregivers learn to carry it more easily. The tools, tips, information, and food for thought that follow are intended to keep you flexible, strong, and capable of carrying your load without being too weighed down by the burden.

Research confirms that caregivers of persons with dementia (PWDs) are at a much higher risk for depression than non-caregivers. Caregivers also often report high levels of stress and psychological strain. Some factors that may contribute to

the emotional roller coaster so many caregivers experience are:

- **The innate unpredictability of the disease.** Never knowing what symptom or behavior will surface from one day to the next along with the inability to control the situation.
- **Fear.** Wondering whether you will have the energy or strength to face the progressive decline of the PWD.
- **The constant shifting** of your relationship with the PWD, of daily responsibilities and roles, 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 are 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.

Know Yourself

Step back for a moment and think about your personality. What kind of caregiver are you and what effect might this have on the way you provide care? Examine who you are: how your personality impacts your caregiving, your sense of burden, your ability to solve problems, and your own health. Do you feel comfortable asking for help? Or do you feel like you have to do everything yourself? Have you chosen this caregiving role or have you been thrust into it? Do you feel like you have to be eternally cheerful? Can you get in touch with your own emotions, even the not-so-pretty ones? **It's normal to feel grief, anger, sadness, frustration, resentment, guilt, and many other feelings.** You are not alone.

Consider Your Relationship With The PWD

Has it historically been a loving relationship or has it been contentious? Does she push your buttons? Do you have a strong attachment to her? All relationships are complicated and dementia further complicates things in the way it affects not only the person with the disease, but everyone involved.

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 Triggers

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 improve both your quality of life and that of the PWD for whom you care.

Try not to immediately react to a stressful situation with anger. Take a breath, observe what is going on, and



then respond in a thoughtful manner. Try to slow your words and actions down. Keep in mind your desired outcome, and evaluate whether your actions and words are likely to achieve that outcome. If you lose your temper, forgive yourself for being human and try again next time. This can be very difficult, and as with any new skill it will require time and practice.

Give Yourself Permission To Care For Yourself

Caregivers often put their needs last on the daily list of things to do. Here are some small things that can make a big difference in the quality of your day and in the way you are able to handle stressful situations:

- **Nourishment** – Make sure you eat and drink enough to maintain your blood sugar levels and energy. Breakfast is truly the most important meal of the day. If your response to stress is to eat too much, try to keep healthy snacks on hand to replace less healthy food items.
- **Sleep** – Try to get at least seven hours of sleep per night. When you're fatigued in the afternoon, try to take a nap.
- **Exercise** – Even if the exercise is as simple as taking a walk around the block, or dancing in your living room, get your blood flowing so your brain and body can get the benefits of movement.
- **Spiritual practice** – Including prayer, meditation, or just sitting and being aware of the breath.
- **Social connection** – Reach out and call a friend, or attend a support group.
- **Physical health** – When was the last time you went to the doctor for yourself? It's important to take care of your own health conditions because stress tends to make these conditions worse.
- **Mental health** – Who can you turn to for emotional support? Putting a lid on unpleasant feelings of anger and guilt will only make them bubble up and boil over at another time. Look for healthy ways of acknowledging and expressing your emotions that are not directed at the PWD.

Educate Yourself And Others

Read books and newsletters, do research online, and talk to other people. 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. There are some excellent books that have been written by authors who have dementia. Reading about the first-hand experience of dementia may give you valuable insight into what the PWD may be experiencing and feeling.

Develop Creative Problem Solving Skills

When caring for a PWD it is essential 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 an argument. Begin to try and accept the disease process and the changes it creates. Step into the PWD's reality, understand her underlying emotional needs, and provide validation. Think outside the box and avoid reverting to reality and facts.

Join A Support Group

Explore your feelings and form connections with others caring for a PWD. CaringKind has nearly 100 groups with trained and experienced group leaders, which meet during the day as well as in the evening. We offer groups throughout the NYC metropolitan area for many different types of caregiving situations including groups for spouses, adult children, long-distance caregivers, and LGBT caregivers.

