

**H I L L T O P**

# **DEMENTIA TRAINING MANUAL**



**A CAREGIVING TOOL  
FOR FAMILIES & PROFESSIONALS**

Revised January 2015



# PREFACE

This Dementia Training Manual was created in the hopes of offering a comprehensive and practical training on understanding and caring for persons with dementia. This material was compiled to educate as many people as possible, because we live in a world with an increasing number of people with dementia and we know that **the more you understand dementia, the better you can care for people with dementia**, whether it is a family member, friend, or Hilltop resident.

This manual is not copywritten and can therefore be copied and shared with others. This manual is given for free to any individual or family who is caring for a person with dementia. Donations to Senior Daybreak of Hilltop to offset the cost of printing are welcome. (approx. \$10 each manual to print). This manual is also available as a free PDF document for those interested in obtaining an electronic file at

**htop.org → Senior Life Options → Senior Daybreak → Resources →  
“Dementia Training Manual”**

# ACKNOWLEDGMENTS

The information in this “Hilltop Dementia Training Manual” was compiled from various resources by Laurie Frasier, Joni Karp, and Rachel Brown, from their work at the Alzheimer’s Association, their personal experience caring for a loved one with Alzheimer’s disease, various Alzheimer’s websites and books, and by their experience caring for persons with dementia through their positions at Hilltop Community Resources with Senior Daybreak of Hilltop, The Commons Assisted Living, and The Fountains Assisted Living. To the best of their ability they have given credit to all known resources from which the information was collected and adapted.

If you no longer need this manual, please pass it on  
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Or, return to:

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**Donations to offset the cost of printing are welcome.  
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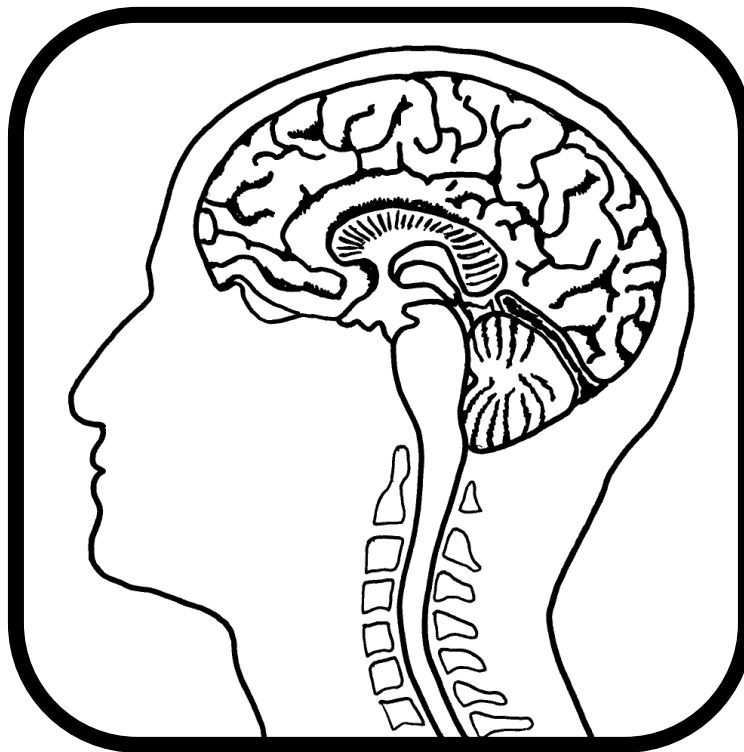


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# CHAPTER 1

## **OVERVIEW OF DEMENTIA & ALZHEIMER'S DISEASE**



**At the conclusion of Chapter 1  
you will have a greater in-depth knowledge of dementia  
and Alzheimer's Disease.**



## **What is common forgetfulness?**

We ALL forget:

- names & faces
- where we put something
- telephone numbers
- words
- that we've told someone something already
- what we walked into a room for
- where we parked our car

As we age we all have:

- Slower recall than when we were younger
- More trouble multi-tasking
- More memory slip ups
- And it takes longer to learn new things

Our brains change just as our sight, hearing and physical abilities change.  
This is normal.

## **When do we start to worry that the forgetfulness is more than normal aging?**

When the forgetfulness has become gradually and noticeably worse over time.  
When the forgetfulness has started to interfere with a person's daily life and their ability to safely care for their self. (See early warning signs and symptoms of dementia on page 15.)

## **What is dementia?**

The word "dementia" describes a broad category of illnesses that affect the brain. It is not a specific disease. It is a broad word like "cancer", and like cancer, there are many types of dementia. Dementia is a word that describes the *symptoms* of memory loss, problems with thinking and understanding, personality changes, a slow progressive decline in the person's ability to perform tasks, and a diminishing ability to tolerate stress. Dementia affects all areas of cognition (thinking and understanding): memory, organization, perception, abstraction, judgment, language, reasoning, and attention. Memory is the most noticeable area affected in the early stages of dementia, but as the dementia worsens, all areas of cognition can become impaired and eventually destroyed.

Dementia is *not* a normal part of aging. Dementia is always caused by something. Dementia can start gradually and get progressively worse or the dementia can onset quickly. Some forms of dementia may be reversible. Most forms are not. The speed and severity of the dementia depends on the cause of the dementia. There are approximately 60 conditions which cause dementia:

- Alzheimer's Disease (leading cause of dementia 50-60% of the time)
- Vascular dementia
- Parkinson's disease
- Dementia with Lewy bodies
- Physical injury to the brain
- Huntington's disease
- Creutzfeldt-Jakob disease (mad cow disease)
- Frontotemporal dementia (Pick's disease)
- Severe liver or kidney disease
- Severe alcohol abuse
- Encephelitis
- Brain Tumor\*
- Hydrocephalus\*
- Depression\*
- Medication side effects\*
- Thyroid problems\*
- Poor diet\*
- Vitamin deficiencies\*
- Certain infections\*

\*The conditions that cause dementia that are marked with an asterisk may be reversible or treatable. Persons with symptoms of dementia should see their doctor in case their symptoms of dementia are caused by one of these treatable conditions.

## **What is Alzheimer's Disease?**

Alzheimer's is a brain disease and the leading cause/type of dementia.

- Alzheimer's disease is a progressive, irreversible condition that destroys brain cells (neurons).
- The disease attacks nerve cells in all parts of the brain, causing brain cells to die, shrink and disappear.
- The disease also causes deficiencies of several chemicals in the brain which are essential for the transmission of nerve messages.
- An autopsy will reveal that healthy brain cells were replaced by dense irregularly shaped spots or PLAQUES and also, thread-like TANGLES will have formed within and choked out the existing healthy brain cells.

## **History of Alzheimer's Disease:**

- The disease was named for Dr. Alois Alzheimer in 1906
- His patient was a 51-year-old woman, Auguste Frankfurt
- She presented symptoms of disorientation, impaired memory, troubles in reading and writing, hallucinations
- She wrote in her diary, *"I have lost myself."*
- Dr. Alzheimer autopsied her brain upon death and discovered the hallmark pathology of plaques and tangles

## **Famous People who have died from or have Alzheimer's:**

- Charles Bronson actor, film director
- Charlton Heston, actor and political activist
- Rita Hayworth, actress
- James Doohan, Scotty from Star Trek
- Sugar Ray Robinson, boxer
- Norman Rockwell, artist
- Ronald Reagan, 40th President of USA
- Perry Como, singer entertainer
- Aaron Copland, composer
- Willem DeKooning, artist
- Barry Goldwater, Senator of Arizona
- Burgess Meredith, actor
- Iris Murdoch, author
- Rosa Parks, civil rights activist
- Glen Campbell, singer

## **What causes Alzheimer's disease?**

- The cause is still a mystery

## What are the risk factors for Alzheimer's Disease?

- Age is the biggest risk factor, as the disease most commonly strikes those who are 65 years and older.
- Twice as many women get Alzheimer's than men. One belief is this could be because women tend to live longer than men, thus more of them reach the age of greatest risk, 65 and beyond. Recent studies indicate hormones may be the reason.
- It is believed that a family history of Alzheimer's places one at higher risk, however, there are just as many people who get Alzheimer's with no prior family history of the disease.
- Scientists believe that genetics likely play a role in the disease, but they do not have all the answers or know all of the genes that are involved. It is possible that genes are involved and are perhaps triggered by something else that brings on the onset of the disease. What they do know about genes:
  - They have identified 1 Risk Gene: APOE-e4 on chromosome 19. Those with this gene seem to have a higher general risk for Alzheimer's. That being said, there are people with this gene who do not have Alzheimer's, so it is not a sure thing. Scientists believe there are probably other unidentified risk genes.
  - They have identified 3 Deterministic Genes:  
If a person has a genetic mutation in one of these three genes: APP, PSEN 1 or PSEN 2, it would be likely (98%) they would develop Alzheimer's before age 65. They will most likely have numerous ancestors in their family who have died from this early onset Alzheimer's.
  - Individuals with Down Syndrome, which we know is genetic, frequently (60-70% of the time) get Alzheimer's disease along with the Down's.



## **Other possible or probable risk factors or triggers include:**

- Race appears to be a risk factor because African Americans are getting the disease at a rate four times higher than other races, and Hispanics two times higher.
- It is theorized that exposure to toxic substances in the environment could be causing the disease.
- Some studies seem to indicate that individuals with less education have a higher risk of the disease. It is theorized that a smarter brain has more dendrites and synapses thus affording them more protection. This is why there are numerous brain games now on the market and a growing belief that the brain can strengthen at any age.
- Individuals with a previous head injury seem to have a higher likeliness of getting the disease.
- Statistics are showing that individuals with cardiovascular diseases, diabetes, obesity, high blood pressure and high cholesterol are all getting Alzheimer's at a higher rate than others, thus building a strong case for the belief that brain health is linked to body health. It is possible that these conditions are triggering the disease.

## **Are there different types of Alzheimer's Disease?**

Yes, there are considered to be two, based on the age of the person at onset of the disease, but the symptoms are all the same. If the person is stricken with the disease at the age of 65 years or older it is considered "late onset". This is the most common form.

If a person is stricken younger than 65 years of age, it is considered "early onset". Of all the people who have Alzheimer's disease, only about 5 percent develop symptoms before age 65. The youngest person ever diagnosed with Alzheimer's was 27 years old. Early-onset Alzheimer's has been known to develop between ages 27 and 40, but that is very uncommon. It is more common to see someone in his or her 50s who has the disease. Early onset often runs in families. Many people with early-onset Alzheimer's have a parent or grandparent who also developed Alzheimer's at a younger age. It is believed that early-onset Alzheimer's is linked to genetics.

## How is Alzheimer's disease diagnosed?

There is no single laboratory test, at this time, that confirms a person has Alzheimer's unless the brain is autopsied at death. However, by doing a careful medical evaluation, physicians can diagnose Alzheimer's with more than 90% accuracy. They can almost always determine that a person has dementia based on the results of family discussion and physical and mental assessments, and can offer the diagnosis of “**probable** dementia of the Alzheimer's type”.

Diagnosing Alzheimer's requires:

- A thorough medical history and discussion with the family regarding the symptoms and behaviors their loved one is exhibiting which is causing their concern.
- A physical exam and tests performed to help identify and rule out other potential causes of dementia. This exam will normally include a general physical, blood tests and urinalysis. Through a blood test, for example, the physician can measure thyroid function. Hypothyroidism or failure to produce sufficient thyroid hormones, which is common in the elderly, can cause symptoms of dementia. Dementia may also be the result of a vitamin B12 deficiency, a condition common in older people. A vitamin B12 deficiency can be measured through blood tests. Physicians may use brain scans (such as magnetic resonance imaging or MRI) to rule out other possible causes of dementia, including brain tumors, stroke, blood accumulation on the brain surface or other conditions. In addition, brain scans can show characteristic structural brain shrinkage present in Alzheimer's disease. Physicians may administer an electroencephalogram (EEG) to measure the electrical activity in the brain. Occasionally, spinal fluid may be tested through a lumbar puncture.
- A neurological exam with neuropsychological tests to identify behavioral and mental symptoms associated with brain injury or abnormal brain function. Usually, physicians start with a brief screening tool, such as the Mini-Mental Status Examination (MMSE), to help confirm that the patient is experiencing problems with intellectual functions of memory, attention, mathematical calculation and language.
- In recent years, scientists have been experimenting with the PET scan (positron emission tomography) for diagnosis and research. The brain is injected with a radioactive tracer which lights up the plaques and tangles in the brain showing the disease pathology. The PET scan is very expensive, mainly used for research, and not readily available to the general public at this time (2014).

An early diagnosis of dementia from Alzheimer's disease enables more time to plan for the future and put affairs in order. It also allows the person with dementia to participate in the plans for their own future.

## **How does Alzheimer's progress?**

- Alzheimer's most commonly progresses slowly and gradually.
- *Symptoms and stages will vary from person to person.*
- The disease is categorized generally as having early, middle, and late stages and is also specifically broken down into 7 detailed stages (see handout on page 21.)
- The disease can last anywhere from 3 to 20 years with the average number of people living from 8 to 12 years after onset of symptoms.
- A person with Alzheimer's will go backwards in time – losing abilities in the reverse order they were learned. This is sometimes referred to as retrogenesis.
- A person with Alzheimer's will eventually revert to being an infant in an adult's body, requiring total dependence on others for care.

## **Mysterious Moments of Clarity:**

- A person with dementia from Alzheimer's will have a mixture of clarity and confusion. In the beginning, small moments of confusion will gradually start to appear, affecting daily life. As the disease progresses, the confusion will increase and the clarity will decrease. The person will have days where they seem very clear and with it, and families might wonder if they truly have dementia. On other days, they will be much more confused and out of it. This might also happen from one hour to the next. Throughout the course of the disease, and far into advanced dementia, the person with dementia will exhibit mysterious moments of clarity, where they do or say something that is so normal, so with it, and so characteristic of who they were before dementia. These mysterious moments of clarity are often viewed as gifts or treasures to the family. It is important to know, that one never knows when the person with dementia will have a moment of understanding. For this reason, be very careful when talking about people with dementia in front of them, especially those in the advanced stages.

## Does a person know that they have dementia or Alzheimer's disease?

- Some people are very aware that something is wrong, and can be very good at covering up or hiding their difficulties in the beginning. They may or may not know what to call the cause of their difficulties.
- As the disease progresses they become less and less adept at covering up their difficulties, and less aware that they are even having difficulties.
- Others seem to have no clue from the beginning that anything is wrong, despite observances and concerns of their family.

*“If there is one thing that I want to impart to others, it is this: please remember how terrifying dementia can be. Those of us who have it are fearful every minute of every day, although we sometimes do not show it. We need a great deal of physical and emotional support to help us find and use all the brainpower that we still have.” –Bill, person with dementia  
from Voices of Alzheimer's by Betsy Peterson*

## Do people actually die from Alzheimer's disease?

Alzheimer's disease is always fatal, but more often than not, a person will die from something else first. Many seniors already have other serious health issues occurring before or simultaneously with the Alzheimer's, such as cancer, heart problems, or pneumonia, and will die from one these before the long slow insidious Alzheimer's runs its course. If a person with the disease is physically healthy, their body can hang on for a long time despite the loss of mental awareness and cognitive ability. Their body will eventually shut down causing death when the destruction to the brain is great enough.

## **How prevalent is Alzheimer's disease?**

- 26 million people in the world currently have Alzheimer's disease
- 5.3 million people in U.S. have Alzheimer's
- 64,000 of these people live in Colorado
- Approximately 2,714 in Mesa County
- 7<sup>th</sup> leading cause of death
- "Babyboomers" (the generation born between 1946-1964) have just entered the age of greatest risk, age 65
- By the year 2050, it is estimated that 11-16 million people will have Alzheimer's
- Currently, 1 in 8 people in the age range of 65-75 years old have Alzheimer's
- 1 in 4 people between 75-85 years old have Alzheimer's
- 1 in 2 people over the age of 85 have Alzheimer's

## Are there medications used to treat Alzheimer's disease?

- Medications currently used are: Aricept (Donepezil), Exelon (Rivastigmine), Razadyne (Reminyl), Namenda (Memantine).
- Aricept, Exelon (oral or patch form), and Razadyne are all the same class of meds called acetylcholinesterase inhibitors, and a person would take only one of the three. If they exhibited no benefit on one, the doctor might try one of the others. These medications are thought to slow down the progression of dementia and improve alertness to reduce caregiver burden. They do not change the underlying disease. Studies have shown continued benefit for up to 4 years (this length of time is debated). The cognitive dysfunction (memory, attention, learning) in dementia of the Alzheimer type is related to a significant reduction in acetylcholine (a chemical messenger in the brain) transmission. Razadyne, Aricept and Exelon work by inhibiting an enzyme called acetylcholinesterase. By blocking this enzyme the breakdown of acetylcholine, released by the remaining healthy brain cells, is slowed down leaving more chemical messengers available to support normal brain function. In addition, Razadyne also increases the action of acetylcholine on another receptor site called nicotinic receptors. This has been associated with improved cognitive function.
- Namenda is a glutamate pathway modifier and works differently from the acetylcholinesterase inhibitors. It is often taken in conjunction with *one* of the three acetylcholinesterase inhibitors. Because the two types of medications work in different ways, taking them together may be helpful—this is called **combination therapy**. Namenda can also *sometimes* reduce anxiety and agitation in *some* individuals.
- None of these medications will stop or reverse the disease. It is believed that they may slow down the progression of the decline and buy the person more time functioning at a higher level.
- Some individuals show benefit from the medications. Some individuals do not. Some individuals suffer from side effects from the medications when they first start taking them and then develop tolerance and benefit. Some have side effects that last resulting in the need to stop the medication.
- Because it is difficult to determine their effectiveness due to the gradual progression of the disease many doctors do not see the benefit of prescribing these medications. Families must learn about these drugs and decide for themselves if they want to try and see what effect they have with their loved one.

## What is happening with research and finding a cure for Alzheimer's?

- Although there is no cure at this time, the combined efforts of the federal government, led by the National Institutes of Health (NIH), the scientific community, the pharmaceutical industry and the Alzheimer's Association, *phenomenal progress in the diagnosis and treatment of Alzheimer's disease has been achieved in the last 25 years.*
- On January 4, 2011, President Barak Obama signed into law the National Alzheimer's Project Act (NAPA) which formed a historic council to create and maintain a national plan to overcome Alzheimer's disease and to address the many challenges facing those with the disease and their families.
- Research evidence is linking heart health with brain health – what is good for your heart is good for your head.
- Research evidence is linking Alzheimer's with high blood pressure, cardiovascular disease, high cholesterol, diabetes and obesity.
- Research evidence is showing nutrition and exercise may help to prevent or delay Alzheimer's.
- Research evidence is showing that brain games and challenging the brain to learn new things may help to prevent or delay Alzheimer's.
- Advanced imaging technologies, including PET, MRI, SPECT and others, are improving early detection of Alzheimer's. Accurate, early diagnosis would help treat people earlier and speed up testing of new drugs in treatment trials.
- Research is investigating the possibility that protein patterns found in spinal fluid may detect Alzheimer's.
- Numerous treatment medications are currently being tested in clinical trials.
- Potential vaccine has worked in mice to reduce and reverse buildup of plaques, and though complications have occurred in human trials, research continues along this line.

- One small study showed benefit from intravenous immunoglobulin therapy (IVIG), which is used to treat various autoimmune, infectious and idiopathic diseases.
- Several studies claim caffeine from coffee may reduce the risk of Alzheimer's (5-6 cups per day)
- Some research claims that THC in marijuana has a positive effect in reducing symptoms and possibly even halting the progression of Alzheimer's.
- Some studies claim coconut oil has the ability to reverse symptoms and halt progression of Alzheimer's.
- Some studies claim Gingko Biloba has the ability to improve memory.
- Some studies claim that Vitamin E has the ability to improve memory.
- Some studies claim that anti-inflammatory drugs such as Ibuprofen can prevent Alzheimer's disease.
- Some studies claim that increased intake of foods rich in antioxidants can prevent Alzheimer's disease.
- Some studies claim that diets high in curry (curcumin) can prevent, slow or halt Alzheimer's disease. (Curry is a dietary staple in India, a country where the rate of Alzheimer's disease is among the world's lowest. Curry is a powerful antioxidant and anti-inflammatory).
- Some studies claim that certain super foods will enhance one's brain power: blueberries, walnuts, almonds, fish, tomatoes, broccoli, and sage.
- Some studies claim that losing one's ability to smell is a precursor to Alzheimer's, and specifically, the ability to smell peanut butter.

**THERE IS A CONSTANT BUZZ IN THE MEDIA AROUND NEW MIRACLE CURES OR TREATMENTS FOR ALZHEIMER'S DISEASE...NO ONE DRUG OR PROCEDURE HAS BEEN SUBSTANTIALLY PROVEN TO PREVENT, DIAGNOSE, STOP, OR CURE ALZHEIMER'S DISEASE AT THIS TIME.**



# **What are the early warning signs and symptoms of dementia or Alzheimer's disease?**

A person may exhibit some or all of these signs.

## **Short term memory loss that affects daily life**

- May repeat stories or questions
- May forget appointments
- May have difficulty recalling recent events, such as what they ate for breakfast or who they talked to on the phone earlier in the day
- May have difficulty remembering & taking medications
- May have difficulty learning new things

## **Difficulty performing familiar tasks**

- May neglect or forget how to perform usual routine chores such as cooking and laundry
- May neglect or forget about housekeeping, allowing food to spoil and clutter to overwhelm
- May hoard food and other items
- May ruin household tools or equipment such as a blender or lawn mower by taking them apart “to fix” or using them inappropriately
- May neglect or overfeed a pet

## **Problems with language and conversation**

- May have trouble finding the right word
- May have trouble keeping up with a conversation
- May respond inappropriately to a conversation
- May have difficulty reading or spelling

## **Disorientation to time and place**

- May have confusion about what day of the week, month, season, or year it is
- May have confusion of where they are and how they got there
- May get lost driving to familiar places, including finding their way home
- May get lost in shopping malls or stores
- May get lost walking in their own neighborhood

**Poor or decreased judgment**

- May become vulnerable to scams
- May choose inappropriate clothing for the weather
- May have difficulty making judgments about their own safety
- May have difficulty making decisions, and may make some decisions without any regard for consequences

**Problems with numbers and money**

- May have trouble balancing their check book, paying bills, or getting change
- May withdraw large sums of money from the bank and lose it
- May give away large sums or money to telemarketers or be easily suckered by scams
- May spend large amounts of money on items they already have or don't need

**Misplacing things**

- May constantly search and even obsess over misplaced items such as keys, purse, wallet, or jewelry
- May put things in unusual places like jewelry in the sugar bowl or a dirty coffee cup in a dresser drawer

**Problems with hygiene**

- May stop bathing and grooming appropriately
- May wear the same item of clothing day after day even when it is obviously soiled
- May neglect dental care

**Changes in personality and behavior**

- May become more aggressive, or more passive, or just different from how they've always been
- May exhibit bizarre or eccentric behaviors that they have never shown before
- May become extremely suspicious, fearful, or paranoid
- May say or do embarrassing things (social graces become compromised)
- May have an inappropriate emotional response to a situation

## **Loss of Motivation & Initiative**

- May have difficulty entertaining their self by thinking of activities to do
- May have difficulty planning and executing projects or events
- May become very unmotivated and unwilling to do much other than sit and stare or watch TV
- May sleep more than usual
- May have no desire or initiative to do activities or hobbies that they used to do
- May say they don't feel good to avoid doing activities

## **How does a person with dementia feel?**

A person with dementia, no matter what the cause, lives in a world of confusion. This confusion is often accompanied by fear and depression.

### **Imagine...\***

- It's winter – bad weather – and you are driving your car.
- It is your least favorite time of day for driving -- the light is very poor.
- You are driving on your least favorite section of the freeway – lots of merging traffic and lane-shifting going on.
- The road conditions are terrible – it's icy and slippery.
- Now it's starting to snow – fat, wet snow that quickly covers your windshield.
- Your windshield wipers aren't working too well.
- There is very heavy traffic – very little space between cars.
- Because of the traffic, you have to be driving much faster than you like.
- You have a young child in the back seat who starts to scream and cry.
- In your sideview mirror you see an 18-wheeler about to pass you very closely.....

### **Experience your feelings for a moment:**

“How do you feel?”

“What do you want to do?”

“What would you like to have happen?”

***Or,*** have you ever traveled to a foreign country where you could not speak the language, and where everything was new and unfamiliar?

***This is how a person with dementia feels much of the time.***

\*Imagine scenario adapted from the Savvy Caregiver program, Alzheimer's Association

## To My Family and Friends

*The following piece was written by Laurie Frasier, in memory of her Mom, Sarah, to help give people insight into the feelings of a person with Alzheimer's disease.*

- I have Alzheimer's. No one wants this horrible disease, and certainly not me. I am afraid.
- I feel guilty and sad and angry because I don't want to be a burden or put you through this. Please forgive me.
- I am not contagious. Please stick by my side and be there for me.
- I am confused. Please know that I will need constant reassurance and guidance from you from now on.
- I will repeat the same things over and over and over again, ad nauseum. Please don't interrupt or tell me that I am repeating myself. Please listen and be patient.
- I may invent or say things that are not true because I cannot remember. Please don't correct me, or point out my untruths. Help me to save face in front of you and others.
- I will lose the ability to keep track of money. Please subtly handle this for me, without making me feel inferior.
- I will lose the ability to drive safely. Please subtly prevent me from driving, without making me feel incapable. This will be one of the hardest things for me to give up.
- I will forget how to dress properly. Please make sure that my clothing is clean and that the tops match the bottoms. Please subtly straighten me up if I put clothes on inside out or underwear on top of outerwear.
- I will forget how to entertain myself. Please encourage me and plan things for me to do. Even when I say "no", keep trying.
- I will get lost. Please don't let me out of your sight when in a crowd or an unfamiliar place.
- I will lose and misplace things. Please help me find them and subtly protect items that cannot be replaced.

- I will forget how to prepare meals. I will forget what kind of food I just ate minutes earlier. I will forget that I just ate and will want to eat again. Please keep track and keep me properly fed.
- I won't be able to keep track of my own medications. Please subtly handle this for me, without making me feel inferior.
- I will lose the ability to properly use and operate tools and equipment. I may even break or ruin expensive tools such as lawn mowers. Please subtly remove or disable them without making me feel incapable.
- I will lose the ability to properly use and understand firearms. Please subtly remove these from my environment without making me feel incapable.
- I will gradually forget many many many things. Please don't say "Do you remember...various things or people". I probably won't but I will say that I do and will probably smile. Inside my brain I will panic and feel stupid each time you ask.
- I will have difficulty making decisions for myself, such as what to order at a restaurant, so I will copy what you order. Please let me and don't be annoyed.
- I will forget my social graces. I may say or do very embarrassing things in public. Please forgive me and continue to take me places anyway.
- I will lose the understanding of time. Please have patience when I get up and get dressed and am ready to go to "work" at 3:00 in the morning.
- I may become angry and frustrated as the confusion overwhelms me. Please stay calm and soothing no matter how I am behaving.
- I may obsess over weird and bizarre things. Please distract me and do things to calm me if I work myself up into a frenzy.
- I may not act like my old self. I may exhibit new and different personality traits. Please know the old me is still deep inside no matter how I'm behaving on the outside.
- I may sleep a lot. I may get depressed. Please expect this.
- I won't be able to complete complicated tasks. Please break things into small parts so I can still feel a sense of independence and accomplishment, without feeling stupid and overwhelmed.
- I will lose the ability to show appropriate emotion. Please understand that I am not being callous or unkind.

- I may refuse to bathe or shower. Please cajole and encourage and gently guide me through the process.
- I may refuse to cooperate with anything you want me to do. Please cajole and encourage and gently guide me through the task.
- I may have hallucinations. Please reassure and distract me onto other tasks and topics.
- I may make inappropriate sexual advances towards others. Please gently but firmly remind me not to do this and distract me onto other tasks and topics.
- I will have trouble toileting myself. This is one of the most embarrassing and humiliating things that I will need your help with. Please forgive my helplessness and keep me clean and dry and odor free to preserve my dignity.
- I may do things that are very undignified. Please forgive me and help me save face.
- I may say things that are unkind and hurtful to you. Please forgive me. I will always have immense love for you in my heart, though I may not be able to show it the way I used to.
- It may become too difficult for you to care for me at home. Please don't promise me that you will never place me in a care facility. When it comes to dementia and Alzheimer's, the rules change, and promises may have to be broken. Though I may not be able to show it, deep inside I will understand.
- I will lose the ability to do many things and each loss will cause you to grieve. Please do not dwell on my losses, but try and focus on the existing abilities that I still have.
- And last, but not least...I will forget you. This will be heartbreaking for you and I won't even know. Please understand that no matter what this disease takes away from us, you will always be a part of my heart and a part of my soul. This can never be taken away.
- I have Alzheimer's. Please remember and treasure the special memories of our relationship for both of us.

*Sarah's Stories, which chronicle her journey with Alzheimer's, can be found in Chapter 10, page 185.*

# Alzheimer's Association - Stages of Alzheimer's Disease

**Stage 1: No impairment** (normal function): Unimpaired individuals experience no memory problems and none are evident to a health care professional during a medical interview.

**Stage 2: Very mild cognitive decline** (may be normal age-related changes or earliest signs of Alzheimer's disease): Individuals may feel as if they have memory loss and lapses, especially in forgetting familiar words or names or the location of keys, eyeglasses or other everyday objects. But these problems are not evident during a medical examination or apparent to friends, family or co-workers.

**Stage 3: Mild cognitive decline:** Early-stage Alzheimer's can be diagnosed in some, but not all, individuals with these symptoms. Friends, family or co-workers begin to notice deficiencies. Problems with memory or concentration may be measurable in clinical testing or discernible during a detailed medical interview. Common difficulties include:

- Word- or name-finding problems noticeable to family or close associates
- Decreased ability to remember names when introduced to new people
- Performance issues in social or work settings noticeable to family, friends or co-workers
- Reading a passage and retaining little material
- Losing or misplacing a valuable object
- Decline in ability to plan or organize

**Stage 4: Moderate cognitive decline** (Mild or early-stage Alzheimer's disease): At this stage, a careful medical interview detects clear-cut deficiencies in the following areas:

- Decreased knowledge of recent occasions or current events
- Impaired ability to perform challenging mental arithmetic - for example, to count backward from 75 by 7s
- Decreased capacity to perform complex tasks, such as planning dinner for guests, paying bills and managing finances
- Reduced memory of personal history
- The affected individual may seem subdued and withdrawn, especially in socially or mentally challenging situations

**Stage 5: Moderately severe cognitive decline** (Moderate or mid-stage Alzheimer's disease): Major gaps in memory and deficits in cognitive function emerge. Some assistance with day-to-day activities becomes essential. At this stage, individuals may:

- Be unable during a medical interview to recall such important details as their current address, their telephone number or the name of the college or high school from which they graduated
- Become confused about where they are or about the date, day of the week or season

- Have trouble with less challenging mental arithmetic; for example, counting backward from 40 by 4s or from 20 by 2s
- Need help choosing proper clothing for the season or the occasion
- Usually retain substantial knowledge about themselves and know their own name and the names of their spouse or children
- Usually require no assistance with eating or using the toilet

**Stage 6: Severe cognitive decline** (Moderately severe or mid-stage Alzheimer's disease): Memory difficulties continue to worsen, significant personality changes may emerge and affected individuals need extensive help with customary daily activities. At this stage, individuals may:

- Lose most awareness of recent experiences and events as well as of their surroundings
- Recollect their personal history imperfectly, although they generally recall their own name
- Occasionally forget the name of their spouse or primary caregiver but generally can distinguish familiar from unfamiliar faces
- Need help getting dressed properly; without supervision, may make such errors as putting pajamas over daytime clothes or shoes on wrong feet
- Experience disruption of their normal sleep/waking cycle
- Need help with handling details of toileting (flushing toilet, wiping and disposing of tissue properly)
- Have increasing episodes of urinary or fecal incontinence
- Experience significant personality changes and behavioral symptoms, including suspiciousness and delusions (for example, believing that their caregiver is an impostor); hallucinations (seeing or hearing things that are not really there); or compulsive, repetitive behaviors such as hand-wringing or tissue shredding
- Tend to wander and become lost

**Stage 7: Very severe cognitive decline** (Severe or late-stage Alzheimer's disease): This is the final stage of the disease when individuals lose the ability to respond to their environment, the ability to speak and, ultimately, the ability to control movement.

- Frequently individuals lose their capacity for recognizable speech, although words or phrases may occasionally be uttered
- Individuals need help with eating and toileting and there is general incontinence of urine
- Individuals lose the ability to walk without assistance, then the ability to sit without support, the ability to smile, and the ability to hold their head up. Reflexes become abnormal and muscles grow rigid. Swallowing is impaired.



## Other Conditions/Diseases which cause Dementia

Seniors may have dementia from varying conditions, although the most common cause will be Alzheimer's Disease. The following information will help to understand some of the other conditions:

**VASCULAR DEMENTIA** is an umbrella term that describes impairments in cognitive function caused by problems in blood vessels that feed the brain. In some cases, a blood vessel may be completely blocked, causing a stroke. Not all strokes cause vascular dementia. It depends on the severity of the stroke, where the stroke occurred and the portion of the brain that's affected. Vascular dementia also can occur when blood vessels in the brain narrow, reducing the amount of blood flow to those sections of the brain. The prevalence of vascular dementia ranges from 1 to 4 percent in people over the age of 65. Because few treatments are available for vascular dementia, prevention is crucial.

**FRONTOTEMPORAL DEMENTIA**, also known as PICK'S DISEASE (frontotemporal lobar degeneration) is an umbrella term for a diverse group of uncommon disorders that primarily affect the frontal and temporal lobes of the brain — the areas generally associated with personality, behavior and language.

In frontotemporal dementia, portions of these lobes atrophy, or shrink. Signs and symptoms vary, depending upon the portion of the brain affected. Some people with frontotemporal dementia undergo dramatic changes in their personality and become socially inappropriate, impulsive or emotionally blunted, while others lose the ability to use and understand language. Frontotemporal dementia is often misdiagnosed as a psychiatric problem or as Alzheimer's disease. But frontotemporal dementia tends to occur at a younger age than does Alzheimer's disease, typically between the ages of 40 and 70.

**LEWY BODY DEMENTIA** shares characteristics with both Alzheimer's disease and Parkinson's disease. Like Alzheimer's, it causes confusion. Like Parkinson's, it can result in rigid muscles, slowed movement and tremors. But the most striking symptom of Lewy body dementia may be its visual hallucinations, which can be one of the first signs of the disorder. Hallucinations may range from abstract shapes or colors to conversations with deceased loved ones. In Lewy body dementia, abnormal round structures — called Lewy bodies — develop in regions of the brain involved in thinking and movement. While risk increases with age, Lewy body dementia is estimated to affect less than 1 percent of the population over the age of 65.

**MILD COGNITIVE IMPAIRMENT** is a transition stage between the cognitive decline of normal aging and the more serious problems caused by Alzheimer's disease. The disorder can affect many areas of thought and action — such as language, attention, reasoning, judgment, reading and writing. However, the most common variety of mild cognitive impairment causes memory problems. According to the American College of Physicians, mild cognitive impairment affects about 20 percent of the population over 70. Many people with mild cognitive impairment eventually develop Alzheimer's disease, although some remain stable and others even return to normal.

**PARKINSON'S DISEASE** is a progressive disorder of the nervous system that affects movement. It develops gradually, often starting with a barely noticeable tremor in just one hand. But while tremor may be the most well-known sign of Parkinson's disease, the disorder also commonly causes a slowing or freezing of movement. Friends and family may notice that your face shows little or no expression and your arms don't swing when you walk. Speech often becomes soft and mumbling. Parkinson's symptoms tend to worsen as the disease progresses. In the later stages of Parkinson's disease, some people develop problems with memory and mental clarity. While there is no cure for Parkinson's disease, many different types of medicines can treat its symptoms. In some cases, the doctor may suggest surgery.

**ENCEPHALITIS:** Although the term "encephalitis" literally means "inflammation of the brain," it usually refers to brain inflammation resulting from a viral infection. The severe and potentially life-threatening form of this disease is rare. Experts suspect that the actual incidence of encephalitis is probably much higher — but because most people have such mild signs or symptoms, many cases go unrecognized. Encephalitis occurs in two forms — a primary form and a secondary form. Primary encephalitis involves direct viral infection of your brain and spinal cord. In secondary encephalitis, a viral infection first occurs elsewhere in your body and then travels to your brain. Seeing a doctor and receiving timely treatment is important because the course of the encephalitis is unpredictable.

A **STROKE** occurs when blood flow to a part of the brain is interrupted or severely reduced. This deprives part of the brain of oxygen and nutrients, which can destroy brain cells and result in some degree of permanent disability. Stroke symptoms may include trouble walking and speaking, as well as paralysis or numbness on one side of the body. Prompt treatment is essential. The longer a stroke goes untreated, the greater the risk of permanent disability.

**TRANSIENT ISCHEMIC ATTACK:** The term "mini-stroke" is a misnomer that typically refers to a transient ischemic attack (TIA) — a temporary interruption of blood flow to part of the brain. The symptoms of a TIA are similar to those of a stroke but resolve quickly — within several minutes to several hours. A TIA doesn't destroy brain cells or cause permanent disability. However, TIAs may recur. Each TIA increases the risk of a subsequent stroke.

## CHAPTER 2

# **INDIVIDUALIZED CARE, COMMUNICATION, & ENVIRONMENT**



**At the conclusion of Chapter 2 you will have a better understanding of how to interact, communicate, and adapt the environment to the unique needs of each individual with dementia, thus treating them with the utmost dignity and respect.**



## INDIVIDUALIZED CARE

If you've met one person with dementia, you've met one person with dementia. Each individual will journey with dementia along a different path.

The better you understand the personality traits of the individual and the way the dementia has affected them, the better you can care for them.

It is important to learn as much about the individual as possible. Every person with dementia is very unique.

### **Dementia affects each person differently.**

**Personality:** Some will have drastic personality changes, and some will not. Some people will be sweet and complacent while others will be angry and agitated, and all the rest will be somewhere in between these two extremes.

**Behaviors:** All will exhibit behaviors that can be very difficult and challenging to deal with. Some will exhibit more of these behaviors than others.

**Course of the dementia:** Some will decline very slowly and gradually over the years as the dementia damages their brains. Others will decline more rapidly and drastically.

**Ability levels:** Each person's ability to take care of their daily needs such as dressing, bathing, toileting and eating will be dependent on how much dementia is present, and these abilities will decline as the dementia progresses. It is important to know what each individual can and cannot do. It is important to understand that their ability level will constantly change.

**Routines and quirks:** Each of us human beings have our own routines and quirks that only we know. When a person has dementia, knowing their routines and quirks will help you understand behaviors, provide familiar routines, and will give you material for conversation, comfort, moments of joy, and distraction.

Families already know this information! Other care providers will need to seek out this information by getting a personal history from the family.

## **Each individual with dementia is very unique.**

- What was the person's personality like before the dementia?
- What is the person's personality like now?
- What things does the person particularly enjoy or respond to (HAPPY BUTTONS)?
- What gets the person angry or agitated (UPSET BUTTONS)?
- Can the person still communicate and make their needs known?
- How much help do they need with dressing, grooming, toileting, eating, walking, bathing?
- What do they like to wear?
- Do they wear dentures, glasses, hearing aids?
- What is their career history? Significant family members? Significant life events? Children? Pets? Friends?
- Do they prefer to be around people or like to be alone?
- Do they have other health issues which are compounding the dementia?
- Do they have any immediate behaviors or quirks that would be helpful to know?

## **What are the emotional needs of a person with dementia?**

### **To feel:**

Calm and in control...despite the fog of confusion

Safe & secure...despite the fog of confusion

Reassured...despite the fog of confusion

Moments of joy & happiness...despite the fog of confusion

Respected...despite the fog of confusion

Needed and productive...despite the fog of confusion

Loved...despite the fog of confusion

# COMMUNICATION & INTERACTION

We all respond to others based on their tone and attitude. This is especially true of people with dementia. People with dementia seem to be especially sensitive to the emotions and behaviors of those around them. They seem to have a sixth sense.

- Be aware of the **tone** of your voice. A gentle and relaxed tone with a lower voice pitch is usually best. If your tone projects agitation and impatience... they will most likely respond with anger or hurt feelings.
- Be aware of the **volume** of your voice. Just because a person has dementia doesn't mean they are deaf.
- Always have a **positive approach**. Smile and make eye contact with positive and friendly facial expressions.
- Speak to a person with dementia using **adult language**, not baby talk. There may be times when they act childlike and need a firm parenting type voice, but be very careful. These are adults, and they need to be treated like adults.
- Stay **calm and low key**, especially if they are not.
- Do not try to **rush or push** to hurry up. People with dementia need more time to process things. Rushing will only cause them to feel inadequate and more confused.
- Do not **overwhelm**. Give choices but not **too many** choices, understanding that you are not taking away their right to choose, you are making it easier for them to choose.

## Try the “best friend” approach

Think of how you greet and act around your best friend. People with dementia often respond amazingly well to this approach as it kicks in their old social tapes and memories of their response to their best friends.

## Provide “affectionate care”

For professional caregivers, it is best to treat the person with dementia with the kind of affection one would give to their own relatives, developing close positive relationships based on kindness and love: listen to them, sing to them, laugh with them, pat them on the shoulder and say sweet things, hug them, and show understanding and empathy if they feel sad and lonely.

## **Expect changes to occur with communication**

The way in which Alzheimer's disease affects communication will vary with each person. Research has found that a person with dementia's inability to communicate their needs causes them to feel inept and frustrated, leading to behaviors which in turn lead to caregiver frustration and burnout. Understanding common communication difficulties and strategies for dealing with them is key to successful communication and interaction.

**Constant repetition of words, phrases or questions:** If the person is telling you the same story or joke over and over again, understand that they don't remember they have already told you. Smile and laugh and pretend as if you haven't heard it each time. Plan on answering the same question over and over in a calm and pleasant voice. Remember that the person is not asking you on purpose to irritate and annoy you. If this repetition gets on your nerves, turn it into a game with yourself. Predict how many times the question will be asked and see if you are right. Try seeing how many different ways you can respond to the same question. If you don't have the energy to keep answering, write the answer on a note card and tell the person to read their card each time they ask.

**Difficulty finding words:** Some people with dementia will exhibit trouble finding the right word. They will know the word, but be unable to find it in their brain. Assist with word finding if they are struggling, you have already given them some response time, and you have an idea of what they might be trying to say. You want to help them before they get too frustrated.

**Difficulty keeping up with a conversation:** Persons with dementia may have difficulty keeping up with a conversation resulting in their saying things that don't apply to what is being discussed, or answering your questions with an inappropriate response. Repeat your statement or question if their response is off base, or just let it go.

**Difficulty understanding and following directions:** A person with dementia will have trouble comprehending and remembering how to do tasks and will need help understanding your directions. Give visual cues to aid with comprehension. Demonstrate a request by pointing, touching or beginning the task for the person. Signs taped up on the doors or cabinets (i.e. "Bathroom" "Plates") can help, too. Arrows or a line of tape on the floor can help with finding a specific room such as the bathroom. Sometimes a person's brain can interpret written words or pictures easier than verbal words.



**Saying things that aren't true:** A person with dementia is going to get the facts and figures mixed up. They may even say things that you know aren't true. People with dementia don't always remember the truth so they will often make things up (tall tales) that they then seem to really believe. **DO NOT CORRECT OR CRITICIZE THEM.** This will make them feel stupid and could lead to an argument. Just smile and agree with them and be glad that they are still able to communicate.

**Saying things that are rude or sexually inappropriate:** Dementia damages a person's social filters and social graces resulting in a lack of understanding for what is appropriate and what is not. Embarrassing and awkward situations can arise! Despite this, one should not **SCOLD** or **HUMILIATE** the person with dementia. Help them to save face. Gently remind them that what they are saying is "inappropriate" or downplay or ignore.

**Becoming argumentative:** Because of their memory loss, a person with dementia will be very likely to argue with you over things that they don't remember. On top of this, a person with dementia loses the art of reasoning and the ability to follow a logical assumption. Therefore, arguing is pointless. If the person starts an argument, or says something you don't agree with, let it go. With the short term memory loss, you will win an argument only to have your words forgotten shortly thereafter! What's the point? You will be wasting your breath and causing unnecessary feelings of anger and frustration for both of you. **AVOID ARGUING AT ALL COSTS.**

**Word Salad:** As the dementia progresses, a person with dementia may speak using jumbled up words and sentences, known as "word salad". Smile and nod and pretend you understand even if what they are saying makes no sense. Remember that they are trying their best to communicate. You can try and ask a few questions for clarification and see if that helps. If you can't figure out what they are saying, just smile and change the subject or distract them with a task.

**Loss of language ability:** A person in the advanced stages of dementia may lose the ability to speak all together, resulting in nonverbal communication such as hitting or kicking, grabbing, picking at self or an object, repetitive movement or sounds, or uncontrolled laughing or crying, or walking around zombie like with no expression. Caregivers must learn to pay close attention to nonverbal body language in order to meet care needs.

## **Tips for Communicating:**

- Gain the person's attention before you begin talking to them.
- Call them by name.
- Be patient. Allow enough time for a response.
- Try not to interrupt. Allow them to finish their chain of thought.
- Maintain good eye contact showing them that you are interested in what they have to say.
- Choose simple words and short sentences if necessary.
- Avoid talking to them as if they were a baby or a child.
- Avoid talking about them in front of them as if he/she weren't there.
- Reduce background noise.
- Repeat as necessary, but avoid repeating things too much. Try to rephrase or find a different way of saying something if they aren't comprehending.

## **2 Interaction Do Nots**

- **Do not ask DO YOU REMEMBER** "any subject or person"?  
Chances are a person with dementia doesn't remember "any subject or person" but they will smile and nod their heads and panic on the inside because they can't remember.
- **Do not take anything they do or say to you personally.**  
Dementia causes people to say and do things that may be embarrassing or hurtful to you. It is not them being mean or evil...it is the dementia that is damaging their brain. They are not doing it on purpose!

## **Conversation is stimulating to the brain.**

Keeping a person with dementia engaged in conversation is very good for them and is stimulating to their brain. Conversing with them makes them feel valued and loved. Conversation triggers old memories and kicks in old social tapes. Caregivers should initiate conversation and interact with persons with dementia as much as possible. Depending on the level of dementia and personality, some participants will be more conversational than others.

## **Conversation Starters:**

When and where were you born?

Did you have any siblings?

What are some of your early childhood memories?

Who were your parents?

Tell me about your parents.

Tell me about your grandparents.

Did you attend school and where?

Do you have any special memories from school?

What did you do as a young adult?

Did you attend college? What degrees or certificates did you achieve?

Were you married? How did you meet your spouse?

Did you work? What kind of career(s) did you have?

Were you in the service?

Did you have children? How many? Where do they live?

Do you have any grandchildren? How many? Where do they live?

What are some fond memories of raising children? What is one piece of advice you would give about child rearing?

Who were some of the influential people in your life?

What were some of your greatest accomplishments?

Are you religious? Tell me about your church.

Did you ever do any traveling? Where?

Do you or did you have any hobbies?

Do you or did you have any pets?

Do you like music? What kind? Do you sing?

Do you like art, theatre, museums?

Tell me about retirement?

What are your fondest memories after retiring?

What were some of the things you had to get used to?

How did things change after retirement? How did you adjust?

Have you had any major health issues in your life?

What do you enjoy doing for fun now?

Who are the most important people in your life now?

What is it that you want others to remember about you when it is your time to go?

## Keep a sense of humor!

Funny and bizarre things are frequently said and done in the world of dementia. People with dementia will do things that are extremely funny and it is okay and good for you to laugh. People with dementia will laugh at themselves and it's perfectly okay to laugh with them. Just make sure you are laughing with them and not pointing out their mistakes.

Find and create as many moments of joy and laughter as possible.

Record these moments. Cherish these moments. Share these moments...they usually make great stories at parties!

## Laughter

Laughter is truly a miraculous phenomenon, impacting all. Laughter in the face of dementia is imperative.