Meet With A CaringKind Social Worker, Or Seek Individual Counseling

Not everyone is a “group person.” Some issues are best dealt with individually or as a family. Our social workers are licensed and, like all of CaringKind's programs and services, consultations with them are available free of charge.

Understand There Are No Perfect Solutions

Caregivers are human beings, and can never be perfect all the time. The care systems with which we interact (doctors,

hospitals, home care agencies, day programs, and residential facilities) are often far from perfect. **Your best efforts toward keeping the PWD safe and getting her needs met may not always have the expected result, but your best is all you can do.**

Be Three Steps Ahead Of A Crisis Instead Of Continually 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. Call the 24-hour Helpline to register for upcoming dates.
- **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.
- **Keep a current list of the PWD's medications with you** for doctor's appointments and in case of an emergency.
- **Prepare for wandering. Keep a current photo of the PWD with you at all times.** Enroll the PWD in the MedicAlert® NYC Wanderer's Safety Program. Register yourself in the program, too, as a caregiver, so that if something happens to you, emergency responders will know that you are caring for someone who relies on your help.
- **Remove important papers such as birth certificates from the home or keep them somewhere safe.** Give the PWD a laminated copy of her ID card, insurance card, etc. in case she loses or misplaces her wallet or purse. Consider securing valuable jewelry or family heirlooms as well.
- If the PWD is at risk for spending large sums of money by responding to telephone calls requesting money or donations to charities, **remove the credit card and checkbooks from the home or stop telemarketers from calling** by registering with the National Do Not Call Registry at 1-888-382-1222 or www.DoNotCall.gov. Consider having mail sent to a forwarding address or P.O. Box.

- If the PWD still has access to her money and is having difficulty spending it appropriately or accounting for how the money is being spent, **consider placing a spending limit on the credit card or capping the amount that can be withdrawn from an ATM at one time.** If she is anxious about not having enough cash, give her a big stack of one-dollar bills so that it feels like a lot of money but won't be too much of a problem if it is lost. Sign up for direct deposit of monthly checks rather than taking the chance that the PWD will lose the check.
- **Get help in the home.** If the PWD refuses help but needs it, find a way to get help anyway. Our 24-hour Helpline can provide you with information about home care agencies, paying for home care, and how to successfully introduce help in the home. CaringKind offers an online resource for private aides, www.TogetherWeCare.com, and this has profiles of graduates of our Dementia Care Training for Professional Caregivers program. Home care is a transition for both the caregiver and the PWD, but it is worthwhile. CaringKind's "Making Home Care Work For You" booklet is available through the 24-hour Helpline. Caregivers can also register through the Helpline for CaringKind's monthly Medicaid Home Care Seminar.
- **Consider placement in a residential care facility** (assisted living or nursing home). In some cases, residential placement is the best option for the PWD and caregiver. A PWD may even thrive in a residential facility because she will receive social stimulation and structured activities that are appropriate for her level of functioning. It's helpful to obtain information about all your options, even if you are not considering residential care right now. CaringKind offers a monthly seminar, Moving Your Relative to a Nursing Home, and our "Easing the Transition: Moving Your Relative to a Nursing Home" booklet is available through the 24-hour Helpline at 646-744-2900.

Connect To Your Community And Its Resources

Find out about programs in your area including day programs, overnight respite options, programs at local museums and other cultural institutions, dancing for caregivers and the PWD, music and singing events, meal delivery programs, bill payer programs, visiting nurse

services, and visiting doctors in a variety of disciplines. Visit CaringKind's Find Local Resources webpage for options at www.caringkindnyc.org/resources, or call our 24-hour Helpline at 646-744-2900.

Give Yourself Permission To Enjoy Life

You deserve it! Take care of yourself first and you will be able to better care for the PWD. If you are happier and more relaxed, 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.
- Get a hair cut.
- Watch your favorite sporting event.
- Read a magazine.
- Take a class.
- Visit a museum.
- Take a vacation (If a vacation isn't possible, try a "staycation" – take a weekend at home when you don't have anything scheduled).
- Garden.
- Cook.
- Listen to music.
- Play.
- Make art.
- Keep a journal.
- Read a book.
- Sit quietly by yourself.
- Meditate.
- Pray.
- Exercise.