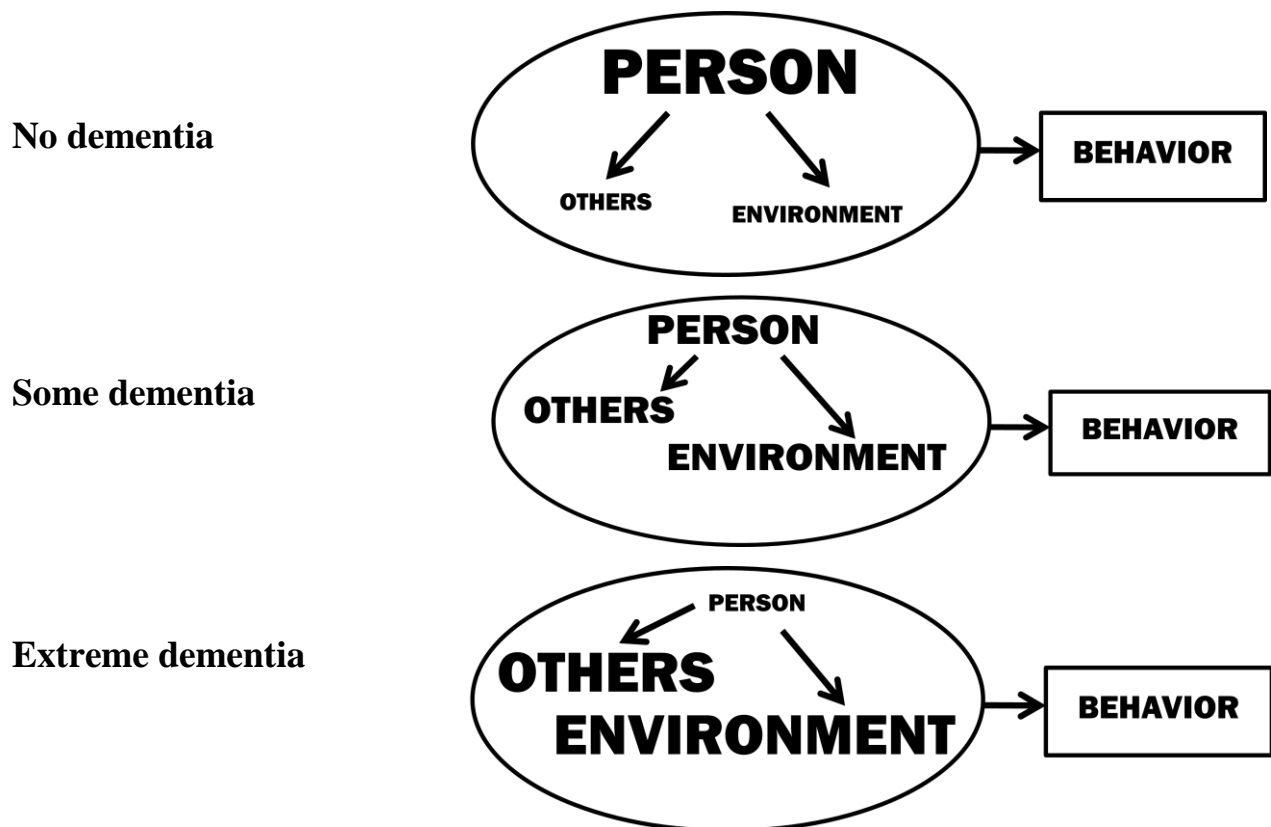
- **Laughter relaxes the whole body.** A good, hearty laugh relieves physical tension and stress, leaving your muscles relaxed for up to 45 minutes after.
- **Laughter boosts the immune system.** Laughter decreases stress hormones and increases immune cells and infection-fighting antibodies, thus improving your resistance to disease.
- **Laughter triggers the release of endorphins,** the body's natural feel-good chemicals. Endorphins promote an overall sense of well-being and can even temporarily relieve pain.
- **Laughter protects the heart.** Laughter improves the function of blood vessels and increases blood flow, which can help protect you against a heart attack and other cardiovascular problems.
- **Laughter dissolves distressing emotions.** You can't feel anxious, angry, or sad when you're laughing.
- **Laughter helps you relax and recharge.** It reduces stress and increases energy, enabling you to stay focused and accomplish more.
- **Humor shifts perspective,** allowing you to see situations in a more realistic, less threatening light. A humorous perspective creates psychological distance, which can help you avoid feeling overwhelmed.

# ENVIRONMENT

Everyone is affected by their environment. People with dementia seem to be even more sensitive to the environment. Factors such as how much light or lack of light, how much clutter or lack of clutter, how much noise or lack of noise, how familiar or unfamiliar, how crowded or uncrowded, the temperature of the room, and the actions of other people can all have an impact on the person with dementia and their behaviors. This is probably because a person with dementia has difficulty making sense of things and often their brain doesn't interpret what they see correctly.

Too much noise, being too hot or too cold, visual clutter, or inability to see in low light may all contribute greatly to a person's level of confusion and/or agitation.

**People with dementia are more influenced by others and the environment than are people without dementia.** Knowledge and understanding of this can help caregivers have a greater influence on the behaviors of the person with dementia. Caregivers should use this to their advantage!



Adapted from the Savvy Caregiver program,  
Alzheimer's Association

## **Familiar & Comfortable Environments**

A person with dementia may not recognize a familiar environment. They may not remember how to find a room in their home such as their bedroom or the dining room or patio. A person with dementia may say they want to go home, even when they are already home. They may be looking for their childhood home and their parents.

It is believed that surrounding a person with dementia with their own familiar and loved objects in a homelike environment fosters a level of comfort and helps spark their memories. Surrounding one with their own familiar furniture and pictures, knick knacks, jewelry, and trinkets can be beneficial. This is especially true in the early stages of dementia but may become less effective as the dementia progresses. It is also important to mention that at some point valuable items should be “replaced” or traded for items with no sentimental value or dollar value in order to protect the real item from getting lost or misplaced.

## **10 Things to Remember When Working With Persons With Dementia**

- 1. Never argue with them – you can't win. Instead, agree with them, then distract them or come up with alternatives.**

Every time it is time for Mrs. Smith's shower, she claims that she had one yesterday. Instead of telling her she is a liar and you know she didn't have one the day before because she stinks, suggest that a nice, warm shower will help her relax before bedtime.

- 2. You may have to repeat yourself several times – be patient.**

There is no "may" in this. You *will* have to repeat yourself constantly.

- 3. Don't let anything surprise you.**

This means anything. One patient flushed her dentures down the toilet. One gentleman urinated on the house dog. One woman strolled down the hallway naked during a Christmas concert. Some may have BMs in trash cans. One lady itched, so she rubbed liquid soap all over herself.

- 4. They were busy their whole lives, and still want to be useful. Let them help with tasks they can still do.**

You would get bored sitting and watching TV all day, wouldn't you? They can help in many ways, get creative. They can help sweep the dining area after meals, fold rags or towels (some facilities keep a basket of cloths for just the residents, once they fold the basket, take it into another room, shake them all and, and return, telling them another load just came out of the dryer.) Some like to dust, help with the dishes, serve snacks, etc. They can help with many things that are not complicated. Being active may even reduce the appearance of some behaviors.

- 5. The person with dementia is not doing these things to irritate you.**

It may seem like, at times, they are doing these things just to irritate you. Keep in mind that it is the disease, and if they had full mental capacities, they would not be having these behaviors.

**6. Don't be afraid to laugh.**

You will go mad if you can't laugh at some of the situations you are faced with. One gentleman could dress himself – except he sometimes put his pants on backwards. On those occasions, he would come out – with his pants neatly buttoned and zipped up – in the back. I'm not even sure I could do that! Another time, we were getting the floors in the house re-tiled. We blocked off that area of the house as well as we could. Later, we heard one of our residents calling. We found her in the blocked off area. She had sat down in the glue and her shoes and the seat of her pants were stuck to the floor!

**7. Alzheimer's is not contagious.**

Don't be afraid to hug, kiss, or rub their back. Often, this can decrease agitation and wandering. No matter how much of their mind is destroyed, their hearts are not damaged. They still need affection and love, and can give love back.

**8. Remember the Tortoise and the Hare.**

Go slowly, and do one thing at a time. Being hurried, or trying to do multiple tasks at once will only confuse and frustrate the person with dementia, and yourself. Don't say "lets go take a shower, brush your teeth, and get ready for bed." That may overwhelm the person. Instead, first take them to their room, away from chaos and noise. Break down each task into as small of steps as possible. To undress, for example: untie right shoe, remove, untie left shoe, remove, take off socks, unbutton pants, pull pants down, sit on chair, remove pants, etc....

**9. Don't get frustrated – get creative.**

"Mary" gets up several times a night. Every time she awakens, she thinks it is time to get up. So she dresses as well as she can, gets her purse, and heads towards the dining room. The aides then have to take her back, change her back into her nightclothes, and put her back in bed. This happens many times a night. Instead of getting frustrated, try putting a note on her mirror or closet that tells her to go back to bed. Or perhaps just leaving her bedroom door open so you can catch her as soon as she wakes up, instead of after she is dressed.

**10. First impressions are important.**

Farther along in the disease process, all short term memory is gone. You may talk to them, walk away, return 2 minutes later, and they will not know you. You are always a new person. Therefore, always greet them with a smile and a pat, even if you have just spent time with them. Act like you are excited to see them. Ask how they are. They will respond better to any requests that you make.



## CHAPTER 3

# BEHAVIORS AND INTERVENTION STRATEGIES



**After completing Chapter 3 you will know some of the typical behaviors expected with dementia and Alzheimer's and you will learn intervention strategies for dealing with them.**



## **Dementia Behaviors**

People with dementia will behave in ways that can create difficulties and challenges for themselves and their caregivers. Dementia compromises a person's social graces, and this can lead to awkward and embarrassing situations. People with dementia lose the ability to make good decisions about their own safety or the safety of others, and this can lead to dangerous situations that require the need for intervention by others, namely their caregivers.

People with dementia are unique individuals, and each unique individual will exhibit behaviors unique to them. There are classic dementia behaviors, however, that are common and most likely to occur. Behaviors will come and go with the progression of the dementia.

In simplistic terms, caregivers of persons with dementia will spend their time trying to get a person with dementia to do something, or, trying to get a person with dementia to stop doing something!

### **Possible/probable behaviors and difficulties to expect in the *early stages* of dementia:**

These are the same “behaviors” that were discussed in Chapter 1: Overview of Dementia and Alzheimer's, as the early warning signs and symptoms of dementia. (see Chapter 1, page 15)

- **Short term memory loss that affects daily life**
- **Difficulty performing familiar tasks**
- **Problems with language and conversation**
- **Disorientation to time and place**
- **Poor or decreased judgment**
- **Problems with numbers and money**
- **Misplacing things**
- **Problems with hygiene**
- **Changes in personality and behavior**
- **Loss of motivation and initiative**

## Responding to difficulties in the early stages:

A family's or caregiver's goal at this stage of dementia is to preserve the person's feelings and dignity, and help them maintain as much independence as possible.

### How:

- Do not point out or make a big deal about their mistakes.
- Cue and help them as much as possible with visual, verbal and written reminders.
- Answer repeated questions in a calm and supportive voice as often as necessary.
- Avoid arguing, and trying to reason or convince.
- Continue to do as many things as you can that you have always done: travel, eat out, movies, concerts, visit family, hobbies, etc.
- **Do whatever it takes to help the person save face and feel independent.**

Remember, people in the early stages of dementia are just beginning to struggle against the cloud of confusion which will gradually envelope them. Their family or caregiver must try to help them feel calm and in control, safe and secure, reassured, respected, and loved. The goal is to help them find joy and happiness in spite of the fear and confusion. **THE CAREGIVER MUST LEARN TO BALANCE THE NEEDS OF THEIR LOVED ONE WITH THEIR OWN NEEDS.** This can be difficult and tricky.

## Transitioning, and changing roles:

The early stages of dementia can be a very challenging time, not only for the person with dementia, but especially for the person who will take on the role of primary caregiver/copilot. This person, most often a spouse or adult child, must transition into their new role and take on new responsibilities. This is no easy feat. At the same time they are transitioning, they are experiencing an emotional rollercoaster of sadness, anger and loss. Plans and hopes for the future have been dashed. Dealing with uncharacteristic personality changes and bizarre and unexplainable behaviors can be overwhelming, frightening, and exhausting. Finding support from others, and learning techniques and tips for dealing with these new and challenging behaviors is the best line of defense and hope for survival. Preparing oneself for what to expect is empowering.

## **Possible/probable challenging behaviors to expect as the dementia progresses, which will happen along with the *early* stage behaviors already occurring:**

**Shadowing:** following their caregiver from room to room, afraid to let them out of their sight

**Wandering/Elopement:** leaving the safety of their home or caregiver, by foot or in a vehicle, in search of some place or somebody, or just because they want the freedom and independence of walking or driving alone, oblivious to their lack of ability to find their way back

**Tearfulness:** constantly crying over something from the past, or some real or falsely perceived injustice, or just sadness and frustration with their situation

**Uninhibited actions and language:** loss of social graces resulting in rude or embarrassing behavior, sometimes sexually inappropriate

**Sundowning:** becoming more anxious or agitated or confused in the late afternoon or evening...this is considered a common and universal phenomenon in the world of dementia (See handout on page 67)

**Shopping/hoarding:** picking up of items and moving or hiding them on their person, in their purse, or in odd places...can be their own items or those belonging to others...can often hoard or collect food with the danger of it spoiling

**Wanting to go home:** expressing the desire to go home...sometimes even when they are home...due to not recognizing a familiar place or perhaps being back in time in their minds to previous homes

**Night time wakefulness:** inability to stay on normal day and night time schedules...often waking up in the middle of the night to get dressed and go to work

**Agitation:** anxious and irritable and nervous with no apparent cause other than the dementia

**Pacing:** inability to sit calmly and relax...a mysterious innate need due to the dementia to be on the move, often to the point of exhaustion

**Repetitive noises:** making an odd sound or noise over and over

**Delusions resulting in suspicion and accusation:** paranoia and falsely perceived ideas (i.e. others are out to get them or steal from them, or spouse cheating on them)

**Hallucinations:** seeing, hearing, tasting, or smelling things that are not really happening - sometimes pleasant, sometimes frightening

**Obsessions:** obsessing over items or routines or food

**Talking to the mirror:** talking to their own reflection in the mirror as if it were another person

**Arguing or Anger:** anger and upset due to impaired social graces and falsely perceived ideas that others have done something to them

**Combativeness in personal care:** uncooperativeness, most commonly with bathing, due to fear or confusion as to what is happening to them, or belief that they have already bathed

**Childlike behavior:** reverting back to childhood in both voice and actions, going backwards in time as the dementia progresses

**Undressing in public:** removing clothing due to being confused, hot, or feeling restricted

**Getting stuck:** physically stuck in a closet or room after walking in there and unable to figure how to get out

**Damaging household tools or equipment:** trying to use or fix equipment that they don't remember how to operate resulting in damage or danger

**Incontinence and going to the bathroom in inappropriate places:** loss of the ability to control bowel and bladder, plus loss of the memory of how to use the toilet or recognize a toilet

## **Dealing with challenging behaviors:**

Caregivers are often in hopes of discovering a magic answer for dealing with a dementia behavior. While there are strategies a caregiver should try with a trial and error approach, there is rarely a magic answer. Dealing with dementia behaviors requires a lot of creative problem solving and an understanding that what solution works today, may not work tomorrow. People with dementia are often inconsistent and unpredictable. Dealing with dementia behaviors can be very difficult and stressful.

There will be many times when there is absolutely nothing a caregiver can do to change or stop a behavior, resulting in the need for extreme patience and tolerance and acceptance.

There will also be many times when a caregiver can successfully modify or stop an unwanted behavior by discovering triggers and by trying various strategies. Knowing an individual's happy buttons and upset buttons is also very helpful.

Behaviors can also be stopped or modified by changing the environment.

## **When faced with a challenging behavior the first step (1) is to decide if intervention is really necessary.**

Some behaviors are annoying and irritating, but not really harmful in the big scheme of things. Sometimes these behaviors are giving the person with dementia something to do and keeping them busy or entertained. If this is the case, intervention is not always necessary. (example: taking all the clothes out of a closet)

Some behaviors compromise the safety, health, or dignity of the person with dementia or the other people in the environment. These behaviors require intervention. (example: hitting others, peeing on the floor, taking off clothing)

## **Second step (2) is to analyze the environment or physical needs of the person with dementia for triggers:**

People with dementia can be very sensitive and influenced greatly by what is happening in their environment. Knowing and understanding this gives caregivers an advantage. Behaviors can be triggered by the list below. Fixing or changing the situation or environment can oftentimes modify or stop behaviors. Caregivers do have the power to change some of these influences\*.

- Other people\*
- Caregiver approach\*
- Noise and/or lighting\*
- Task too complex\*
- Skewed perception of environment due to the dementia

Physical issues or needs which the person with dementia may not be able to express verbally can also trigger behaviors:

- Effects of medications\*
- Impaired vision/hearing
- Illness
- Dehydration or hunger\*
- Constipation\*
- Depression or fatigue

Some behaviors are just the result of the CONFUSION, caused by dementia, leading to frustration, fear, or discomfort.

## **The third step (3) when intervention is necessary, is to try one of the following Caregiving Strategies:**

There are 9 potentially effective CAREGIVING STRATEGIES to use on people with dementia that may help stop challenging behaviors or may help initiate necessary tasks: Distraction, Gentle Guidance, Therapeutic Fibbing, Validation, Reassurance, Best Friend Approach, Prevention, Simplification, and Walk Away.



## **Distraction (Redirection)**

Distraction (also called redirection) is the most important strategy to learn when caring for a person with dementia. Distraction takes advantage of the loss of short term memory. Distraction is the technique you will usually try first when trying to stop a challenging behavior, and you will frequently use it along with the other techniques. Knowing the individual's history, family, likes and dislikes, happy buttons, and upset buttons will give you lots of material for distraction:

### ***Examples of Distraction:***

- “Tell me about your husband, Jack?” (children, pets, first love, career, home, etc.)
- “Let's go into the kitchen for a snack.” (chocolate, sweets, beverage, etc.)
- “Give me a hug!”
- “Let's put on some music and dance!”
- “Look at that beautiful sky!” (tree, sunset, mountain, flower, etc.)
- “What a beautiful outfit you have on.” (shirt, shoes, vest, sweater, etc.)
- Break out into song
- Pop in a favorite video

## **Gentle Guidance**

Often when you ask a person with dementia if they want to do something, such as take a bath, go with you to the store, etc., they will say “no”. In many cases, especially if it is necessary that a task get done, IT IS BETTER NOT TO ASK. These instances call for gentle guidance. Simply physically guide the person to and through the activity, staying very calm, gentle, and in control. Take their hand and lead them. Use conversation as a distraction at the same time you are employing gentle guidance. Give the person a part of the task to do to distract and make them feel independent and useful. (Example, give them a washcloth and have them wash their own face while you are washing their hair.)

## Therapeutic Fibbing

We've all been taught not to lie. In the world of dementia, the rules change. It is okay for caregivers to tell a person with dementia "little white lies" to preserve their loved one's feelings. Caregivers might have to tell their loved one a little fib to keep them safe, to calm their fears, to keep from hurting their feelings or causing emotional pain, or to get them to do something. Below are some examples of therapeutic fibbing. If a caregiver is not comfortable with using the strategy of therapeutic fibbing, then they just have to rely more on the other techniques.

***Keep them safe:*** Therapeutic fibbing is often necessary to keep a person with dementia from doing something that is no longer safe for them to do independently.

***Scenario:*** A person with dementia is showing many signs of unsafe driving, however, he believes his driving abilities are just fine and insists on continuing to drive.

***Possible fib:*** "The car is broken. It's in the shop for repairs." (When in reality you have removed the car or disabled it.)

*or*

***Scenario:*** A person with dementia is showing many signs of being unsafe living alone, however, she believes she is still perfectly capable, and doesn't want to leave her home.

***Possible fib:*** "The landlord has sold your house. I need you to live near/with me so we can be together more often and so you can help me with the children." (When in reality the time has come when living alone is no longer safe.)

***Calm their fears:*** Therapeutic fibbing will also preserve a person's feelings if they are fearful or upset due to a skewed perception of reality.

***Scenario:*** A person with dementia thinks people are trying to get in the house at night.

***Possible fib:*** "The police are driving by each night to keep an eye on our house and I've installed a burglar alarm to keep out intruders." (When in reality, you know the person with dementia is hallucinating, and there is no need for the police to be notified.)

***Prevent emotional pain:*** Therapeutic fibbing will also preserve a person's feelings if they have forgotten a tragic event in their past.

***Scenario:*** A lady with dementia keeps asking where her husband is. Her husband, died 5 years ago. He was a farmer.

***Possible fib:*** "I haven't seen Jack today. Perhaps he is out working in the fields." (If people are told each time they ask that their loved one has died, they frequently experience the grief over and over. It is kinder not to tell them.)

***Coax Person with Dementia to Do Something:*** Therapeutic fibbing may also help you accomplish a task that needs to be done.

***Scenario:*** A person with dementia needs to take a bath as they have not had one for several days, but they are resistant.

***Possible fib:*** "We have to get cleaned up today because we are expecting company." (When in reality, no one is coming, and you're pretty sure they will forget this, but you need them to take a bath.)

It helps to follow a therapeutic fib with a distraction so you can get the person on to a less sensitive topic. "Let's go into the kitchen for a snack and then watch that movie we've been wanting to see."

## Validation

Like all of us, a person with dementia has the right and *needs* to express feelings of sadness, anger, despair, or whatever. We all have times when we need to vent, and venting makes us feel better. When caring for a person with dementia, most of us work hard to keep that person calm and happy, so we forget that they sometimes need to vent. We often, with best intentions, try to stop them from venting and this can sometimes make them even more upset. Think how you would feel if someone said to you, "Oh, honey, you don't need to be upset," when you really have something that you are truly upset about! Wouldn't those words make you mad?

Validation is a technique where we listen with heartfelt empathy to the beliefs and feelings of the person with dementia, then verbally express our understanding by using similar words, tone and volume, back to the person. "Someone stole your purse and you are sooo angry! Oh my gosh, I can't believe someone stole your purse. This would make me so angry, too!" This validates their feeling, and makes them feel that you believe them and understand.

Validation then goes a step further. Once you have verbally expressed belief and understanding to the person with dementia, and allowed them to vent for awhile, next try to deescalate the situation by calming *your* tone and lowering *your* volume. You might also offer a solution, if there is one, to help further deescalate the situation. “Let’s search for your purse together. Maybe whoever took it dropped it somewhere.” A nice stop in the kitchen for some cookies or chocolate might be a good distraction as well. A person with dementia will often mirror the feelings and tone of those around them, so if you validate their feelings and beliefs, then project calm and quiet, this often helps.

**Scenario:** A lady with dementia is mad and upset because she believes her son has brought her to adult day care without telling her he was going to do so, and she doesn’t understand why she can’t stay home alone. (It’s her first day, and he did tell her, but of course she forgot that she agreed to give it a try!)

**Validation:** “Oh my gosh! I can’t believe your son brought you here without telling you he was going to. You must be really really mad! I bet you are going to tell him a thing or two when he comes to pick you up”. ...then let her vent some more...then try and deescalate by asking, “Is he your only son? What kind of work does he do?” (You are then trying to distract by changing the subject.)

The opposite of validation would be the dismissal of her belief and feelings.

“Yes, your son did tell you he was going to bring you and you agreed to it. You are not able to stay home alone by yourself. Don’t worry, you’re going to have lots of fun here.” (This will probably make her madder, because in her mind she believes that he did not tell her, and that she *can* stay home alone.”

### **A side note about “Validation Therapy”:**

“Validation Therapy” was created by Naomi Feil between 1963 and 1982, based on her beliefs and care of people with dementia. Her book, *The Validation Breakthrough*, is widely acclaimed. The above description of “validation” was adapted and greatly simplified from Feil’s teachings. Feil’s process of validation therapy is much more complicated and in depth than what has been described above.

## **Reassurance**

A person with dementia lives in a world of confusion. They live on a sinking ship and their caregiver is their life preserver. They hang on to that life preserver in an attempt to feel some sense of control and safety. They need constant reassurance with words and affection from their caregiver/co-pilot/life preserver. Many behaviors are simply an expression of this need for reassurance.

- When a person with dementia asks the same question over and over – they need reassurance.
- When a person with dementia doesn't remember a name or a word – they need reassurance.
- When a person with dementia feels their independence slipping as they lose their car, their home, control of their finances – they need reassurance.
- When a person with dementia follows their caregiver around like a shadow – they need reassurance.
- When a person with dementia feels scared, depressed, overwhelmed, frustrated – they need reassurance.

People with dementia are often in a different place in time in their minds, often back in their past. It used to be the practice to employ “Reality Orientation” which meant saying to them, “No, you are not a kid back in Kansas. Your parents are both deceased. You are 89 years old and now live in Colorado.” This type of reassurance is no longer believed to be the best approach, and is not that effective anyway due to the memory impairment. It is now believed that it is kinder and okay to just go along with where the person with dementia is in their mind, and ask them questions to spark reminiscing or conversation. “What is it like growing up in Kansas? What do your parents do for work?” A good rule of thumb is: if reassuring the person with the real truth calms or satisfies them...do it. If the real truth distresses them...don't tell them.

## **Best Friend Approach**

The Best Friend Approach was discussed in Chapter 2 with regards to interaction and communication because people with dementia usually respond positively when treated in the fashion of a best friend. This approach is also a very effective strategy for stopping or intervening with a behavior. The caregiver simply calls the person's name and acts as if they are extremely happy and joyful to see their long lost friend! It is similar to distraction, and often will stop a person in their tracks, with a huge smile, as they react to the caregiver's enthusiasm and tone of voice.

## **Prevention**

A person with dementia is often triggered by what he/she sees in their environment resulting in a behavior or action. For example, a set of car keys lying on the counter might trigger a person to want to drive. Caregivers should constantly assess the environment for triggers and remove them when necessary. The old saying, “Out of sight, out of mind,” is really applicable when caring for people with dementia. Some behaviors can be prevented by simply removing an item (the trigger) from the environment.

## **Simplification**

A person with dementia can get frustrated at tasks that are too complicated, resulting in anger and depression and embarrassment. They are often aware that they used to be able to do something, and the fear and anger at the loss of that ability can cause them to overload. Caregivers should closely watch a person with dementia for signs of frustration, and if able, simplify the task by breaking it into a smaller part, or quickly help them complete the task, all the while praising them for their efforts.

## **Walk away & try later**

There are times when a caregiver tries every technique to get a person with dementia to complete a task, or stop a behavior, and nothing works.

When this happens – walk away and try later. Later can be in 5 minutes, one hour, or the next day. Short term memory loss is an advantage at these times!

This is not failure. This is just part of the challenge of dealing with dementia.

## **Practice Scenarios: Would you intervene, and if so, how?**

Mrs. Smith and Mr. Jones have dementia. How would you respond to each of these behaviors? What technique(s) would you use? **THERE ARE NO RIGHT OR WRONG ANSWERS.** Think about how you would handle the situation, then read the suggestions on the next page.

### **Scenarios**

1. You are visiting the family in their home, and Mrs. Smith asks you where you work over and over.
2. Mr. Jones lives in an assisted living. You go to visit him and he asks you when his wife is coming. You know that his wife died a year ago.
3. Mr. Jones is peeing in the trashcan instead of using the toilet.
4. Mrs. Smith is trying to set the table for dinner. She is getting frustrated because she can't remember where to properly put the knives, forks, and spoons.
5. Mr. Jones believes you have stolen his car.
6. Mrs. Smith wants to go home. She doesn't recognize or understand that she is already at home. The more you try to explain this to her, the more she gets upset.
7. Mrs. Smith is taking all the clothes out of her closet and piling them on the bed.
8. Mr. Jones is coming to the kitchen every 5 minutes saying he is hungry, even though he was just served lunch an hour ago.
9. Mr. Jones wants to "fix" the vacuum cleaner which is working just fine. He is starting to take it apart.
10. Mr. Jones wants to drive the car. His driving ability is greatly impaired at this point. He adamantly insists that he be allowed to drive, and gets angry and screams when told that he cannot.
11. Mrs. Smith has not gotten out of her room all day, and refuses all invitations to join others in the dining room.
12. Mrs. Smith is crying for her mother. She is wandering around looking for her and crying because she is worried about her.
13. Mr. Jones has recently been placed in a secure (locked) care facility. He is very angry and wants out. Staff has tried to engage him in activities, with food, and with music to no avail. Staff has tried to validate his anger and it makes him angrier.

## POSSIBLE WAYS TO RESPOND:

1. You are visiting the family in their home, and Mrs. Smith asks you where you work over and over. I WOULD SMILE EACH TIME SHE ASKS AND ANSWER HER OVER AND OVER, PRETENDING AS IF I WAS HEARING THE QUESTION FOR THE FIRST TIME. MY GOAL IS TO MAKE HER FEEL SOCIAL AND CONVERSATIONAL, AND NOT STUPID BY POINTING OUT THAT SHE IS REPEATING HERSELF. **(Strategy: no intervention needed)**

2. Mr. Jones lives in an assisted living. You go to visit him and he asks you when his wife is coming. You know that his wife died a year ago. I WOULD SMILE AND TELL MR. JONES THAT I DON'T KNOW WHEN HIS WIFE IS COMING BECAUSE I HAVEN'T SEEN OR TALKED TO HER. I WOULD THEN ASK HIM QUESTIONS ABOUT HIS DAY OR SOMETHING IN HIS ROOM TO CHANGE THE SUBJECT AND DISTRACT HIM ONTO ANOTHER TOPIC. I WOULD NEVER TELL HIM THAT HIS WIFE HAS BEEN GONE FOR A YEAR. THIS MIGHT CAUSE HIM TO RELIVE THE GRIEF, AND CHANCES ARE HE WILL FORGET MY RESPONSE SHORTLY ANYWAY AND ASK AGAIN. I DON'T WANT HIM TO RELIVE THE GRIEF EACH TIME. **(Strategy: Distraction)**

3. Mr. Jones is peeing in the trashcan instead of using the toilet. I WOULD REMOVE THE TRASHCAN OR PLACE IT OUT OF MR. JONES SIGHT IF POSSIBLE. I WOULD DIRECT HIM TO THE TOILET EVERY COUPLE OF HOURS AND HOVER CLOSE BY TO OVERSEE AND ASSIST HIM USING THE RIGHT VESSEL. I WOULD NOT TRY AND TALK TO HIM OR LECTURE HIM ABOUT PEEING IN THE RIGHT PLACE...HE WON'T REMEMBER OR POSSIBLY UNDERSTAND. **(Strategy: Prevention)**

4. Mrs. Smith is trying to set the table for dinner. She is getting frustrated because she can't remember where to properly put the knives, forks, and spoons. SINCE SHE IS FRUSTRATED, I WOULD QUICKLY STEP IN AND HELP HER AND PRAISE HER EFFUSIVELY FOR DOING SUCH A GOOD JOB AND BEING SUCH A GREAT HELP. NEXT TIME I WOULD PUT THE FORKS AND KNIVES DOWN MYSELF, THEN ASK HER TO ADD THE SPOONS. THIS MIGHT BE EASIER FOR HER. IF SHE COULD NOT DO THAT, I WOULD AVOID GIVING HER THIS TASK AGAIN AS I DON'T WANT TO SET HER UP FOR FAILURE AND FRUSTRATION. **(Strategy: Simplification)**



5. Mr. Jones believes you have stolen his car. I WOULD TELL MR. JONES, “NO, I DID NOT STEAL YOUR CAR, BUT MY GOODNESS, WHAT ON EARTH COULD HAVE HAPPENED TO IT...YOU MUST BE VERY UPSET...I CAN’T IMAGINE HOW I WOULD FEEL IF SOMEBODY STOLE MY CAR.” **(Strategy: Validation)** I AM SHOWING HIM I UNDERSTAND HOW UPSETTING IT MUST BE. I WOULD THEN START ASKING HIM QUESTIONS ABOUT THE VARIOUS CARS HE HAS DRIVEN...WHAT IS HIS FAVORITE...HOW OLD WAS HE WHEN HE GOT HIS LICENSE... WHERE DID HE LEARN TO DRIVE. **(Strategy: Distraction)** MY GOAL IS TO GET HIM REMINISCING ABOUT DRIVING, AND WORK MY WAY INTO CHANGING THE SUBJECT ONCE I GET HIM OFF THE “STOLEN” ASPECT. I WOULD NOT TRY TO CONVINCE HIM THAT HIS CAR HAS NOT BEEN STOLEN, OR TELL HIM THAT IS SILLY OR RIDICULOUS. THIS WOULD MAKE HIM FEEL STUPID AND PROBABLY MAKE HIM ANGRIER.

6. Mrs. Smith wants to go home. She doesn’t recognize or understand that she is already at home. The more you try to explain this to her, the more she gets upset...I WOULD IMMEDIATELY STOP EXPLAINING AS THIS WAS MAKING HER MORE UPSET. I WOULD GET HER ONTO ANOTHER TOPIC WITH OFFERS OF FOOD, SINGING, WALKING, REMINISCING, PLAYING A GAME, ETC. **(Strategy: Distraction)**

7. Mrs. Smith is taking all the clothes out of her closet and piling them on the bed. IF THIS WAS MAKING HER HAPPY, I WOULD LET HER KEEP DOING IT. YES, IT WILL CAUSE MORE WORK FOR ME TO PUT THEM AWAY...BUT WHO CARES. MAYBE I’LL PUT THEM AWAY WHEN SHE’S NOT AROUND. I MIGHT TRY GETTING OUT A SUITCASE AND SEE IF SHE WILL FOLD THEM TO PUT THEM IN THE SUITCASE. I WOULD NOT GET MAD OR SCOLD HER FOR MAKING A MESS. THIS WOULD MAKE HER FEEL STUPID. **(Strategy: no intervention needed)**

8. Mr. Jones is coming to the kitchen every 5 minutes saying he is hungry, even though he was just served lunch an hour ago. I WOULD REMIND HIM IN A SWEET VOICE THAT HE JUST ATE, BUT I WOULD ALSO PULL OUT SOME TYPE OF HEALTHY LOW CAL SNACK AND GIVE THAT TO HIM...A COUPLE OF TIMES EVEN. IF HE WAS STILL ASKING FOR FOOD. AFTER THAT, I WOULD TRY AND GET HIM BUSY WITH ANOTHER TASK OR ACTIVITY TO TRY AND GET HIS BRAIN ONTO ANOTHER TRACK. **(Strategy: Distraction)**

9. Mr. Jones wants to “fix” the vacuum cleaner which is working just fine. He is starting to take it apart. I WOULD QUICKLY OFFER HIM FOOD IN THE OTHER ROOM OR ASK HIM TO HELP ME IN THE OTHER ROOM TO GET HIM AWAY FROM THE TASK. THEN, I WOULD TAKE THE VACCUUM CLEANER AND GET IT OUT OF SIGHT AND HOPE HE FORGOT ABOUT IT. I WOULD PUT IT WHERE HE COULD NOT FIND IT. IF HE ASKS ABOUT IT, I WOULD MAKE UP SOME EXCUSE THAT I LOANED IT TO ANOTHER FAMILY MEMBER. I WOULD NOT POINT OUT THAT IT WAS NOT BROKEN OR THAT HE WAS INCAPABLE OF FIXING IT. THIS WOULD MAKE HIM FEEL STUPID. **(Strategy: Distraction, Prevention, Therapeutic Fibbing)**

10. Mr. Jones wants to drive the car. His driving ability is greatly impaired at this point. He adamantly insists that he be allowed to drive, and gets angry and screams when told that he cannot. I WOULD STAY VERY CALM AND SOFT SPOKEN. I WOULD TELL MR. JONES THAT I UNDERSTOOD HOW ANGRY HE MUST FEEL AND HOW I KNEW HOW DIFFICULT THIS MUST BE FOR HIM. I WOULD MOVE THE CAR TO ANOTHER LOCATION SO IT WAS NOT A CONSTANT REMINDER. I WOULD CHANGE THE SUBJECT AND TRY AND DISTRACT WHENEVER THE DRIVING IS BROUGHT UP. I MIGHT TELL HIM THAT THE CAR IS IN THE SHOP IF HE KEEPS ASKING. IF THIS DOESN'T WORK, I WOULD ASK HIS PHYSICIAN TO WRITE A LETTER STATING HE CAN NO LONGER DRIVE AND CALMLY REMIND HIM OF THIS. I WOULD NOT GET INTO AN ARGUMENT WITH HIM. **(Strategy: Validation, Prevention, Distraction, Therapeutic Fibbing)**

11. Mrs. Smith has not gotten out of her room all day, and refuses all invitations to join others in the dining room. I WOULD COME INTO HER ROOM AND SAY “HELLO, MRS. SMITH!!!!!! IT HAS BEEN SUCH A LONG TIME SINCE I HAVE SEEN YOU!!!! HOW ARE YOU!!! I'M REALLY HUNGRY AND THOUGHT I WOULD GO DOWNSTAIRS AND GET SOME DINNER. I HEAR THEY ARE HAVING YOUR FAVORITE. I'VE GOT YOUR SWEATER. LET'S PUT THIS ON. COME WITH ME...HOW'S YOUR SON DOING?...I HEAR HE'S A CHIROPRACTOR? I NEED TO GET SOMEONE TO LOOK AT MY NECK...IS HE TAKING NEW PATIENTS?” **(Strategy: Best Friend Approach, Gentle Guidance, Distraction, Therapeutic Fibbing)**

12. Mrs. Smith is crying for her mother. She is wandering around looking for her and crying because she is worried about her. I WOULD PUT MY ARMS AROUND HER AND GIVE HER A HUG. I WOULD TELL HER THAT I HAVEN'T SEEN HER MOM BUT THAT I'M SURE SHE'S OKAY...SHE'S PROBABLY SHOPPING OR PREPARING DINNER. I WOULD LET HER CRY AND JUST SIT NEXT TO HER AND POSSIBLY HOLD HER HAND. I WOULD THEN TRY TO GET HER INVOLVED IN AN ACTIVITY OR LISTENING TO MUSIC. **(Strategy: Reassurance, Therapeutic Fibbing, Distraction)**

13. Mr. Jones has recently been placed in a secure (locked) care facility. He is very angry and wants out. Staff has tried to engage him in activities, with food, and with music to no avail. Staff has tried to validate his anger and it makes him angrier. I WOULD FIND OUT WHAT HIS FAVORITE MUSIC IS AND PUT THAT ON IN THE BACKGROUND. I WOULD JUST LEAVE HIM ALONE FOR AWHILE, BUT CONTINUE TO OFFER HIM FOOD AND BEVERAGE AND ACTIVITY OPTIONS EVERY 30 MINUTES OR SO. IF POSSIBLE, I WOULD TRY AND GET HIM TO SIT IN A SPOT THAT WAS NOT BY THE DOOR SO HIS ANGER WAS NOT FURTHER TRIGGERED BY PEOPLE GOING IN AND OUT. **(Strategy: Walk Away and Try Later, Prevention)**

## Dealing with Extreme Anger or Upset or Physical Violence:

There seems to be a myth in our society that *all* people with dementia and Alzheimer's turn angry and violent. This is definitely not true and is more the exception than the rule. On rare occasions a person with dementia may get extremely worked up and angry. More often than not, when a person with dementia is this upset, their fire has been fueled by an untrained and uneducated caregiver, or by another person with dementia. An untrained caregiver is probably arguing, or trying to reason and convince, or raising their voice back, or trying to physically force the person to do something. Or, the person may have a misperception about their caregiver that is causing them to be upset. Or they may be upset and irritated by the behaviors of another person with dementia.

The rules of thumb for dealing with an upset and angry dementia person are:

- Stay calm and low key *no matter what*
- Use a quiet and soothing tone and volume of voice
- Distract, validate, or walk away to diffuse the situation
- Analyze the environment for triggers and remove the person or others if necessary
- **DO NOT ARGUE, DO NOT TRY TO REASON OR CONVINCE, DO NOT RAISE YOUR VOICE, AND DO NOT TRY TO PHYSICALLY FORCE THE PERSON TO DO SOMETHING (unless they are in danger without your physical intervention) - ANY OF THESE ACTIONS WILL MORE THAN LIKELY ESCALATE THE SITUATION!**

## Using Medications to Help with Behaviors

If a person with dementia is continuously agitated, angry or distraught, to the point that they are miserable and making all of those around them miserable, it is sometimes helpful to speak to their physician about prescribing a medication. The goal is not to “drug” the person. The goal is to “take the edge off” their anxiety and make them more comfortable and less anguished. Each individual responds to medication differently. Some people may benefit. Some may show no change and some may even get worse.

The physician usually begins with a low dosage and increases it slowly. This is a safer approach for the person with dementia. It allows the physician to monitor the individual's response to a medication. Lower dosages allow the body to gradually adjust to the medication.

Generally, medications can produce only moderate changes. Caregivers must not change the dosage even if the behavior is still occurring. In fact, more of the medication could create more severe symptoms. Giving more medicine than prescribed can also create more side effects, which can be dangerous for the person with dementia. Only the physician should change dosages.

The caregiver should inform the physician of any other medications, vitamins and herbal pills the individual may be taking. The caregiver should consult the physician if side effects develop or if the medication is simply not working.

## **Types of Medications used for dementia behaviors**

There are several types of medications that caregivers and physicians can try with the person with dementia to help alleviate behavioral symptoms. These include antipsychotics, anti-anxiety meds, and anti-depressants.

### **Antipsychotics**

There is current debate and disagreement over the use and effectiveness of antipsychotic drugs with dementia patients. In 2005, the FDA warned that clinical trial data strongly suggested that antipsychotics increase the risk of death in dementia patients. The FDA does not suggest that doctors avoid the use of antipsychotic drugs in dementia patients. The warning is meant to help families balance the risks of these medications against their benefits.

The use of antipsychotic medication is intended to decrease psychotic symptoms. These symptoms may include hallucinations, delusions, excessive suspiciousness and paranoia. Other symptoms, such as agitation and aggression, are also frequently reduced with these drugs. In general, low doses of antipsychotics tend to be effective. The side effects of the antipsychotics are numerous and often the person with dementia cannot express how they are feeling. Therefore, it is very important for the caregiver to be aware of the following potential symptoms. They include: drowsiness, sensitivity to light, weight gain, dry mouth, shakiness, difficulty urinating, constipation, restlessness, blurred vision, dizziness, hypotension, stiffness, fast heartbeat, drooling, headache and shuffling gait.

If the person is routinely taking an antipsychotic, it is recommended that periodically a dosage reduction be tried by physician order only. This is to assess if the current amount of medication the person is taking is still necessary. The person may benefit from reducing the amount of medication, thereby reducing the potential side effects.

Antipsychotics drugs: Compazine (prochlorperazine), Haldol (haloperidol), Loxitane (loxapine), Mellaril (thioridazine), Moban (molindrone), Navane (thithixene), Orap (pimozide), Prolixin (fluphenazine), Stelazine (trifluoperazine), Thorazine (chlorpromazine), and Trilafon (perphenazine), Abilify (aripiprazole), Clozaril (clozapine), Fluphenazine (generic only), Invega (paliperidone), Thorazine (chlorpromazine), FazaClo, Orap (pimozide), Geodon (ziprasidone), Invega, Risperdal (risperidone), Seroquel (quetiapine), Zyprexa (olanzapine), and Symbyax (fluoxetine & olanzapine).

### **Anti-anxiety Medications**

The purpose of anti-anxiety medications is to reduce symptoms of anxiety and agitation and related insomnia. They may be more appropriate for controlling anxiety and agitation when the individual is not experiencing more severe psychotic symptoms, such as hallucinations and delusions.

Side effects can include: over sedation, dizziness, fatigue, drowsiness, light-headedness, depression, unusual excitement, headache, blurred vision, nervousness, irritability and breathing problems.

As with other medications, use of anti-anxiety agents may not be appropriate if the person has certain other medical conditions. The doctor will take this into consideration. Withdrawal from this type of medication should also be supervised by a doctor since there can be problems if the person has taken the medication for a long time.

Anti-anxiety meds: Xanax (alprazolam), Ativan (lorazepam), Oxazepam (generic only), Tranxene (clorazepate), Valium (diazepam) Serax, Klonopin (clonazepam) and BuSpar

Mood stabilizing and anticonvulsants: Depakote (divalproex sodium), Eskalith (lithium carbonate), Lamictal (lamotrigine), Lithobid (lithium carbonate), Neurontin (gabapentin), Tegretol (carbamazepine), Topamax (topiramate), Trileptal (oxcarbazepine)

Combination antipsychotic & antidepressants: Fluoxetine & Olanzapine (Symbax, Prozac, Zyprexa)

## **Antidepressants**

It is difficult to know how common depression really is in older persons. It can be masked by other physical problems or the symptoms can be similar to those of dementia.

The purpose of the antidepressants is to improve the mood, increase energy, appetite, sleeping habits and social functioning. Some depressions can be treated successfully and the person's mental status will improve. The person with dementia cannot always tell you they are feeling "blue" or why they are sad. The caregiver can be aware of the following depressive symptoms of sleeping problems, agitation, fatigue, isolation, loss of appetite, excessive crying, feelings of hopelessness, or a preoccupation with physical complaints.

There are differences between each of the antidepressant medications that should be considered in choosing the right treatment. Side effects may include nausea, vomiting, diarrhea, headache, insomnia, nervousness and tremor. Some antidepressants may take several weeks to reach a level where they have an effect.

Antidepressants: Elavil, Asendin, Wellbutrin, Celexa, Anafranil, Norpramin, Pristiq, Sinequan, Cymbalta, Lexapro, Prozac, Sarafem, Lubox, Tofranil, Marplan, Ludiomil, Remeron, Aventyl, Paxil, Pexeva, Nardil, Vivactil, emsam, Zoloft, Parnate, Desyrel, Surmontil, Effexor.

## **Pain Management**

People with Alzheimer's disease and other dementia usually lose the ability to accurately express bodily discomfort or pain. The pain the person experienced from other medical conditions such as arthritis may be present with Alzheimer's disease and other dementia. They will also experience other common discomforts such as headaches, muscle aches, back pain, toothaches and skin conditions, to name a few.

The caregiver will need to watch for signs of unexpressed pain. These signs could include but would not be limited to increased pacing, inability to rest or relax, decreased appetite and increased agitation. Discuss these signs with the physician and provide pain medication to the person as ordered. The effectiveness of the medication and potential side effects will need to be monitored closely.

## **Sleeping Medications**

Difficulty in falling asleep or awakening during the night without being able to go back to sleep, is frequently a problem for the person with Alzheimer's disease.

There are some medications that can be helpful for short-term use. Sleeping medications that will take days to be metabolized by the body or habit forming should be avoided. They will "build up" in the body and have adverse effects on the person with dementia. Consult with your physician to obtain the most effective medication. Sleep aids should only be used for a short time while other non-drug treatments are tried including avoiding caffeine, alcohol, and nicotine.

Sleep medications: Zolpidem, Zaleplon and Chloral Hydrate

## **Sexual Behaviors and Dementia:**

Sexually inappropriate behaviors are commonly seen in persons with mild to severe dementia, affecting up to 25% of patients. Behaviors can include anything from disrobing and rubbing genitals in public, to making sexual remarks and climbing into bed with another person. These behaviors can pose major challenges for families and for staff in care facilities. Current research shows that compassion, understanding and love are key to helping dementia caregivers cope with these situations.

One of these behaviors that can be especially difficult for spouses, families and caregivers to deal with is the development of a heightened sexual attraction to the person's spouse, neighbor, family member or another resident in a care community setting. We would think that a renewed physical and sexual attraction to one's spouse would not be the worst thing that could come from this disease, but take into consideration that other changes are also occurring:



- **Difficulty with proper hygiene**

- Brushing teeth
- Inability to properly clean themselves after using the restroom
- Bowel or bladder incontinence
- Requiring adult garments due to incontinence issues
- Refusal to bathe
- Dirty and messy hair
- Dirty hands and fingernails

- **Difficulty remembering**

- Spouses name or using a different name; maybe an old flame or former co-worker
- That they are even married
- That they've just had sex and want more
- The sexual act was consensual – accusing partner afterward of violation, rape or even incest – especially with the person who is further advanced in the disease and may confuse their spouse with a sibling or parent.

All of this can be very devastating and overwhelming to a spouse or family, especially when their loved one exhibits a strong attraction to another person as a result of their dementia.

Keep in mind that sexuality and intimacy is part of human nature throughout one's life. The giving and receiving of affection, affirmation, and pleasure is needed, no matter what our age, mental or physical ability, marital status, sexual orientation or gender identity. People with dementia still have the same needs as all other individuals.

## **When a sexual or intimate relationship develops in residential care setting:**

It is not uncommon for a person with dementia who lives in a residential care facility to show signs of sexual attraction toward another resident who is not their spouse. In their demented state, they may think the other person is their spouse. Or, they just may need to fulfill the basic human desire for touch, warmth and intimacy. They may just be responding to affection and intimacy initiated by another person with dementia.

Spouses and families may be understanding and accepting, or, they may be devastated and appalled. Concerns over “consent” when a disease compromises the mind are real. It is often difficult to know whether intimacy between two persons with dementia is consensual. This is a judgment call that will need to be made based on the individual circumstances and events. Supervisors and families should discuss the situation. If the families are not supportive of the relationship, the facility staff must be respectful of their decision.

If a relation develops in a care facility between two persons with dementia:

- Report the situation to the supervisor who will then notify the resident’s family
- Document the type and frequency of occurrences - is it a one-time event or an ongoing attraction? What specific behaviors have been happening?