Connect With The PWD

The relationship that you share with your mother, father, spouse, sister, brother, or grandparent with dementia is now different than before, but it is still a relationship. Look for ways to honor and enhance that relationship. Try to find enjoyable activities, separate from day-to-day medications,

meals, bills, and medical appointments, that you can do together. The goal is to have fun! Here are some ideas:

- Take a walk.
- Window shop.
- Look at family photos and reminisce.
- Create a scrapbook from images in magazines or printed off the Internet.
- Storytelling – check out Anne Basting’s TimeSlips program for ideas at www.timeslips.org.
- Movies – the PWD may not be able to follow the plot of an entire movie, but she may like short clips of famous scenes, or classic TV programs that rely on physical comedy such as *The Three Stooges* or *I Love Lucy*.
- Read out loud – corny jokes, poetry, or religious verses.
- Sing or dance together.
- Make art or look at art.
- Visit a museum – visit the connect2culture® page on our website for more information about local museum programs for people with dementia and their caregivers (www.caringkindnyc.org/connect2culture).
- Share a treat – ice cream, chocolate, or other favorite food.

Refer to the second section of this Family Caregiver Guide for more information about tailoring activities to the PWD’s level of functioning. As always, try to think of activities that the PWD historically enjoyed. The activities may need to be adapted for attention span, ability, and safety, but they can be an excellent way to reconnect with each other. **Positive emotional and relationship benefits can be retained long after the PWD has forgotten about the details of the activity or outing.**

Strike A Healthy Balance

Olivia Eames Hoblitzelle, author of *Ten Thousand Joys & Ten Thousand Sorrows: A Couple’s Journey Through Alzheimer’s* (2010), quotes a Tibetan Nun who is discussing balance:

“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.”





The Heart of Alzheimer's Caregiving

Take advantage of programs and services offered by CaringKind all of which are free of charge.

If you would like to learn more about any of the services please call our **24-hour Helpline** at **646-744-2900** or visit our website **www.caringkindnyc.org**.

We are here to help.

Social Work Services - Our social workers provide in-depth, personalized consultations for individuals and families facing the decisions and challenges associated with Alzheimer's disease and other dementias. Our professional social workers address each family's unique concerns to develop a care plan. Social workers can meet, by appointment, in person in Manhattan, Brooklyn, Queens, the Bronx, and Staten Island, or by phone and email.

Education & Training - Our training and education programs help you understand and navigate the challenges of Alzheimer's disease and caregiving. We provide knowledge and skills to help you more successfully care for someone with dementia and take care of yourself.

The Harry & Jeanette Weinberg Early Stage Center - We provide programs and services for those in the early stage of the disease or caring for someone who is. The services include consultations for families and opportunities to participate in programs in our Harry and Jeanette Weinberg Early Stage Center.

Support Groups - Support Groups provide a comfortable place to discuss caregiving challenges, share your feelings and find emotional support. Talking with people who truly understand will help you feel less alone as you confront the many challenges of caregiving. Support Groups take place in multiple languages throughout the five boroughs.

MedicAlert® NYC Wanderer's Safety Program - Everyone with dementia is at risk for wandering. Our Wanderer's Safety Program, MedicAlert® NYC, provides a safety net for your family member and for you in the event someone is missing or found. Our 24-hour nationwide emergency response service provides assistance in finding people who have wandered locally or far from home, or who have a medical emergency.

connect2culture® - Our cultural arts program, connect2culture®, creates unique opportunities for people living with dementia and their caregivers to stimulate conversation and engagement through art, music and dance.

Together We Care - Are you a family member looking to hire private home care workers? Together We Care posts profiles of graduates of our Dementia Care Training for Professional Caregivers, making it easier for families to find the right person for their needs.