If the relationship is supported by both families, appears consensual, and brings joy and comfort to the two individuals:

- Provide privacy
  - which will ensure each person’s dignity
  - validate their relationship with positive words
  - allow the act to be truly intimate by not making it into a joke
  - protect the rights of other residents

If the relationship is not supported by both families, care facility staff may find themselves in the difficult position of “discouraging” the relationship. This can be challenging. Some strategies to try are:

- Redirect with other activities in another area of the building
- Distract with food, music, conversation, photos of their family and spouse
- Ask for their help with a known favorite hobby or chore

## **Hypersexual behaviors**

Whatever the type of behavior, whether the person is rubbing their genitals, standing naked in a public space, or making verbal sexual advances to others, it is the job of the staff or caregiver to preserve their dignity, provide comfort and reassurance and make sure once the incident is over that they know that are still loved and needed regardless of what happened. Caregivers must be sensitive and compassionate with regards to these delicate issues. Appropriate steps to take:

- Gently take the person by the arm and, without shaming or humiliating them, move them away to a quiet private space.
- Tactfully cover them up, with a pillow or clothing item, so as to discourage and try and stop them from carrying on the sexual activity.
- If they are saying sexually explicit things, ignoring and not responding may be the best approach. Or, it may be necessary, depending on where they are and who is around, to remind them in a gentle yet firm voice that what they are saying is inappropriate. Do not scold or humiliate.
- Distract the person with conversation, a task, food, or beverage.
- Analyze the environment for possible triggers. Is the person removing their clothes because they are too warm? Are they touching their genitals because they need to urinate? Are their clothes too tight?
- Remain calm and do not overreact, even though the behavior may be upsetting, shocking, or embarrassing. Remember that the person is likely reacting to what feels good and does not remember the rules they were taught about proper social behavior.
- Medications can help in cases of severe sexual aggression, which cannot and should not be allowed in a care facility. Families and staff should consult with the physician for medication options.

## **When residents turn their affections toward the staff**

Regardless of where the person is in the disease process, they may still become verbally or physically inappropriate with staff. In such situations staff should:

- Put space between the resident and their self.
- Address the resident in a formal manner, Mr. or Mrs.
- Do not enter the resident's room / apartment alone. Ask a co-worker to accompany them.
- Document inappropriate occurrences with resident and report to their supervisor.
- Keep the relationship with resident professional to avoid misleading the resident in any way.
- Remain calm and do not overreact, even though the behavior may be upsetting, shocking, or embarrassing. Remember that the person social filters and graces have been damaged by the dementia.

## **Communicating Behavior Solutions with Others:**

Each individual with dementia is a complicated puzzle. Caregivers need to share their knowledge of each person with dementia's behavior strategy successes and failures with all persons on their caregiving team. (This applies to both professional and family member teams). If this information is put in writing it doesn't have to be repeated verbally every time a new player joins the team. This information should be updated frequently as it changes.

## **Sundown Syndrome**

Dementia patients frequently exhibit behavior shifts as the sun starts to set. Notable symptoms are confusion, agitation and forgetfulness to a greater degree than during the day. Scientists studying Alzheimer's disease and other types of dementia are still searching for the answer that explains the relationship between time and mood swings.

Sundowning has been observed around the globe. Medical experts believe the cause is biological, not environmental. As a caregiver, you can look for these symptoms: irrational or impromptu feelings of being judged, criticized and or berated, or a sense of paranoia that erupts late in the day or out of the blue. Because the brain is a complex nerve center, it's reserve of the chemicals that keep it moving and processing become depleted. The combination of too many stimulating experiences, with too few biological chemicals to process them, causes the brain to go haywire. Left to it's own devices, the brain fights back by firing off hallucinations to right itself, and sundowning is one of the results. It is recommended that caregivers stay calm and reassuring to convey a sense of peace and tranquility. NEVER confront a sundowner, or try to convince them that the feelings they are experiencing aren't real. Close drapes or shades late in the day and divert attention from clocks and watches. Make certain basic needs are met to reduce stress. At the most extreme, drugs and/or sedation may be prescribed to help sundowners find peace from the storms raging in their brains.

## An Affair to Remember

By Melinda Henneberger

Bob's family was horrified at the idea that his relationship with Dorothy might have become sexual. At his age, they wouldn't have thought it possible. But when Bob's son walked in and saw his 95-year-old father in bed with his 82-year-old girlfriend last December, incredulity turned into full blown panic. "I didn't know where this was going to end," said the manager of the assisted-living facility where Bob and Dorothy lived. "It was pretty volatile."

Because both Bob and Dorothy suffer from dementia, the son assumed that his father didn't fully understand what was going on. And his sputtering cell phone call reporting the scene he'd happened upon would have been funny, the manager said, if the consequences hadn't been so serious. "He was going, 'She had her mouth on my dad's penis! And it's not even clean!'" Bob's son became determined to keep the two apart and asked the facility's staff to ensure that they were never left alone together.

After that, Dorothy stopped eating. She lost 21 pounds, was treated for depression, and was hospitalized for dehydration. When Bob was finally moved out of the facility in January, she sat in the window for weeks waiting for him. She doesn't do that anymore, though: "Her Alzheimer's is protecting her at this point," says her doctor, who thinks the loss might have killed her if its memory hadn't faded so mercifully fast. But should someone have protected the couple's right to privacy—their right to have a sex life?

"We were in uncharted territory," the facility manager said—and there's a reason for that. Even the *More* magazine-reading demographic that thinks midlife is forever (and is deeply sorry to see James Naughton doing Cialis ads) seems to believe that while sex isn't only for the young, exceptions are only for the exfoliated. We're squeamish about the sex lives of the elderly—and even more so when those elderly are senile and are our parents. But as the baby boom generation ages, there are going to be many more Dorothys and Bobs—who may no longer quite recall the Summer of Love but are unlikely to accept parietal rules in the nursing home. Gerontologists highly recommend sex for the elderly because it improves mood and even overall physical function, but the legal issues are enormously complicated, as Daniel Engber explored in his 2007 article "Naughty Nursing Homes": Can someone with dementia give informed consent? How do caregivers balance safety and privacy concerns? When families object to a demented person being sexually active, are nursing homes responsible for chaperoning? This one botched love affair shows the incredible intensity and human cost of an issue that, as Dorothy's doctor says, we can't afford to go on ignoring.

Dorothy's daughter, who contacted me, said that, in a lucid moment, her mother asked her to publicize her predicament. "We're all going to get old, if we're lucky," said the daughter, who is a lawyer. And if we get lucky when we're old, then we need to have drawn up a sexual power of attorney before it's too late. Who controls the intimate lives of people with dementia? Unless specific provision has been made, their families do. And for Dorothy, which is her middle name, and Bob, which isn't his real name at all, that quickly became a problem.

"Who do you love?" Dorothy asked me, right after her daughter introduced us. She'd married her first—and only other—sweetheart, a grade-school classmate she'd grown up with in Boston and waited for while he flew daylight bombing raids over Germany during World War II. Together they had four children, built a business, and traveled all over the world, right up until she lost him to a heart attack 16 years ago. But she never mentions him now and doesn't like it when anyone else does, either, because how could she not remember her own husband? Her daughter visits every evening, and because Dorothy loves kids, her daughter pays the housekeeper to bring hers over every afternoon, "and she thinks they're her grandchildren, and it makes her happy."

But even showing me around her well-appointed, little apartment in the nice-smelling assisted-living facility was an exercise in frustration for Dorothy: She joked and covered, but she might as well have been guiding me through Isabella Stewart Gardner's house, because all around were tokens from her past that have lost their meaning for her. There were tiny busts of Bach and Brahms, a collection of miniature porcelain pianos, Japanese woodcuts, and some Thomas Hart Benton lithographs she picked up for a few dollars in the '40s. "These are all my favorites," she said, pointing to shelves of novels by the Brontes and books about Leonardo da Vinci and Franklin and Eleanor Roosevelt. But her expression said that she couldn't recall why she liked these volumes best, and what I think she wanted me to know is that she once was a person who could have told me. When her daughter mentioned Bob's name—Bob, who was led away in January, shouting, "What's going on? Where are you taking me?" right in front of her—it wasn't clear how much she remembered: "He came and he went, and there's nothing more to say."

So it was left to her daughter, her doctor, and the woman who runs the assisted-living facility to explain how this grown woman, who lived through the Depression and survived breast cancer, managed a home and mourned a mate, wound up being treated like a child. "Come back anytime," Dorothy told me sweetly.

Downstairs, in her bright, tidy office, I met the woman who runs the facility—one of the nicest I've seen, with tea service in the lobby and white tablecloths in a dining room that's dressed up like a restaurant. In 30 years of taking care of the elderly, she's seen plenty of couples, but none as "inspiring" or heartbreaking as Dorothy and Bob. Which is why she keeps a photo of the two of them on her desk. In the picture, Dorothy is sitting at the piano in the lobby, where she used to play and he used to sing along—with gusto, usually warbling, "I dream of Jeanie with the light brown hair," no matter what tune she was playing. She is all dolled up, wearing a jangly red bracelet and gold lamé shoes, and they are holding hands and beaming in a way that makes it impossible not to see the 18-year-olds inside them.

Before Dorothy came along, the manager said, Bob was really kind of a player and had all the women vying to sit with him on the porch. But with Dorothy, she said, "it was love." One day, the staff noticed that they were sitting together, then before long they were taking all their meals together, and over a matter of weeks, it became constant. Whenever Bob caught sight of Dorothy, he lit up "like a young stud seeing his lady for the first time." Even at 95, he'd pop out of his chair and straighten his clothes when she walked into the room. She would sit, and then he would sit. And both of them began taking far greater pride in their appearance; Dorothy went from wearing the same ratty yellow dress all the time to appearing for breakfast every morning in a different outfit, accessorized with pearls and hair combs.

Soon the relationship became sexual. At first, Dorothy's daughter and the facility manager doubted Dorothy's vivid accounts of having intercourse with Bob. But aides noticed that Bob became visibly aroused when he kissed Dorothy good night—and saw that he didn't want to leave her at her door anymore, either. (Note to James Naughton: Bob did not need what you are selling.) His overnight nurse was an obstacle to sleepovers, but the couple started spending time alone in their apartments during the day. When Bob's son became aware of these trysts, he tried to put a stop to them—in the manager's view because the son felt that old people "should be old and rock in the chair." When I called Bob's son and told him I was writing about the situation without using any names, he passed on the opportunity to explain his perspective. "I don't choose to discuss anything that involves my father," he said, and he put the phone down. But according to the facility manager, the son was convinced that Dorothy was the aggressor in the relationship, and he worried that her advances might be hard on his father's weak heart. He wasn't the only one troubled by the physical relationship. The private-duty nurse who had been tending Bob also had strong feelings about the matter, said the manager: "At first, she thought it was cute they were together, but when it became sexual, she lost her senses" for religious reasons and asked staff members to help keep the two of them apart.



Employees wound up choosing sides—as did other residents, including some women who were apparently jealous of Dorothy's romance. And because the couple now had to sneak around to be together—for instance, cutting out when they were supposed to be in church—their intimacy became more and more open and problematic. At one point, the manager had to make Bob stop "pleasuring her" right in the lobby, where Dorothy sat with a pillow placed strategically over her lap. In all of her years of working with elderly people, the manager said, this was not only her worst professional experience but was the only one that left her feeling she had failed her patients. She had a particularly hard time staying neutral and detached, she said, because she kept thinking that "if that was my mom or dad, I'd be grateful they'd found somebody to spend the rest of their lives with."

One day when Dorothy's daughter arrived to visit, she found Bob sitting in the lobby, surrounded by a wheelchair brigade of dozing people who had been posted around him by the private-duty nurse to block Dorothy from approaching him. That's when Dorothy's daughter got the state involved and started throwing around the word *lawsuit*, which only made things worse, the manager said. "Once she started talking legal, that pushed things over the edge." The state did send someone in to try to mediate the situation—but then the mediator was diagnosed with cancer and died just five weeks later. Though the mediator's replacement tried to pick up where he had left off, she was never able to establish a rapport with Bob's son.

Finally, Bob's family decided to move him and insisted that neither he nor Dorothy be told in advance. No one in either family was there the morning Bob's nurse hustled him out the door. Later, the manager called his son and asked if there was any way Dorothy might come and visit just briefly, to say goodbye. The son thought about it for a few days and then said no, his father was already settled into his new home and was not thinking about her at all anymore. The lawyers told Dorothy's family that there was no way they could make the legal case that Bob's rights were being violated by his family, because you couldn't put people with dementia on the witness stand.

Dorothy's son-in-law, who is a doctor, suspects Bob's son of fearing for his inheritance. Bob had repeatedly proposed for all to hear and called Dorothy his wife, but his son called her something else—a "gold digger"—and refused to even discuss her family's offer to sign a prenup. According to Dorothy's daughter, Bob's son told her, "My father has outlived three wives, including the one he married in his 80s, and your mother is just one of many." But surely Bob's safety was a true concern, too, and maybe his son had religious or moral qualms?

"I don't think so," the manager said. "I don't think he meant his dad any harm, but he couldn't see what his dad needed. He wanted his dad to have a relationship but on his terms: You can sit together at meals, but you can't have what really makes a relationship, and be careful how much you kiss and don't retire to a private place to do what all of us do."

Though Dorothy might or might not remember what happened, "there's a sadness in her" that wasn't there before, the manager said. Bob "gave her back something she had long lost—to think she's pretty, to care about her step and her stride." She eats in her room now rather than in the dining room where she shared meals with Bob. And she no longer plays the piano. A new couple in the facility has gotten together in the last few weeks. The manager called their families in right away and was relieved to see that they were happy for their parents, and the families have been taking them on outings together. As a result of the whole experience, the manager, who is 50, recently had a different version of "the talk" with her 25-year-old daughter, instructing her never, ever to let such a thing happen to her or her husband: "I hope I get another shot at it when I'm 90 years old."

Dorothy's doctor also took their experience personally. "Can you imagine as a clinician, treating a woman who's finally found happiness and then suddenly she's not eating because she couldn't see her loved one? This was a 21<sup>st</sup>-century *Romeo and Juliet*. And let's be honest, because this man was very elderly, I got intrigued; my respects to the gentleman." His patient was happier than he could ever remember; she was playing the piano again, and even her memory had improved.

And though the doctor never laid eyes on Bob, in general, he said, the fear of sex causing heart attacks is wildly overblown: "If you've made it to age 95, I'm sorry, but having sex is not going to kill you—it's going to prolong your life. It was as if someone had removed the sheath that was covering [Dorothy], and she got to live for a while." But after the trauma of losing Bob, Dorothy's doctor came close to losing his patient, he said, adding that most people her age would not have survived the simultaneous resulting insults of depression, malnutrition, and dehydration. "We can't afford the luxury of treating people like this. ... But we don't want to know what our parents do in bed."

Then the daughter interjected that Bob's son certainly didn't want to see them having oral sex, and the doctor proved his own point. Holding a hand up to stop her from saying any more, he told her, "I didn't need to know that." But maybe the rest of us do.

## CHAPTER 4

# **SAFETY ISSUES**



**After completing Chapter 4 you will have  
a greater awareness of safety issues that occur when caring  
for a person with dementia.**



## **SAFETY ISSUES:**

Providing for the safety of a person with dementia is an ongoing concern for caregivers. A caregiver must constantly assess the environment and the actions of the person with dementia for the potential for harm. It is sometimes a delicate balance to preserve the person's sense of **INDEPENDENCE**, privacy, and dignity while keeping them safe.

### **Home Alone**

At some point it will no longer be safe to leave a person with dementia home alone, or even unsupervised. This point in time will be different for every person and will have to be evaluated on an individual basis. This can be a challenging judgment call for families, because most people with dementia will not understand why they can't stay home alone. They may become resentful if they are told this directly. They may balk if a professional caregiver is brought in "to babysit" or they are taken to an adult "day care" program. Caregivers must handle this situation delicately and subtly with all effort to preserve the person's feelings and sense of independence. Caregivers must be very careful with the words they choose to explain the need for supervision. Avoid words such as "babysitting" and "day care". Avoid statements such as "you can't stay home alone" or "you can't take care of yourself".

### **Medications**

People with dementia lose the ability early on to properly take medications. Due to their memory loss, they may not remember which medications to take or what time to take them, and they can easily double dose or worse. Caregivers must take over the responsibility of medication administration and keep medications hidden and locked up. It is best to do this subtly, so as not to embarrass or anger the person over their inability to manage their own meds.

### **Tripping, Slipping and Falling**

Dementia affects a person's balance, coordination and spatial judgment, thus making them more prone to accidents. Steps, stairs, and curbs are more difficult to navigate. Throw rugs and pets underfoot are potential obstacles for a trip or fall. Caregivers must provide constant oversight, and it is helpful and often necessary to hold a person's hand or arm when moving on uneven terrain.

## **Operating Tools and Household Machinery**

Be aware that a person with dementia may not remember how to properly use appliances and tools. Potential hazards include toaster ovens, microwaves, blenders, coffee makers, curling irons, knives, space heaters, electric blankets, power tools, lawn mowers, and barbecue grills. Know that even apparently safe devices can be hazards. For example, a person may try to open a can by jabbing it with a screwdriver instead of using a can opener. It is common for a person with dementia, especially men, to take appliances apart to “fix” them, and subsequently ruining them. Prevention goes a long way in this arena. Putting things out of sight, locking the item up, or disabling an item (such as taking the knobs off of a stove) is often necessary to avoid costly repairs or replacement or injury.

## **Guns**

A person with dementia should never be allowed to handle a gun. A person with dementia could easily shoot themselves or others due to their inability to remember proper gun safety procedures, or their inability to remember or recognize close family members. Remove guns from the home. If this is not possible, lock them away out of sight and store ammunition in a separate place.

## **Alcohol Consumption**

Alcohol impairs judgment. Dementia impairs judgment. Mixing the two is a recipe for disaster and could lead to dangerous consequences with falls, driving and/or decision making. Restricting or preventing a person with dementia from drinking alcohol can be challenging, especially in the early stages of dementia. The best approach is to do it gradually and subtly by watering down drinks or serving non alcoholic drinks and pretending they have alcohol content.

## **Environment Proofing**

When babies start crawling and getting into cupboards and closets we learn to child-proof the house for their safety. This same concern applies to people with dementia, usually those in the middle to late stages. They may eat or drink toxic household chemicals or plants. They may eat spoiled food. They may mess with electrical outlets or chords. They may turn the water so that it is scalding hot. They may touch a hot stove or pan. They may trap themselves in a closet. The possibilities are endless. They will find ways to get into trouble in the blink of an eye...just like a small child. Caregivers must practice constant vigilance and proof the environment to avoid hazards as much as possible.

## **Getting Lost**

Getting lost in familiar places is one of the early signs of dementia. This can happen when a person is driving to and from places or when walking around a neighborhood or a mall or store. Many people with dementia will forget how to get back to their own home, even when just walking to the mailbox. When a person with dementia is out of their home it is important to realize just how easily they can get separated, turned around, and lost. This can be extremely frightening for both parties. Caregivers should also never assume that the person with dementia will stay on a bench or in the car while they run into a store. The person with dementia will most likely forget the instructions to stay put and start walking around to look for their loved one.

A person with dementia who lives in a care facility may have trouble remembering where their room is. They may have to be shown and led to their room each time. Caregivers cannot expect them to eventually “learn” and remember the location. The part of the brain that used to be able to hold onto this information is too damaged.

## **Driving**

Most dementia patients should stop driving in the early phases of their illness. Driving is a complex task that requires focus, multi-tasking, and memory. If a person is showing signs of dementia or has been diagnosed, chances are their driving skills are already impaired. Losing the ability to drive and the subsequent loss of freedom is difficult for the person with dementia to accept and puts a burden on those that will then have to drive them around. Letting a person with dementia continue to drive is dangerous for them and other people on the road. Fender benders and unexplained dents are common. The caregiver/co-pilot, with hopefully the support of other family members, must decide when and how to prevent their loved one from driving. This can be difficult, especially if there is resistance. The family should try and discuss the idea of no longer driving with their loved one, acknowledging the hardship of losing this privilege. If the person is resistant, firmer steps must be taken. Involving the physician or taking the person for a driving test may be necessary. Removing or disabling the car may be necessary. Hopefully and eventually, the person with dementia will forget about driving or become accustomed to not driving. An excellent video called “The Driving Test” can be found online at [www.hbo.com](http://www.hbo.com) – the Alzheimer’s Project – The Caregiving Tapes.

## **Wandering**

Wandering is another big challenge that a caregiver will face. According to the Alzheimer's Association, 6 in 10 people with dementia will wander away from their home or caregiver and become disoriented or lost. Most, in their confusion or panic, will not be able to remember their own name or address or how to ask for help. Most will not be able to figure out how to keep safe and warm. Most will not remember how to avoid traffic. If not found within 24 hours, up to half of those who wander risk serious injury or death. Wandering and becoming lost is a huge safety concern for the person with dementia.

Wandering will happen when the family or caregiver least expect it. Wandering usually happens to those families who are positive it will never happen! Persons with dementia are very unpredictable, and similar to caring for a toddler, must be under constant vigilance for their own safety.

Wander-proofing the environment is the best means of prevention. Some tips for accomplishing this are:

- Place door locks out of the line of sight by installing them way at the top or bottom of the door. Slide locks work well for this.
- Add a dead bolt that requires a key.
- Camouflage the door by covering it with a poster of a bookcase or a floor to ceiling drape. Hang something over the doorknob to hide it.
- Try monitoring devices such as door alarms or floor mat pressure alarms that signal the caregiver when a door is opened.
- Place a black mat in front of the door. This sometimes tricks the person with dementia to perceive it as a hole.

Planning ahead in the event of a person wandering is a good idea.

- Alert all neighbors that your loved one has dementia, should not be wandering outside alone, and may need assistance getting back home.
- Keep a recent close-up photo on hand.
- Keep a list of people and phone numbers to call if loved one wanders.
- Keep a list of places where the person may wander to, such as past jobs, former homes, church, or favorite restaurant.



- Put an identification bracelet on your loved one that includes their name and the caregiver's emergency phone number.
- Enroll the person in the Alzheimer's Association's "Medic Alert + Safe Return" program, which is a 24-hour nationwide emergency response service. The individual wears an identification bracelet with a unique ID number and the 800# emergency number. When lost, caregivers will call this number and a community support effort is activated including the Alzheimer's Association and law enforcement. Critical medical information will be provided to emergency responders when needed.
- Enroll your loved one in the Colorado Life Trak program offered for free through the Mesa County Sheriff's Department (also known as Project Lifesaver in other states). They will place a bracelet, that is difficult to remove, on your loved one's wrist or ankle. The bracelet transmits a unique signal which can be picked up by special equipment if the person wanders and is lost. The person must no longer be driving and still live at home.

Persons with dementia may even "escape" from an environment that has been secured. Caregivers should never assume that the environment is totally fool proof when it comes to dementia. People with dementia can be as slippery as Houdini!

### **Living in a secure facility**

A person with dementia who lives in a secure facility may or may not have a problem with the fact that the door is locked and they are unable to leave on their own. The majority of residents will be oblivious, based on their level of dementia, or it just won't bother them. A rare few will have enough where-with-all to question why they can't get out. Sometimes, depending on their level of cognition, if you explain to them that the security is for others, not them, they will be satisfied with this answer. A rare few will become angry and upset over the lack of freedom. They may stand at the door and pound or scream to get out, or go from door to door and window to window to look for a way to get out. They may successfully escape.

There is no one right answer for dealing with this situation and it must be handled on an individual basis. Distraction or directing on to other tasks might work. Camouflaging the door may help. Validating the person's frustration could help. Ignoring the person is sometimes necessary if all of the above fail. As a last resort, talking to a physician and prescribing a mild anti anxiety medication may be necessary. Ultimately, escape proofing the environment is the best way to ensure the safety of the resident.



## CHAPTER 5

# PERSONAL CARE



At the completion of Chapter 5 you will develop a greater knowledge of how to meet the personal care needs including dressing, grooming, bathing, oral care, and toileting of persons with dementia and Alzheimer's.



# **PERSONAL CARE**

Personal care activities include dressing, bathing, brushing teeth, putting on makeup, hair & nails, shaving, and toileting. A person with dementia will need assistance with all of these activities and caregivers should strive to make the activity as pleasant and as comfortable as possible in the hopes of improving self esteem and preventing discomfort, embarrassment, aggression and agitation.

Good grooming is a gift that caregivers can give to their person with dementia. Good grooming encourages a positive attitude and promotes dignity. Men always want to look handsome and women always want to look pretty, no matter their age.

A general rule for personal care is to encourage and cue the person to do as much as possible for themselves, but be ready to assist when needed.

## **Personal Care General Tips:**

### **Know the person's level of dementia**

- How much can the person still do safely and adequately on their own?
- How much cueing, supervision, or hovering do they need?
- ENCOURAGE PARTICIPATION AND INDEPENDENCE

### **Know the preferences, rituals, likes, and dislikes of the person**

- Bath or shower – what time of day?
- Female caregiver or male caregiver?
- Hairwash during bath or at beauty shop?
- Electric razor or Bic?

### **Know if there are physical problems that could cause pain**

- Hip problems
- Mouth sores
- Shoulder pain

### **Know when to ask...know when to employ the strategy of “gentle guidance”**

- Don't give the opportunity for a “NO”
- Avoid trigger words: BATH, WASH HAIR
- Guide slowly and gradually
- Never physically force – try and persuade – try later

**Use Distraction**

- Conversation
- Music

**Use the Right Tools**

Products and tools make the task easier for both the person with dementia and the caregiver.

- Bath chair
- Toilet riser
- Walker

**Give the Person A Sense of Control**

- Communicate and explain what you're doing using short simple words.
- Give simple choices
- Give them a part of the task to do – simple one step instructions

**Preserve Dignity and Privacy Needs when Undressed**

- Have environment **warm** and ready
- Have clean clothes ready
- Have plenty of towels

**Avoid Fear Triggers**

- Water on the face
- Chair lifts
- Cold
- Modesty

**Be Aware of Your Approach**

- Be calm, soothing, gentle
- Don't rush
- Reassure, praise
- Smile

**Be Flexible**

- What works today may not work tomorrow – what does not work today, might work tomorrow!
- Explore other options beyond the traditional such as a wash cloth bath or bed bath instead of a shower or tub bath.

# DRESSING

## Persons with dementia may:

- Wear same clothes over and over, dirty or not
- Obsess over having to wear a certain item (*Rose would only wear black pants*)
- Have trouble putting clothing on correctly (*bra on top of shirt, pants backwards*)
- Refuse to change or take off clothes
- Be totally cooperative and/or be able to dress self far into the disease

## Dressing Tips:

### If they can dress themselves but need assistance:

- Give the person an opportunity to select a favorite outfit or color. Offer just two choices so as not to overwhelm, making sure the choices are appropriate for the weather and match appropriately.
- Hand person one item of clothing at a time while giving short simple instructions.
- Choose comfortable and loose-fitting-easy-to-get-on-and-off-clothing.
- Let the person do their own buttons, snaps and zippers as long as they can. Assist and/or simplify the clothing when they can't.
- If the person wants to wear the same outfit repeatedly, try getting a duplicate of it or have a similar option available. If this is not possible, you may have to slip the garment out of the room at night to wash.

### If they need to be dressed:

- Dress the person while they are sitting on the toilet or sitting in a chair. Placing a walker in front of them to hold on to while they stand up and sit down during the process is helpful.
- Put your hand up the arm sleeve or pants leg first as this makes it easier to put the garment on.
- If they have an injured or weak arm, put the clothing on that limb first, so it doesn't have to twist and contort quite as much as the other arm.

## **BATHING:**

Bathing is often the most difficult personal-care activity that caregivers face. Because it is such an intimate experience, people with dementia may perceive it as unpleasant or threatening. In turn, they may act in disruptive ways, like screaming, resisting or hitting. Such behavior often occurs because the person doesn't remember what bathing is for or doesn't have the patience to endure such unpleasant parts of the task like lack of modesty, being cold or other discomforts.

### **A person with dementia will:**

- Need increasing help with bathing that will usually occur gradually
- May refuse to bathe or say they already had a bath/shower when they haven't
- May be frightened or combative during bathing
- May be totally cooperative

Knowing the individual's routine, ability level, and current dementia feelings towards bathing is the most important step in accomplishing a successful bathing experience.

## **Bathing Tips:**

*Adapted from the Alzheimer's Association Bathing Fact Sheet*

### **Know the person's abilities**

Encourage the person to do as much as possible, but be ready to assist when needed. Assess his or her ability to:

- Know how to use different products (soap, shampoo, washcloth, etc.).
- Sense water temperature.

### **Prepare the bathroom in advance**

- Put a nonskid mat in the tub or shower.
- Install grab bars and use a seat in the tub or shower.
- Gather bathing supplies such as towels, washcloths, shampoo and soap before you tell the person that it's time to bathe.
- Make sure the room is warm.
- Use large beach towels or bath blankets that completely wrap around the person for privacy and warmth.



- Have a washcloth ready to cover the person's eyes to prevent stinging from water or shampoo.
- Fill the tub, monitor the water temperature, and then assess the person's reaction to getting into the water. It may be better to fill the tub after the person is seated.

### **Focus on the person, not the task**

- Give the person choices. For example, ask if he or she would like to take a bath or a shower. Try saying "Let's wash up" instead of "Let's take a bath."
- Be sure the person has a role in the steps of bathing. For example, have the person hold a washcloth, sponge or shampoo bottle.
- Be aware that the person may perceive bathing to be threatening. If the person resists bathing or acts out, distract him or her and try again later. Soothing music or breaking out into a song may help.
- Often praise the person for his or her efforts and cooperation.
- Always protect the person's dignity, privacy and comfort.
- Pad the shower seat and other cold or uncomfortable surfaces with towels.

### **Be flexible and adaptable**

- Set a regular time of day for bathing. If the person usually bathes in the morning, it may confuse him or her to bathe at night.
- Use simple phrases to coach the person through each step of the bathing process, such as: "Put your feet in the tub." "Sit down." "Here is the soap." "Wash your arm."
- Use other cues to remind the person what to do such as the "watch me" technique. Put your hand over the person's hand, gently guiding the washing actions.
- Use a tub bench or bath chair that can adjust to different heights. The person can sit while showering if it is easier.
- Washing the person's hair may be the most difficult task. Use a washcloth to soap and rinse hair in the sink to re-duce the amount of water on the person's face.
- Be sure the person's genital areas are washed, especially if incontinence is a problem.
- Be sure the person is washed between folds of skin and under the breasts.

### **Consider bathing alternatives**

A person doesn't have to totally submerge in water to be clean.

- Consider a sponge bath.
- Consider shampooing hair at another time or on a different day or at the beauty shop.
- Consider a towel bed bath.

### **Remember after-bath care**

- Check for rashes and sores, especially if the person is incontinent or unable to move around.
- Seat the person while drying and putting on fresh clothes.
- Make sure the person is completely dry. Pat the person dry instead of rubbing.
- Apply lotion to keep skin soft.
- Use cornstarch or talcum powder under the breasts and in the creases and folds of skin. If the person won't use deodorant, use baking soda.

## **BRUSHING TEETH:**

A person with dementia will have difficulty maintaining good oral hygiene. The caregiver will need to assume increasing responsibility for the person's dental care. A person with dementia will forget how to brush their teeth and as the disease progresses, the person may forget that dental care is important and completely neglect caring for their teeth and gums.

### **Caregivers need to:**

- Watch and assess the person's ability to properly brush their teeth
- Assist in whatever capacity is needed: from putting the toothpaste on the brush and getting them started to literally brushing for them
  - ask permission
  - explain each step
  - gently guide their hand
  - provide reassurance and praise
  - respect and preserve comfort
  - thank them for helping you
- Be diligent about making sure the person's teeth are brushed twice a day (no matter how uncooperative the person becomes) as poor dental care can quickly turn into serious dental problems such as gum disease and oral cancer

- Assist with care and insertion of dentures and **EXPECT DENTURES TO BE A CHALLENGE** (losing them, throwing them away, putting in other people's)
  - Remove the top denture by placing your thumb inside the mouth and against the back side of the denture. Press upward and outward toward the nose.
  - Remove the lower denture by slowly pulling on the denture while applying a rocking motion.
  - Dentures should be cleaned daily and stored in denture cleanser or water - never place in hot water as this may warp them.

## **HAIR, MAKEUP, and NAILS:**

A woman with dementia will have difficulty remembering how to fix her hair, put on makeup, and manicure and paint her nails. Most women will, however, still enjoy having all of this done with and for them and this can be a great pampering activity for ladies with dementia. Each individual will have hairstyle preferences and lipstick and nail polish color preferences that should be honored.

## **SHAVING:**

A man with dementia will have difficulty remembering how to shave. Before assisting with shaving, make sure the gentleman wants you to shave him or help him shave. Wearing gloves when shaving is necessary for professional staff and helps prevent infection and the chance of coming into contact with blood if the gentleman is accidentally nicked or cut.

- **Safety or disposable razors:** use a blade that is sharp as a dull blade is hard on the skin. Soften the beard with a warm, wet washcloth on the face a few minutes before shaving. Lather the face with shaving cream or soap and warm water. Hold the skin taut and shave in the direction of hair growth. Shave beard in downward strokes on the face and with upward strokes on the neck. Rinse the blade often. Wash, rinse, and dry to finish.
- **Electric razors:** Do not use near a water source, around oxygen, or if the gentleman has a pacemaker. Turn on the razor and hold the skin taut. Shave with smooth, even movements. Shave beard with back and forth motion in direction of beard growth or in circular motion with 3-head shaver. Shave the chin and under the chin. If desired, pat after-shave lotion onto the face.

## **TOILETING & INCONTINENCE:**

People with dementia will gradually lose the ability to toilet themselves and will eventually become incontinent of both bowel and bladder.

Each person will be unique in their needs. In the early stages of dementia they may need help:

- Finding the bathroom
- Finding and wiping with toilet paper
- Remembering where to put the used toilet paper
- Remembering how to pull clothing down and then back up

As the dementia progresses they may start to “have accidents” requiring the need for adult protective briefs, and they may or may not be resistant to the need for these products. The shift from continence to total incontinence is usually gradual and a combination of various products is available for different purposes.

- Stick on pads worn in regular underwear
- Pull-ups
- Pull-ups with an extra pad
- Button style briefs
- Tab style briefs, with extra pads at night

### **General Toileting Tips:**

- Establishing a routine of taking the person to the toilet every 2 hours can help prevent accidents.
- Identifying the bathroom with a sign and/or putting a line of tape on the floor that leads/points to the bathroom may help the person find the bathroom easier.
- Protecting the bed with waterproof pads positioned strategically underneath the person can lessen total bed changes and laundering of bedding.
- Plan ahead if the person is to be taken out of their home. Pack along an extra set of clothing and adult protective briefs.

- Persons with dementia may go to the bathroom in inappropriate places such as trashcans, drawers, potted plants, outdoors or in a corner of the floor. If this starts to happen, remove the items from sight if possible.
- Keeping a person with dementia as dry and clean as possible is critical to prevent skin breakdown

### **Changing and cleaning a person who is wet or soiled:**

- Preserve dignity, whisper in ear and ask permission
- Gently guide if they refuse or deny – distract with conversation
- Have supplies ready in bathroom: fresh adult protective brief, fresh clothes, gloves, bag for wet items, wet wipes
- Decide which changing technique is appropriate for that person based on their ability level and type of protective brief.

### **Changing a person who can still communicate and stand and sit on their own, who wears pullups.**

- If person is able to stand - position person in front of toilet, pull down pants, remove soiled brief (tear if pullup and place in bag), seat person on toilet and encourage them to go to bathroom in toilet if they can. When they are finished, tell person what you are going to do and thoroughly clean their private area with wet wipes, being careful to wipe from front to back. If they are able to do this part for their self, give them a wet wipe and let them. Use as many wipes as necessary.
- While still seated, thread new pullup through pants legs on ankles – have person stand and pull everything up
- Help person wash hands

## **Changing a person who is totally incontinent, who can no longer use toilet, but who can still stand - wearing button or tab briefs**

- Position person in front of handicap bar or towel rack and place hands so they will grip and hold on.
- Pull down pants to ankles and remove soiled brief. Place in bag. Tell person what you are going to do and thoroughly clean their private area with wet wipes, being careful to wipe from front to back. Use as many wet wipes as necessary.
- Put fresh button or tab brief in place and secure – pull up pants.

## **Changing a person who is bedridden – tabbed briefs**

- Place person on a cloth or disposable pad.
- Roll the person to one side, pull pants down as far as possible on that side, and undo tab on the briefs. Roll to other side, pull down pants on that side and undo tab on that side of the briefs. With the person still on their side, roll the back and front of the soiled brief into itself and remove. Clean the person's private area using as many wet wipes as necessary being careful to wipe from front to back.
- With the person still rolled on to one side, position the new brief in place with one side tucked under the person. Roll the person to the other side and pull the brief in place. Roll the person flat on their back. Pull the brief up through the legs and fasten the tabs, making sure the briefs are snug but not too tight. Pull up the person's pants, rolling them from side to side as necessary.

## **Other Toileting Issues:**

- Urinary tract infections are a common issue with the elderly and can increase problems with incontinence. A person with dementia is more prone to these infections if they aren't drinking enough water. Watch for symptoms: blood in urine, a burning feeling, cloudy urine with sediment, lower back pain, foul smelling urine, frequent intense urge to void, cramping in the lower abdomen or side. UTIs can also manifest themselves quite noticeably in the mental state of a person. They may rapidly become very confused and disoriented, beyond their normal state.
- Diarrhea or constipation issues can be ongoing with persons with dementia. Diet, hydration, and the body's inability to function properly due to the brain damage can all contribute. These issues are discussed in greater detail in Chapter 7, Medical Issues.

# **BATHING TROUBLESHOOTING TIPS:**

*From “Solving Bathing Problems in Persons with Alzheimer’s Disease and Related Dementias,” by Sharon Dwyer, Philip Sloane, and Ann Barrick.*

## **Person doesn’t want to come to bathing area**

- Try later
- Create a reason (it’s time for work, church, a visitor, clothes need to be changed)
- Ask if they would prefer a tub, shower, or bed bath
- Bathe in another location, such as in own room
- Try different transportation method, such as wheelchair
- Offer reward: activity or food
- Try another caregiver or invite family along to help
- Approach resident alone
- Walk and talk with resident a few minutes before inviting them to bathe
- Invite resident into bathing area when he or she is walking by it or already up and about

## **Person does not want to get undressed**

- Create a reason, “You’ll look nice in these fresh clothes” or accidentally spill something on clothes and apologize and offer to clean up
- Bathe resident in morning before he/she gets dressed
- Offer choices, “Shall I undo your belt or do you want to?”
- Begin bathing while resident is dressed
- Distract; try talking about other things
- Offer snack or treat
- Keep resident covered as often as possible
- Start undressing by taking off the shoes
- Undress resident from under a covering, such as a wrapped towel

## **Person is incontinent during bath**

- Toilet resident first
- Don’t bathe after bowel care
- Know residents toileting schedule and bathe around it
- If movement occurs in tub, stand resident up and finish bath
- Stay calm
- Run bath water before resident enters room
- Use shower chair that has a bucket to catch waste



**Person hits and slaps during bath**

- Identify mildly agitated behaviors that occur before hitting and take action or back off at that point
- Call resident's name firmly and directly, without yelling
- Say firmly that the behavior is unacceptable, "That hurts. Stop kicking."
- Give resident something to hold, such as cloth, soap, or someone's hand
- Encourage resident to help with the bath
- Learn defensive self-protection if needed
- Team approach for difficult residents

**Person grabs and holds onto objects**

- Give resident something to hold such as cloth, ball or cookie
- Have resident hold grab bars, tub or seat
- Provide more support, both verbal and physical, during transfers
- Have resident help with bath (face washing, etc.)
- Try a different kind of bath

**Person refuses to get into tub/shower**

- Use chairlift or shower chair
- Have resident test water temperature
- Reassure resident he/she won't fall ("We have you. You'll be safe with me.")
- Apply gentle pressure behind knee with a chair or your hand to stimulate sitting
- Break down the task into simple step-by-step movements
- Let resident support self during transfer and seating using grab bars
- Bathe the resident standing in the tub and have resident hold bars (best with two caregivers)

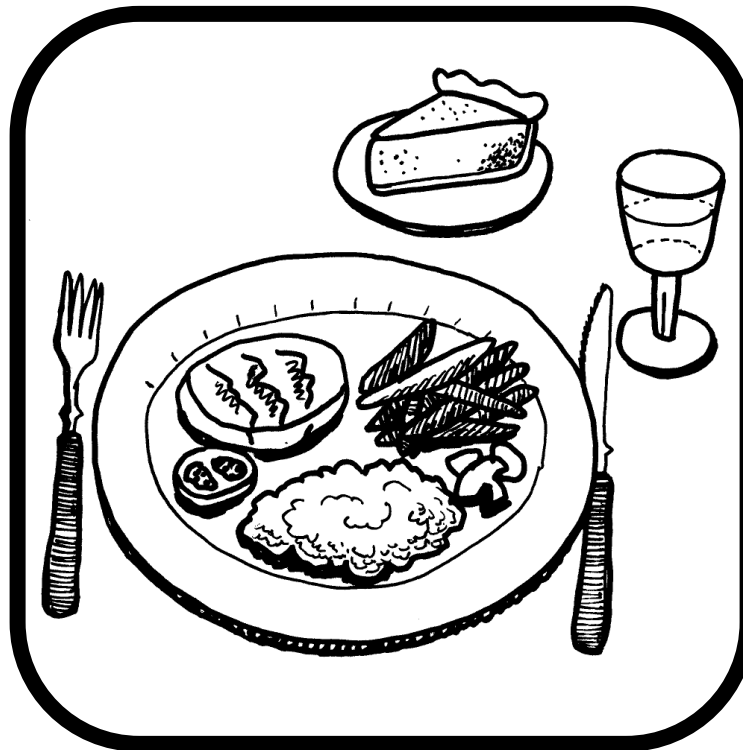
**Person complains of being cold**

- Acknowledge the residents feelings, "I'm sorry you're cold. Let's warm you up."
- Keep resident wrapped up as long as possible before bath
- Use extra towels or bath blanket during bath as covering especially on areas not being washed at the moment
- Begin undressing by taking shoes off first. Similarly, dress the resident by putting on the shirt first
- Close doors, curtains and windows
- Heat towels and clothes in dryer
- Put a towel on the floor for the resident's feet
- Dry hair completely
- Increase room temperature
- Keep water warm and let resident test water
- Try a towel bath (bed bath)



## CHAPTER 6

# **NUTRITION, HYDRATION & FEEDING**



**After completing Chapter 6 you will understand the importance of monitoring the nutritional and hydration needs of a person with dementia, and the need to assist and feed.**



## Nutrition & Dementia

Even healthy adults may develop poor eating habits as they age, and individuals with dementia are at an even greater risk. The portion of the brain that interprets the signals for thirst and hunger are often affected by dementia, leading to poor food and liquid choices and intake. This can lead to weight loss, weight gain, fragile skin, and an increased risk of infection and decreased resistance to illness.

In the earlier and even moderate stages of the disease, if the person is aware their abilities are changing they may begin to “mask” their losses. While they retain the ability to function quite well and live independently, they are in a constant state of trying to “hold-on” and “maintain” that cherished independence, putting them at high risk of poor nutrition and dehydration.

- The task of making a meal becomes increasingly difficult. The person with dementia will slowly (or in some cases rapidly) lose the ability to plan and cook a meal.
- Going to the grocery may be an overwhelming thought, not to mention creating a shopping list.
- The fear of getting lost.
- They simply forget that they have not eaten or have just eaten and will eat again.
- The person with dementia will eat what is easy and available.
- Going to restaurants or someone’s house becomes scary. Restaurant menus provide too many choices and they feel pressured. Many times they will simply order what someone else at the table is having, even if it’s something they would normally never eat.

As the disease progress, their ability to taste and recognize even familiar foods will also change. Many people with dementia develop a love of sweets and sometimes that is all the caregiver can get them to eat, turning the most unlikely person into a “junk food junkie”.

Factors for poor nutrition in the person with advancing dementia can be as many and as varied as the individual themselves:

- The person may have a decreased sense of smell and/or taste.
- The person may have lost the ability to recognize and distinguish certain foods.
- The person may not see the food on the plate: Many people with Alzheimer's dementia have visual-spatial impairments: This makes it difficult for the person to recognize not only faces but to identify and name objects, for example: "The stuff on the thing in front of them" is not recognized as food on a plate.
- The person may be experiencing restlessness and unable to sit at the table long enough to consume a healthy meal.
- The person may be experiencing confusion, agitation or anger.
- The person may be experiencing the inability to use utensils, resulting in frustration. They may not recognize what and how utensils are used for.
- The person may be in pain, need to use the restroom or they may be too hot or too cold.
- There may be *way too much* stimulation in the dining area.

## **Supervising Nutrition and Hydration**

A caregiver must help a person with dementia obtain the nutrition and hydration they need without compromising their dignity and independence and while allowing them to be an active participant in the meal process.

**The best way to keep a person nutritiously fed and hydrated is to KNOW THE INDIVIDUAL and diligently monitor their food and beverage consumption with kind and gentle encouragement.**

Knowing their food likes and dislikes, and their ability level with regards to their being able to get food out of the refrigerator, or make wise choices, or feed and hydrate their self, are all key. Understanding that these preferences and abilities could change daily is also important.

In the earlier stages of the disease, caregivers, family and friends can help by simply decreasing the number of choices, providing pre-made meals and implementing gentle reminders. In the case of a caregiver who is not a family member and therefore not as familiar with the person as other people in their lives, one needs to take the time to gather as much information about the person as they can. Talk directly with the person, asking about their favorite foods and restaurants. What did they order at those restaurants?

Keep in mind that lifestyle, ethnicity, religious and spiritual beliefs can form food choices. Think of how and why we choose the foods and drinks we do.

For the person living independently in their home or the home of a caregiver, here are a few suggested items for the refrigerator:

- Bottles of water and a variety of juices – with lids loosened and easy to consume.
- Pre-made sandwiches or other items that need no preparation.
- Pre-washed and cut vegetables and fruits.
- Food items should be sectioned into smaller portions (don't overwhelm with larger portions).
- Items should be prepared so the person does not have to cut or slice – eliminating the need for sharp knives.
- Put notes throughout the house or make phone calls, reminding the person to “eat lunch” or “get a bottle of water”.

## **Assisted Living or Nursing Home Setting**

In the assisted living or nursing care setting, a number of changes can be made to encourage and maintain good nutrition and hydration for as long as possible.

Meal time DO's:

- Know the individual. Know their diet restrictions, food allergies, likes, dislikes, and ability level with feeding themselves.
- Make sure the resident has been given the opportunity to use the restroom prior to meal.

- Make sure the resident has a sweater or jacket if the room is cool or the air conditioning is on. Residents are sedentary and get cold easier than the staff, who are constantly moving.
- Soft, low music is appropriate.
- Cut larger food items into bite sized pieces, serving smaller portions.
- Make sure food is kept warm but not too hot.
- Provide condiments for appropriate items.
- Provide water with every meal as well as another choice of drink.
- Allow resident to do as much for themselves as possible.
- Be aware and observant. Is the resident having problems using the utensils? Are they too close or too far from the table? Do they have obvious food dislikes? Would they benefit from finger foods?
- Allow resident to take their time.
- Encourage and suggest; NEVER demand or use force.

#### Meal time DONT's:

- Avoid overcrowding at the table.
- Do not overwhelm resident with too much food or too many choices... keep it simple.
- Do not treat residents like children: "If you clean your plate you can have dessert".

## Weight Loss or Weight Gain

People with dementia, at any stage, can have a drastic weight gain or weight loss. Sometimes a gain can be attributed to a factor such as eating more frequently or eating more sweets. Sometimes a loss can be attributed to increased movement due to pacing or restlessness. There are times, however, when the loss or gain is simply unexplainable, and doesn't appear to coincide with the calories that are being consumed.



It is almost impossible to force a person with dementia to eat if they don't want to or say that they aren't hungry. When a person with dementia won't eat, a caregiver must try coaxing and cajoling, but should back off and try later if this doesn't work. Offering favorite foods can sometimes help. High calorie supplements such as Ensure should be given if weight loss is a concern.

Due to their short term memory loss, some individual's with dementia will forget that they just ate and experience no feeling of being full. They will finish a meal and say they are hungry five minutes later. They may argue with their caregiver if told they just ate. They may insist on eating again. It can be difficult to deprive a person of something to eat, that you know they really like, when they don't remember that they just ate! It may be helpful in this circumstance to have the kitchen stocked with healthy, low calorie snack foods that can be offered to the individual without concern of excessive weight gain.

## **Hydration**

Drinking enough fluids every day is critical for good health. Not getting enough fluids can increase the risk for dehydration and constipation, but getting persons with dementia to consume the recommended 64 to 80 oz. of total water a day can be difficult.

### **Practical hydration strategies for caregivers:**

- A good basic approach to caregiving for a person with Alzheimer's disease is to anticipate needs before they occur. Set a daily schedule for drinking as well as eating.
  - Upon or shortly after waking
  - At all meals, providing at least one other drink choice in addition to water
  - Before and after walks
  - During activities
- If the person tends to wander during the day, try offering fluids in a cup with a lid so that resident can continue to walk but may be cued to take a drink from time to time.
- Try a new flavor to an old drink by splashing some fruit juice in a glass of water.

- Provide and encourage the person to eat popsicles throughout the summer days.
- Offer and encourage fluids throughout the day instead of only at mealtimes. Keep a glass or bottle of water near a favorite chair.
- Keep bottles of water and juices accessible, making it quick and easy for the caregiver to grab one.
- The World Health Organization (WHO) developed an oral solution containing sugars and salts to improve absorption and prevent dehydration. This solution can be prepared at home by mixing the following:
  - Table Salt - 3/4 teaspoon
  - Baking Powder - 1 teaspoon
  - Sugar - 4 tablespoons
  - Orange juice - 1 cup
  - Water - 1 quart/liter
- Drinks that are too cold may be uncomfortable, so try a glass of fluid that is slightly cooler than room temperature, but not icy cold.

A caregiver can only do the best they can, however diligence, persistence and patience is necessary. The person with dementia will, over time, lose the process of going to the cupboard for a glass and moving to the sink to fill the glass with water. They will lose the process of asking for a drink, even in a room full of people. Oftentimes even if a glass is handed directly to them they will not have the ability to connect the dots and drink. Therefore, the responsibility of kind, gentle encouragement lies with the caregiver.

## Feeding

Depending on their level of dementia, a person may need assistance with eating, or may have to be fed by a caregiver.

A person with dementia may need no assistance, or varying types of assistance as the dementia progresses. They may just need their food cut up, as they have forgotten or no longer have the dexterity to perform this task. Sometimes a person needs a jumpstart, and if guided with a hand-over to put the food on a utensil and put the food in their mouth, this gets their brain going and they can continue the task alone. Assistance can be in the form of verbal cues: “pick up your spoon” “take a bite” “drink some water”. Some people with dementia need to be monitored for stuffing too much food in their mouth at one time.

Medical supply stores offer assistive eating devices such as utensils with built up handle grips, plate guards, and special drinking cups. Clothing protectors (commonly known as bibs!) can be used if appropriate for the situation, but use with sensitivity so as not to compromise the dignity of the individual, and do not call it a “bib” as this term is more appropriate for babies.

When feeding a person with dementia, it is necessary to be very familiar with their ability to drink, chew, and swallow. It is imperative to **KNOW THE INDIVIDUAL**. Do they pocket food in their cheek? Do they choke and cough during meals? Do they drink better when the beverage is thickened with Thick-It? Do they drink better with a straw? Have they forgotten how to use a straw? Do they need food that is mashed or pureed? Do they dribble food out of their mouth? Do they have difficulty chewing food? Do they wear dentures? How much do they usually eat? Do they eat some types of food more readily than others (i.e. they will eat meat but not vegetables)?

### Feeding Tips:

- Offer the food in bite-sized pieces.
- Tell the person what you are feeding them.
- Alternate bites with the different types of food on the plate.
- Make sure food is swallowed before offering another bite.
- Offer sips of beverage throughout the meal.

- Assess the need for “Thick-it”, a powdered substance (purchased in a pharmacy but non prescription) that is mixed with a beverage to make it a thicker consistency. Those with difficulty drinking can be spoon fed this thicker beverage with less likelihood of choking.
- Monitor that the person with dementia is not pocketing food in their cheeks. Use your finger to sweep the food out if necessary.
- Keep food wiped from the person’s mouth and face as needed during the meal to preserve dignity.

## Choking

People with dementia are at higher risk of choking as the dementia progresses and they lose the ability to chew and swallow properly. Choking occurs when a foreign object becomes lodged in the throat or windpipe, blocking the flow of air. In adults, a piece of food often is the culprit. Seniors with dementia can often put small objects in their mouth. Because choking cuts off oxygen to the brain, a caregiver needs to administer first aid as quickly as possible.

If the victim can speak, cough, or breathe, DO NOT INTERFERE. Some people believe that raising the arms is a technique that helps, while others believe that this is an old wives tale and could possibly cause more harm than good.

The universal sign for choking is hands clutched to the throat. If the person is unable or doesn’t give the signal, look for these indications:

- Inability to talk
- Difficulty breathing or noisy breathing
- Inability to cough forcefully
- Skin, lips and nails turning blue or dusky
- Loss of consciousness

**All caregivers should be trained in delivering first aid to residents who are choking.**

If choking is occurring, the Red Cross recommends a "**five-and-five**" approach to delivering first aid:

- **First**, deliver five back blows between the person's shoulder blades with the heel of your hand.
- **Next**, perform five abdominal thrusts (also known as the **Heimlich maneuver**).
- **Alternate** between five back blows and five abdominal thrusts until the blockage is dislodged.

**To perform abdominal thrusts (Heimlich maneuver) on someone else:**

- **Stand behind the person.** Wrap your arms around the waist. Tip the person forward slightly.
- **Make a fist with one hand.** Position it slightly above the person's navel.
- **Grasp the fist with the other hand.** Press hard into the abdomen with a quick, upward thrust — as if trying to lift the person up.
- **Perform a total of five abdominal thrusts**, if needed. If the blockage still isn't dislodged, repeat the five-and-five cycle.

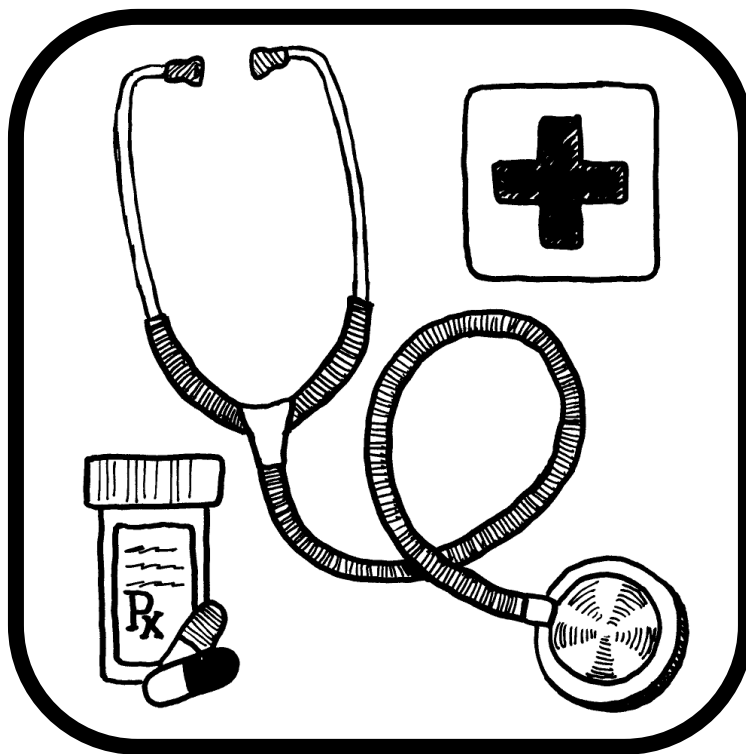
## **Pacers and Eating**

In the advanced stages of dementia, there are some individuals who are not able to sit still long enough to eat or be fed. These people are “pacers” and may have to be fed “on the run”. This is okay. The goal is to get food down them, not make them sit still. Finger foods are sometimes the easiest way to do this. Feeding a pacer requires flexibility and ingenuity and a lot of chasing on the part of the caregiver...but it can be done!



## CHAPTER 7

# MEDICAL ISSUES



**After completing Chapter 7 you will understand the caregiver's challenging role in dealing with the medical needs of a person with dementia.**





## **Dementia & Medical Issues**

Medical care for people with dementia can be very challenging for the caregiver, whether their loved one is still at home or in a care facility. Patients with dementia often have multiple healthcare needs that require careful attention to lessen behavioral consequences and improve quality of life.

Most dementia patients cannot explain their symptoms, cannot remember instructions, and are often resistant to any types of therapy. Some will complain to their caregiver about numerous aches and pains, making it difficult for the caregiver to discern what is a real issue and what is minor. Some will tell the doctor symptoms and problems that have not been mentioned before. The type of physical problems and medical obstacles will depend on the individual and degree of dementia.

Dementia patients in the early stages will typically have healthcare needs that reflect the healthcare needs of cognitively intact individuals. Patients in the middle stages have the additional complication of increasing cognitive challenges like forgetfulness, confusion, and inability to process information accurately. Late stage dementia patients may not even know they are seeing a doctor or what the doctor is or doing.

## **Finding and Partnering with the Right Doctor**

Caregivers must find a primary care doctor that they feel comfortable with, and one who has experience in treating patients with dementia. This is usually a family medicine or internal medicine physician who has numerous senior patients. This primary care doctor should take the lead in treating the person with dementia, but can refer them to a specialist if a medical condition arises that requires specialization. (A neurologist is a specialist who is often brought in initially for the *diagnosis* of dementia or Alzheimer's. Health concerns after diagnosis are usually treated by the primary doctor.)

It is imperative for a caregiver to communicate with the doctor(s) on behalf of the person with dementia. The caregiver must strive to give accurate information with regards to symptoms, behaviors, and severity of pain, as the person with dementia will not be able to do so reliably. Pinpointing and describing what is going on with another person can be very difficult and challenging. The caregiver must communicate this information to the doctor with tact and sensitivity, so as not to make the person with dementia feel inadequate or inferior.

## **Durable Medical Power of Attorney**

It is important for a person with dementia to have a trusted family member appointed to be their health care proxy when that the person becomes unable to make health decisions on their own behalf. This is done through a document called a Durable Medical Power of Attorney. The person appointed as health proxy is supposed to consider what the person with dementia would want, so it is important to have these conversations before the dementia becomes incapacitating. These may be difficult conversations, but letting another person know what their wishes would be under certain circumstances will lessen the burden of responsibility. This document can be drawn up by an attorney or completed on one's own. (See Advance Directives handout on page 122.)

## **The Doctor/Dentist Visit**

The dementia patient can become restless or disruptive in the waiting area if s/he has to wait too long. The caregiver should schedule visits according to the dementia patient's schedule. If s/he is an early riser, schedule the first visit in the morning or if a late sleeper, then schedule the first visit after lunch or the last in the afternoon. The caregiver should ALWAYS accompany the dementia patient into the visit with the doctor/dentist. Sometime, taking the patient into the doctor/dentist exam room without the staff to explain what is expected of him or her will help to alleviate anxiety. Example: "This is the chair where you will sit to let the dental hygienist clean your teeth. You will need to open your mouth and hold it open for him/her when s/he tells you." The trip to the office provides a time to discuss who, what, when and how the visit will occur. Of course, everything will need to be repeated upon arrival at the doctor or dentist office.

The dementia patient is limited by the reliability of his/her memory to provide accurate general health information, describe symptoms, or give accurate information about the effects of a prescribed drug. Limited ability to process information may also contribute to confusion on the part of the dementia patient. The caregiver needs to be calm, reassuring, and confident in answering questions and providing information to medical staff. It is always better to do this when not in the presence of the dementia patient in an effort to preserve his/her dignity.

However, in the presence of the doctor/dentist, it depends on the stage of the dementia patient how much she/he can respond and how much the caregiver must respond.

It becomes the responsibility of the caregiver to know the patient well enough to be able to, some degree, predict what the response of the dementia patient will be to physical exams, simple procedures, treatments and the procedures needed for certain treatments to take place.

## **The Hospital/Emergency Visit**

When a dementia patient must go to the hospital or the emergency room, it is vital that the caregiver is calm, rational and reassuring to the dementia patient. The dementia patient may be fearful and wonder “What is going on?”, “Who are these people?”, “Why are they doing what they are doing to me?”, “What is wrong with me?” “Why are they here?”, and “Am I alright?” Initially, the caregiver becomes the important link for the dementia patient, to provide as much information as possible to the medical staff in order to make the best determination of his/her condition. Constant and calm reassurance by the caregiver is extremely important so that medical staff can do the procedures necessary to determine the condition of the dementia patient. Verbal descriptions of what the medical staff is doing and why may be helpful in lessening the fear and anxiety of the dementia patient.

***A person with dementia should never be left alone in the hospital.*** It is imperative they have constant supervision to keep them reassured and keep them from wandering or causing themselves harm in their confusion.

## **Monitoring Medications**

A person with dementia will lose the ability to monitor their own medications. It becomes the job of the caregiver to stay on top of every prescription and over-the-counter drug the person is taking. A caregiver should make a list of all medications and have this handy for all doctor visits and especially in the case of an emergency. The caregiver must know the name of the medication, what it is for, the dosage, and potential side effects and interactions with other medications. The caregiver will work in partnership with the doctor to decide when medications are needed and when they should be stopped.

If a person with dementia becomes resistant to taking meds, or has difficulty swallowing whole pills, the caregiver can work with the physician to get the medication in liquid form if possible. Or, the caregiver can crush the pills with a pill crusher or a mortar and pestle, mixing the crushed medication with pudding, yogurt, or applesauce.

# **Some Common Medical Issues of Dementia Patients**

## **Depression**

Depression occurs often in individuals with dementia, some studies reporting that it affects 50% of the people with Alzheimer's. Depression occurs for two reasons: the degeneration of the brain cells, and the realization by the person that they have a chronic dementing illness. Antidepressants, along with strong family love and support, may lessen the symptoms.

## **Infections**

### **1. Viral Infections**

Dementia patients should receive yearly flu shots. Cold preparations and antihistamines should be used with caution to avoid drug-induced delirium and confusion.

### **2. Bacterial Infections**

The three common bacterial infections in dementia patients are:

- a) pneumonia
- b) urinary tract infections
- c) infected skin wounds in advanced stage patients

### **Pneumonia**

Pneumonia is a common complication of dementia, especially, those in advanced stages of the disease who have feeding or swallowing issues.

Patients who have forgotten how to chew or swallow also forget how to clear secretions from their mouths. Many patients over 65 do not develop cough with pneumonia and many patients will not develop a temperature above 100 degrees. People with dementia typically have lower body temperatures than other individuals. Dementia patients should be immunized against pneumonia.

## **Urinary Tract Infection**

Poor hydration, genitourinary problems that impair emptying of bladder and medications that disrupt normal GU function may predispose dementia patients to UTI's. Patients with a UTI are often delirious, behaviorally disturbed, and often stop eating as a result of the infection. Meticulous treatment is needed to eradicate the infection.

## **Infected Skin Wounds**

Dementia patients need to be checked regularly for skin tears and wounds as they may not be aware of even having a skin wound. As we age our skin becomes much more susceptible to tears and bruising. Dementia patients are no exception. Skin wounds must be treated immediately to prevent infection. There are many effective over the counter treatments for skin wounds.

## **Management of Diabetes**

Blood sugar regulation for the dementia patient has numerous challenges. Blood sugars vary based on exercise, food consumption, dietary patterns, stress and other medical problems. Caregivers need to be able to monitor blood sugar levels since the dementia patient usually cannot and may not know they even have diabetes. Food preferences may change in dementia patients and glucose control is a challenge. Frequently dementia patients may request or try to consume large numbers of sweets. The caregiver will need to find nutritious snacks and foods that do not contain high levels of sugar. Patients who receive insulin need careful monitoring to assure that food intake matches the dosing of insulin.

Diabetic retinal disease needs to be treated, if possible, since diminished vision can increase confusion as well as other behavioral issues.

Dementia patients can develop painful neuropathy, but be unable to explain the symptoms. Under-managed pain frequently precipitates agitated behaviors.

Diabetic foot care and wound healing becomes a major problem because they are unable to comply with treatment instructions and may pace or wander on injured feet. This management becomes the responsibility of the caregiver.

## **Hypertension**

Hypertension is a common issue in the elderly and many dementia patients have high blood pressure. Medications need to be selected carefully to determine interactions with other drugs being taken by the dementia patient. Each medication has pluses and minuses that should be considered. The dementia patient needs to be regularly monitored for blood pressure issues. The relationship between blood pressure regulation and cognition is unclear although recent studies suggest that long-term blood pressure control may improve cognition.

## **Coronary Artery Disease**

Atherosclerotic heart disease is common in the elderly. Some research suggests that numbers of senile plaques in the brain are related to severity of coronary artery disease and vascular dementia is related to heart disease. If surgery is considered for the dementia patient, be aware that dementia patients are extremely sensitive to the effect of medication and anesthesia. Caregivers should be alerted to the possibility of temporary delirium or a sustained drop in cognitive functioning. Treatment of heart disease does not differ from cognitive intact patients. However, treatment is complicated by the dementia patient's inability to describe pain, and their inability to remember frequency and severity of attacks.

## **COPD**

Chronic Obstructive Pulmonary Disease can be difficult to manage in dementia patients who cannot cooperate with respiratory therapy. Caregivers need to discourage cigarette smoking as soon as possible both for health reasons and safety issues. The caregiver becomes the monitor for whatever treatment is prescribed by the attending physician.

## **Arthritis**

Arthritis and arthralgia occur in 52% of elderly patients. Pain can produce agitation in patients with dementia but anti-inflammatories should be used with care because of gastrointestinal symptoms. Heat and physical therapy are useful treatments.

## **Osteoporosis**

Osteoporosis is a disease that weakens bones over time and puts a person at risk for breaking a bone. Postmenopausal osteoporosis is the most common form and affects many women after menopause. Everyone has cells that remove old bone and other cells that rebuild new bone and this ongoing process is part of what keeps one's bones strong. When a woman has postmenopausal osteoporosis, bone-removing cells cause her to lose bone at a rate that is too fast, resulting in thinner, weaker bones that can break more easily.

## **TIA's**

Trans Ischemic Attacks may occur in some dementia patients. These attacks are usually referred to as "light strokes". The patient may initially exhibit bizarre behaviors such as beginning to remove socks, slacks, etc. for no apparent reason, then not be able to focus, and not be able to walk, even short distances. The patient may talk of tingling in an extremity, leg or arm. The tingling may begin in the foot and move up the body on one side. When a TIA occurs, the dementia patient needs to be laid prone with legs elevated for the blood to return to the brain. Frequently, a TIA does not last very long and usually the dementia patient is extremely tired after an episode, sometimes wanting to sleep for the next couple of days. When a dementia patient experiences a series of TIAs over time, usually losses in abilities and processing can be observed. The caregiver needs to be vigilant in observing the behaviors and listening to the comments of the dementia patient.

## **Weight Loss**

Weight loss is a persistent problem throughout all phases of dementia. Patients with dementia may lose weight for a variety of reasons including increased caloric demand, diminished oral intake or unrecognized medical problems. Many patients will empty their plate but hundreds of calories of food are on the table, clothing and floor. Dementia patients who are pacing, wandering and moving furniture may burn more calories than those with more sedentary behaviors. Patients with Alzheimer's disease begin to lose eating motor skills in the mid phases of their disease. Feeding issues progress from loss of table manners and ability to use utensils through total inability to self-feed. Eventually patients completely forget how to feed, chew and swallow. Patients with dementia can develop a range of physical ailments to include esophagitis, peptic ulcer disease, gastrointestinal

malignancies that will lead to diminished oral intake. Poor oral hygiene can also lead to diminished intake of food. Medications can also depress appetite that can result in weight loss and caregivers need to be aware of side effects of all medications.

## **Chronic Pain**

Pain assessment and management is important for patients with dementia. Patients with mild to moderate dementia can generally report the symptoms of pain, however, individuals with moderate to severe cognitive impairment may underreport or misinterpret pain. Severely demented patients are unable to ask for PRN pain medication and the caregiver must determine whether to place the patient on a standard dose of pain medication or use careful observation (grimacing, groaning, gestures to area of pain, etc.) to determine when pain medication is appropriate. Adequate pain management may lessen agitation and increase appetite in dementia patients who are unable to explain the symptoms.

## **Medical Complications of Antipsychotic Medications**

Approximately 20% of dementia patients in care centers will require antipsychotic medications to maintain a level of control. There should be careful and thorough examinations and behavior assessments for these to be considered and administered, and should be used as a last resort. The use of antipsychotic drugs is linked to serious side effects for people with dementia, creating mobility problems, sedation, dizziness, and sometimes death, particularly when used for longer than 12 weeks. Some common antipsychotics that are prescribed are Haloperidol (Haldol), Quetiapine (Seroquel), and Risperidone (Risperdal). *(For more detailed information see “Using Medications to Help Behaviors” on page 58, Chapter 3.)*

## **Falls**

Falls are common in the elderly and very common in dementia patients. Studies show 5% of community dwelling elders fall every year with 11% sustaining fractures. Many Alzheimer patients (40-60%) fall each year and their fracture risk is increased threefold in comparison to cognitively intact older people. Every dementia patient who falls needs a thorough, basic evaluation which can include but not be limited to, blood pressure, gait assessment, neurological exam, lower strength assessment, etc.



## **Incontinence**

Most middle to late stage dementia patients become incontinent of bowel and bladder and must be managed with a toileting schedule and/or the wearing of Adult Protective Briefs. Keeping a person clean and dry is critical to prevent skin breakdown. In late stages, dementia patients may be unaware of needing to use the bathroom and it becomes the responsibility of the caregiver to carefully monitor toileting and the use of adult protective briefs to avoid embarrassment on the part of the dementia patient.

## **Diarrhea**

Diarrhea is common condition that can occur at any stage of dementia. Diarrhea causes misery to both the person with Alzheimer's and their caregiver as it is embarrassing and stressful to clean up. There are many possible causes of diarrhea including diet, medications, illness and emotional states.

## **Constipation**

At some point in time a person with dementia may suffer from constipation. This can cause pain, loss of appetite and even incontinence (as a result of the pressure/blockage). However, the person may be unable to explain what is wrong or be unaware of the problem. Furthermore, it is not a good idea to use laxatives too often with elderly people suffering from dementia. When used too often, laxatives can cause stomach pains, loss of appetite and even in some cases aggravate the problem. Therefore, it is necessary for the caregiver to look out for the signs of constipation, and the best way to deal with this problem is to try to prevent it from occurring in the first place through proper diet and hydration. *(See handout on page 121.)*

## **End of Life Management**

Patients with dementia usually survive for 8-10 years from onset of symptoms to end of life. End stage dementia patients manifest many symptoms including gait issues, feeding issues, inability to communicate and withdrawal in a number of ways. Caregivers and/or family members must make difficult decisions about resuscitation, treatments for other medical issues, hospice care and issues surrounding food intake.

Dementia patients may no longer be able to eat, drink, walk, or talk. However, they may be able to hear, since hearing is the last of the senses to go and loved ones have an opportunity to still speak to the dementia patient with last words of care and comfort.

*Information for this Module was compiled by Rachel Brown and adapted from the article entitled “Medical Care for the Dementia Patient”, a part of the Dementia Education and Training Program of the National Certified Council of Dementia Practitioners.*

# 8 Things Caregivers Should Know About Constipation and Severe Dementia

Adapted from Paula Spencer Scott, Caring.com senior editor

It's important to be aware of the possibility of constipation when caring for someone with severe-stage Alzheimer's. Constipation becomes more common with age and can cause discomfort for anyone -- especially those with dementia who can't easily articulate what's wrong.

What to know:

**1. Don't overworry about bowel habits.** It's not necessary for your loved one to have a bowel movement every single day. As a general rule, three days without a BM is considered constipation.

**2. Keep track with a toileting chart.** You may think you'll remember your loved one's habits, but it's much easier to simply record this information just as you probably already track medications.

**3. Be aware of facial expressions** (such as grimaces) during toileting or strong emotional reactions that might be signs of fear or discomfort around using the bathroom.

**4. Be especially watchful when there's a change in medication** (including the use of over-the-counter meds) or after your loved one has been ill. Know that opiate painkillers (like Vicodin) tend to worsen constipation. Many medications can cause constipation.

**5. Ask the doctor or pharmacist about constipation options** as each works in a different way. There are two kinds of products commonly used, stool softeners and laxatives. Stool softeners aren't as strong as laxatives, so many people start with a softener to see if it will help. Laxatives can solve the problem but result in diarrhea and loose bowels.

**6. Make sure your loved one is drinking enough fluids.** Many older women limit the amount of fluid they drink to avoid frequent urination or incontinence. Most clinicians recommend 6 to 8 cups of fluid daily. Coffee and other caffeinated beverages such as cola don't count. They are actually dehydrating.

**7. Make sure your loved one is eating enough fiber.** Diets low in fiber can cause constipation. Prunes can be helpful, or fruits such as apples or pears. High fiber cereals or fiber juices such as prune or cherry juice can also be helpful.

**8. Constipation can be caused by lack of activity:** Many people become constipated because they sit around all day. Walks and other exercise can definitely help reduce constipation.

*This story is an example of the challenges and difficulties a caregiver faces when trying to handle the health care issues of a person with dementia.*

# Advance Directives

What kind of medical care would you want if you were too ill or hurt to express your wishes? Advance directives are legal documents that allow you to convey your decisions about end-of-life care ahead of time. They provide a way for you to communicate your wishes to family, friends and health care professionals, and to avoid confusion later on. There are several types of advance directives that you should complete: living will, power of attorney, CPR directive, and organ donation.

None of these documents will do you any good if no one knows about them. Once you've decided what it is you do or don't want, make your wishes known to your doctor and your family.

You do not need to use a lawyer to complete your living will, medical durable power of attorney, or CPR directive. If you have legal questions, however, you should consult an attorney.

## Living Will

A living will is a legal document that a person uses to make known his or her wishes regarding life prolonging medical treatments. You, the declarant, indicate which treatments you do or do not want applied to you in the event you either suffer from a terminal illness or are in a permanent vegetative state. A living will does not become effective unless you are incapacitated; until then you'll be able to say what treatments you do or don't want. They usually require a certification by your doctor and another doctor that you are either suffering from a terminal illness or permanently unconscious before they become effective as well. This means that if you suffer a heart attack, for example, but otherwise do not have any terminal illness and are not permanently unconscious, a living will does not have any effect. You would still be resuscitated, even if you had a living will indicating that you don't want life prolonging procedures. A living will is only used when your ultimate recovery is hopeless.

A Living Will **can be destroyed any time you change your mind**. You can do this by telling someone, revoking it in writing, or by destroying the document. Let your doctor, family and anyone who has a copy of it know that you've destroyed it.

## Medical Durable Power of Attorney

A durable power of attorney for health care is a document that appoints someone you trust to be your health care proxy in the event that you become unable to speak for yourself. Your proxy can make health decisions on your behalf and is supposed to consider what you would want, so be sure to talk with them about it. It may be a difficult conversation, but you're asking someone to take on a great burden for you - letting him or her know what you want lessens that burden.

**CPR Directive**

CPR is an attempt to revive someone whose heart and/or breathing has stopped. This attempt can be made by using special drugs or machines or pressing very firmly on the chest.

In Colorado, it is presumed you would want CPR unless you and your doctor have signed a form that allows you (or your agent or proxy) to refuse CPR.

If you have a CPR directive, and your heart and/or lungs stop, medical personnel won't try to press on your chest, or use breathing tubes, electric shock or anything else to get your heart and/or lungs working again. A CPR bracelet or necklace may be worn, indicating you don't want these emergency measures. Signing a CPR directive won't prevent you from receiving other kinds of needed medical care such as treatment for pain, bleeding, broken bones or other comfort care.

If you are a patient in a health care facility and you don't have a CPR directive or aren't able to sign one, your doctor may decide, usually in consultation with you and/or family members, that resuscitation would be inappropriate. The doctor will write Do Not Resuscitate (DNR) or NO COR on your chart.

A CPR directive must be signed by both the patient (or their Medical Power of Attorney) and their doctor.

**Organ Donation**

Organ donation takes healthy organs and tissues from one person for transplantation into another. Experts say that the organs from one donor can save or help as many as 50 people. Organs you can donate include: kidneys, heart, liver, pancreas, intestines, lungs, skin, bone and bone marrow, cornea. Most organ and tissue donations occur after the donor has died. But some organs and tissues can be donated while the donor is alive.

People of all ages and background can be organ donors. If you are under age 18, your parent or guardian must give you permission to become a donor. If you are 18 or older you can show you want to be a donor by signing a donor card. You should also let your family know your wishes.

The **Organ Procurement and Transplantation Network**, under contract to the U.S. Department of Health and Human Services, ensures fair distribution of donated organs in the United States. It is the model for transplant systems around the world.

**To enroll as an organ donor online:** [www.coloradodonorregistry.org](http://www.coloradodonorregistry.org)

**To receive an enrollment form in the mail:** 1-888-256-4386 or 1-303-329-4747

You may also register at the Department of Motor Vehicles when obtaining or renewing a driver's license.



## CHAPTER 8

# ACTIVITIES



**At the conclusion of Chapter 8, you will have a greater knowledge base from which to plan and execute relevant, stimulating activities for persons with dementia and Alzheimer's.**





## **ACTIVITIES FOR THE PERSON WITH DEMENTIA**

As a person with dementia gradually loses the ability to take care of their own daily needs, they also lose the ability to entertain themselves and to initiate meaningful tasks and activities. They will get bored and not know how to do anything about it. They may sit and stare into space for hours at a time. They may constantly ask their caregiver what they are supposed to be doing. They may constantly ask their caregiver what they can do to help. They may try to do things but not remember how to do them, often resulting in frustration or damage to household items.

It becomes the goal of the caregiver to plan “activities” that help fill and structure the day as well as give a sense of self worth to the person with dementia. Realistically though, caregivers do not have to keep their loved one active and stimulated every minute of the day...this would be exhausting and unrealistic for all! Caregivers should have the mindset, however, that a person with dementia does need someone to plan and guide their day, and the caregiver should do their best to give their loved one a sense of productivity and worth through activities, as well as moments of joy and happiness, despite the extra work and hassle to themselves.

### **What kind of activities work best**

When we think of the word “activities” we often think of hobbies, games or crafts. For the person with dementia, everything becomes an activity: dressing, eating, bathing, dusting, vacuuming, listening to music, watching a movie, games, music, crafts, outings, etc. There is no magic list of activities that is specifically designed for people with dementia. Each person is unique with their likes and dislikes and their level of dementia, and different activities work for different people.

Oftentimes people with dementia will do “weird” activities. This means they will enjoy or be consumed with doing things that we don’t normally consider traditional “activities”. Figuring out weird or unusual things a person with dementia will do can often be intriguing and fun. It is necessary for caregivers to “think outside the box” (thank you Taco Bell) to come up with these activities. And sometimes, the person with dementia will just do something on their own that keeps them engaged for long periods of time.

Examples of these types of activities are:

- tying and untying knots in a piece of rope
- picking up leaves out of the yard one by one
- moving pennies from one bowl to another
- sorting used lottery cards
- stuffing and unstuffing envelopes
- finding small objects in a tub of dried rice
- taking all of the clothes out of a closet
- screwing and unscrewing nuts on bolts

A caregiver's goal should be to help their person with dementia initiate and participate in everyday tasks and all kinds of activities. Doing things and feeling productive will enhance the quality of life of the person with dementia...no matter what the task or activity is.

The trick is finding activities that the person is still able to do...or giving them simplified tasks or parts of tasks...or helping them one-on-one with a task or activity that they want to do but can't do alone.

The end product does not matter, it's the enjoyment while doing that counts!

Participating in tasks and activities remains possible for persons with dementia far into the disease, though it definitely becomes increasingly challenging to find things that the person can still do.

## **Activities and ability level**

Caregiver's must find tasks and activities that match or fit the person's level of ability and remaining strengths. Caregiver's should not focus on what the person CAN'T DO, but what the person still CAN DO...their remaining abilities. The higher functioning the person, the more traditional activities they will be able to do. As the dementia advances, activities lean more toward the "think outside the box" type of weird activities.

## **Breaking activities into smaller pieces or tasks**

As the person's abilities gradually change, they can be given less complex tasks or simpler parts of a task. Almost every task can be broken down into parts.

Activity: Prepare a Meal

|                         |  |
|-------------------------|--|
| Plan the menu           | Put silverware on table                      |
| Grocery shop            | Put napkins on table                         |
| Put away groceries      | Carry food to table                          |
| Wash the food           | Clear dishes from table                      |
| Slice or dice food      | Wipe off table and countertops               |
| Measure ingredients     | Rinse dishes                                 |
| Put food in pans        | Wash dishes by hand or load<br>in dishwasher |
| Stir or mash            | Dry dishes                                   |
| Set temperature on oven | Put dishes away                              |
| Put plates on table     |  |

## **Trial and error and experimentation**

A caregiver will find successful tasks and activities for the person with dementia through trial and error and experimentation.

A person's "bag of activities" will start out based on the person's personal preferences and what they have always liked to do, but don't rule anything out. People with dementia will often become involved in tasks or activities in which they had no previous interest. Caregivers should try anything and everything to engage and stimulate their person with dementia.

## **An activity is successful**

- if it keeps the person happy and involved for any amount of time.
- if the person exhibits no signs of frustration.
- if it brings the person even a moment of joy and happiness or a sense of purpose

## **Jump starting the activity**

Often a person with dementia can engage in a task if they have that initial “jump start” to get started.

To start a task and keep it going a caregiver may have to give:

- Verbal directions
- Demonstrations
- Examples of finished product
- Written directions
- Reminders of steps and purpose
- Prompting
- Guiding touch
- Handing things

## **More activity basics**

1. Activities should be appropriate for ADULTS and appropriate for the INDIVIDUAL. Because of the dementia, activities do have to be simplified, but there is a fine line between simplified and childish. Some people with dementia will be offended by childish types of activities. Others will find them enjoyable. Know the individual’s activity likes and dislikes.
2. When facilitating traditional games such as cards or dominos or checkers, you may have to SIMPLIFY OR CHANGE THE RULES OF THE GAME to make it less complicated and more appropriate. You don’t have to play the game by the real rules. It’s okay to make up rules. Know the ability level of the individual.
3. If a person with dementia doesn’t want to participate in an activity, that’s okay. Try to cajole and encourage, knowing that they will benefit from the stimulation, but if they refuse that’s fine. NEVER FORCE ANYONE TO DO AN ACTIVITY. They will get stimulation just from watching and listening. Depending on the person, sometimes it’s better not to ask if they want to do an activity. Just employ GENTLE GUIDANCE to involve them in an activity because you know they will benefit, because if you ask, you are giving them the opportunity to say no. Know the individual’s activity participation level and interests.

4. If you have to make all the moves or make all the decisions in a game or complete all the steps in a craft for the person, IT IS NOT AN APPROPRIATE ACTIVITY FOR THAT PERSON'S ABILITY LEVEL. However, depending on the person, they may be getting stimulation just by watching and listening and being part of the group. Watch their face for signs of frustration. Know the person's activity ability level.
5. The END PRODUCT of an activity, whether it's a craft, or artwork, or a cleaning task, is not important. What matters most is the process. Is the person enjoying the activity? Are they feeling successful?
6. All activities should be geared for SUCCESS. No one should be made to feel stupid or inadequate by their inability to complete a task or activity. Do not ask a person to do something that you know is beyond their ability level.

## **Planning Activities**

Being responsible for planning another person's activities can be emotionally and physically exhausting.

Caregivers should try and plan activities that they themselves like to do. The more enjoyment you have, the greater enjoyment for all.

A wise caregiver will ask for help and make use of valuable resources such as: family members, friends, home health care agencies that offer companionship, church friends, or adult day care centers. Utilizing a combination of the above is usually the most beneficial. This means that one person doesn't have to be the one and only caregiver.

For professional caregivers, sharing activity ideas and tips on the likes, dislikes, and ability level of the individuals being cared for will make everyone's job easier and improve the quality of care of the person with dementia.

## **Adult Day Care Centers**

Caregivers should take advantage of Adult Day Care Centers as these programs are designed to provide stimulation, socialization, entertainment, exercise and pampering to persons with dementia through activities.

The benefit of these programs is twofold. While the person with dementia is being stimulated, the caregiver is able to take a much needed break.

## **Care Facilities and Activities**

Besides providing a structured activity calendar, care facilities can foster stimulation and activity by providing an environment that is filled with old fashioned memorabilia and knick knacks. These items can spark memories or provide comfort to those with dementia. Some care facilities have a sensory room that is filled with lights, sounds, smells, and tactile objects for those in the more advanced stages of dementia.

## Activity Idea Categories

Use these activity categories to help spark ideas so you can plan a *variety* of activities. People with dementia do need structure, and don't remember if they do the same things every day, but variety does help to keep their brain stimulated.

- **Personal care activities:** bathing, grooming, dressing, eating, brushing teeth, shaving, polishing nails, fixing hair
- **Household chore activities:** vacuuming, dusting, laundry, dishwashing, polishing silver, mopping, scrubbing sinks & toilets, taking out trash, bringing in the mail, sweeping
- **Food activities:** grocery shopping, meal preparation, eating out, baking cookies
- **Pet activities:** feeding, giving treats, fresh water, brushing, walking
- **Musical activities:** singing, dancing, listening, tapping sticks together in time to the music, remembering lyrics and song titles, going to concerts
- **Art activities:** crafts, drawing, painting, visiting museums or art galleries, painting walls or furniture
- **Religious activities:** attending church services, listening to recordings of sermons, listening to or singing religious music, reading faith based publications, praying
- **Career activities:** farming, banking, parenting, etc.
- **Sports activities:** golfing, kicking a ball, fishing, throwing a football, throwing horseshoes, bowling, ring toss, ball toss
- **Outdoor activities:** walking, bird watching, sunset watching, camping, hosing off the patio, trimming bushes, picnics
- **Reminiscing activities:** photo albums, watching home movies, watching old movies
- **Family activities:** holiday get togethers, family reunions, playing with grandchildren, talking
- **Restful activities:** napping, sitting and relaxing, patio sitting
- **Outings:** Sunday drives, running errands, shopping, traveling, museums

## More Activity Ideas:

### TABLE GAMES

Bingo (regular)  
Bingo (picture)  
Yahtzee  
Dominoes  
Checkers  
Cribbage  
Boggle  
Scrabble  
Poker  
Connect 4  
Qwirkle  
Outburst  
Snapshot  
Cards  
Uno  
Hit the deck  
Kings Corner  
Slap Jack  
Cardmania  
Fish  
Crazy Eights  
Skip Bo  
War  
Old Maid  
Addition Flash Cards  
Multiplication Flash Cards

### ARTS & CRAFTS

Watercolor painting  
Coloring  
Drawing  
Holiday crafts  
Seasonal crafts  
Foam crafts  
Stickers

### PHYSICAL ACTIVITIES

Chair exercising  
Walking (inside & out)  
Balloon batting  
Bowling  
Ring toss  
Horse shoes  
Parachute  
Golf putting  
Flyswatter balloons  
Bean bag toss  
Frisbee toss  
Badminton  
Basketball  
Throwing & catching balls  
Noodle hockey  
High rollers  
Darts  
Croquet  
Table ball

### CHORES

Cooking activity  
Folding laundry  
Vacuuming  
Sweeping  
Mopping  
Dishwashing  
Dusting  
Wiping off tables  
Wiping off placemats  
Moving furniture  
Watering plants  
Feeding the birds  
Caring for a baby (doll)

### PAMPERING ACTIVITIES

Shoulder and neck  
massage  
Painting nails  
Brushing, fixing hair  
Lotion on hands/arms

### THINKING / TALKING ACTIVITIES

Regular conversation  
Reminiscing  
News events  
Trivia  
Spelling bee  
Name game (like  
Outburst)  
Dictionary/  
encyclopedia game  
Scattergories  
Index card game  
Category game  
Truth or dare  
Guess the animal  
Listen & do  
Rhyming game  
Hangman  
Crosswords  
Partner words (i.e. salt  
& pepper)  
Famous pictures  
(people/landmarks)  
Shopping scavenger  
game



**SENSORY  
ACTIVITIES**

Identify smells  
Identify tastes  
(blindfold)  
Feel & identify (socks  
with items in them)  
Identify sounds  
Clay  
Pass and describe  
objects (soft, hard,  
etc.)

**INDEPENDENT or  
ONE-ON-ONE  
ACTIVITIES**

Untying knots  
Rice find  
Sorting  
-beads  
-poker chips  
-buttons  
-cards

-lottery tickets  
-paper clips  
-coins  
Stamping  
-lottery tickets  
-envelopes  
-paper  
Letter board  
Stuffing & unstuffing  
envelopes  
Plumbing pipes  
Bolts & screws  
Cutting out  
pictures/shapes  
Stringing beads  
Word search  
Puzzles  
Hidden pictures  
Reading

**MUSIC ACTIVITIES**

Sing Along CDs and  
books  
Bells  
Rhythm-cans and sticks  
Dancing  
Karaoke  
Internet or Radio or  
CDs

**TV VIEWING**

Favorite shows  
Movies  
Sports/Olympics  
Old comedy shows

**LISTENING  
ACTIVITIES**

Jokes  
Poetry  
Stories:  
-Readers Digest  
-Reminisce Magazine

*This list is compiled from the activity menu of Senior Daybreak of Hilltop.*

# 101 things to do with the person who has Alzheimer's

1. Clip coupons
2. Sort poker chips
3. Count tickets
4. Rake leaves
5. Use the carpet sweeper
6. Read out loud
7. Bake cookies
8. Look up names in the phone book
9. Read the daily newspaper out loud
10. Ask a friend, neighbor, church acquaintance who has a baby or young child to visit
11. List to polka music
12. Plant seeds indoors and out
13. Look at family photographs
14. Toss a ball
15. Color pictures
16. Make homemade lemonade
17. Wipe off the table
18. Weed the flower bed
19. Make cream cheese mints
20. Have a spelling bee
21. Read the Reader's Digest out loud
22. Fold clothes
23. Have a calm pet visit
24. Cut pictures out of greeting cards
25. Wash silverware
26. Bake homemade bread
27. Sort objects such as beads by shape or color
28. Sing Christmas carols
29. Say "tell me more" when they start talking about a memory
30. Put silverware away
31. Make a Valentine collage
32. Play favorite songs and sing together
33. Take a ride
34. Make a cherry pie
35. Read aloud from labels
36. Dye Easter eggs
37. Make a basket of socks
38. Take a walk
39. Reminisce about the first day of school
40. String Cheerios to hang outside for the birds
41. Make a fresh fruit salad
42. Sweep the patio
43. Color paper shamrocks green
44. Fold towels
45. Have afternoon tea
46. Remember great inventions
47. Play Pictionary
48. Paint a sheet
49. Cut out paper dolls
50. Identify states and capitals
51. Make a family tree poster
52. Color a picture of our flag
53. Cook hot dogs outside
54. Grow magic rocks
55. Water houseplants
56. Reminisce about the first kiss
57. Play horseshoes
58. Dance
59. Sing favorite hymns
60. Make homemade ice cream
61. Force bulbs for winter blooming
62. Make Christmas cards
63. Sort playing cards by their color
64. Write a letter to a family member
65. Dress in red on a football Saturday
66. Pop popcorn
67. Name the presidents
68. Give a manicure
69. Make paper butterflies
70. Plant a tree
71. Make a May basket
72. Make homemade applesauce
73. Finish famous sayings
74. Feed the ducks
75. Mold with PlayDoh
76. Look at pictures in a National Geographic
77. Put a simple puzzle together
78. Sand wood
79. Rub in hand lotions with a pleasant scent
80. Decorate paper place mats
81. Arrange fresh flowers
82. Remember famous people
83. Straighten underwear drawers
84. Finish nursery rhymes
85. Make peanut butter sandwiches
86. Wipe off patio furniture
87. Cut up used paper for scratch paper
88. Take care of a fish tank
89. Trace and cut out leaves
90. Ask simple questions
91. Finish Bible quotes
92. Paint with string
93. Cut out pictures from magazines
94. Read classic short stories
95. Put coins in a jar
96. Sew sewing cards
97. Put bird feed out for birds
98. Clean out a pumpkin
99. Reminisce about a favorite summer
100. Roll yarn into a ball
101. Make a birthday cake

Reprinted from the Alzheimer's Care Guide Sept/Oct 2006, original source: Susan Lonn, Madonna Adult Day Care, Lincoln, NE

## CHAPTER 9

# FAMILY SUPPORT



**After completing Chapter 9, you will have a greater understanding of what family caregivers are feeling and experiencing. You will recognize the importance of offering empathy and support.**



# **FAMILY SUPPORT**

Families who have a loved one with dementia need a tremendous amount of support and empathy. Caring for and watching a loved one with dementia decline is one of the most stressful challenges a family can face. Each family member or friend will handle the emotional stress differently. All those who know the afflicted person will be touched and affected by the devastation and sadness brought on by the dementia.

For family members, watching a loved one decline with dementia invokes:

- Anger
- Sadness
- Depression
- Helplessness
- Guilt (over placement or feeling like they are not doing enough)

Those who are doing the actual hands on care:

- May or may not neglect their own health
- May or may not be hesitant to ask others for help
- May or may not feel no one else can do the job as well as them
- May or may not be physically and emotionally exhausted
- May or may not resent their caregiving role
- May or may not get criticism from other family members
- May or may not be educated about the disease and what to expect
- May be a natural caregiver, or may struggle with the role

There will not be one single family member who is happy or not stressed about their loved one having dementia.

## Ways to support and interact with family member caregivers

- Initiate daily smiles, hugs, words of encouragement
- Allow family member to talk and vent - be a good listener - don't give unwanted advice
- Share funny stories with family members about things the person with dementia has done
- Encourage the family member to join a support group
- Inform family member of education opportunities
- Inform family member of resources
- Cut them some slack if they have a meltdown or lash out at others

## Tough decisions and landmarks a family will face

- What dementia **medications** should be tried, how to pay for them, when is it appropriate to stop them?
- When to take **driving** privileges away from the person with dementia and how to do it without make them mad?
- When is it no longer okay to leave the person **home alone** and how to arrange for "babysitting" without making them mad, and who provides this type of service and how much does it cost and how will they pay for it?
- How does the caregiver get a **break** (respite) and how do they pay for it?
- What kind of **doctor** is the best and what if they don't like or trust the current doctor?
- When and if to **place** in a care facility, how much does it cost, and how to pay for it?
- What **kind of care facility** should they be placed in: assisted living, nursing home, secure, non-secure, Medicaid?
- How much do they **visit** if the person is placed in a care facility?
- What to do if their loved one is exhibiting **behaviors** that are a problem for others?
- How do they **financially support** themselves *and* pay for care for their loved one?
- What **legal steps** need to be taken?
- How to emotionally handle it when their **loved one no longer knows them**?
- What to do when their loved one is near **end of life**?

## Helping Children Understand Dementia

*Adapted from the Alzheimer's Association pamphlet, "Parent's Guide Helping Children and Teens Understand Alzheimer's"*

Alzheimer's disease can have a big impact on every member of the family, including children and teenagers. Each child will react differently to someone who has Alzheimer's. A child or teen might have questions about what is happening. It's important to answer these questions openly and honestly. It will also help to share with them the changes the disease might bring, now and in the future. Good communication is the best way to help a child or teen deal with the changes that are happening.

When answering a child or teen's questions, one should try not to sugar coat the message. Children are excellent observers and often aware if an answer doesn't sound right. A child or teen should be reassured that just because a person in the family has Alzheimer's, it does not mean that he or she or other family members will get the disease, too.

Dementia can cause a person to direct confusion, fear or anger at the child or teen. If this happens, be sure the child or teen knows the person did not mean to act that way. People with dementia have good days and bad days. Make sure the child or teen does not feel responsible for the kind of day it is. It is also important for them to understand that those who help care for the person with dementia might sometimes seem tired, frustrated, sad or short-tempered. Explain this to your child or teen, assuring them that they are not to blame.

Young people need a way to share their feelings about having a loved one with Alzheimer's disease. Show comfort and support by letting them know that those feelings are normal.

An excellent video to show children can be found online at **www.hbo.com** "The Alzheimer's Project: A 4-part Documentary HBO series". This whole series is phenomenal, but the one titled "Grandpa, Do You Know Who I Am?" is specifically for children. The film tells five stories of children, ages 6-15, who are coping with grandfathers or grandmothers who have Alzheimer's disease.

## The Main Work of the Family Caregiver

*Adapted from the Alzheimer's Association "Savvy Caregiver" program*

In order to survive the caregiving experience a caregiver must learn to **BALANCE** 5 components of caregiving life:

- **Educate** themselves on dementia and what specific disease or condition is causing the dementia of their loved one. Also educate themselves on helpful caregiving tips and strategies.
- **Manage daily life** by keeping their person with dementia involved in tasks and activities and experiencing moments of joy and happiness.
- **Manage behaviors** of their person, helping the person remain as calm as possible.
- **Manage own well being** by keeping themselves rested and rejuvenated and attending to their own health issues.
- **Manage resources** by learning to ask for help, and learning what type of help is available.

## Resources:

**Hilltop Dementia Specialist, Laurie Frasier:** Laurie Frasier is the Director of Senior Daybreak of Hilltop, an adult day care program for seniors with dementia. Laurie has extensive knowledge and experience caring for persons with dementia and is happy to sit down and offer advice and guidance to anyone needing support. Laurie has personal experience caring for both her mom with Alzheimer's disease and her frail grandmother, and has cared for numerous participants with various types of dementia at Senior Daybreak. Prior to Daybreak, Laurie served as the Western Slope Regional Director for the Alzheimer's Association. She has created and taught numerous dementia training classes for the community and families. Call for an appointment, 970-241-7798. This service is free.



**Dementia & Alzheimer's Workshop:** Hilltop offers a workshop for family members or professionals caring for those affected by dementia and/or Alzheimer's. This workshop is offered quarterly through the Western Colorado Community College. There is a fee for this class, and students are given a copy of the Hilltop Dementia Training Manual. The class is sometimes offered as a full day workshop, and sometimes offered as a condensed shorter version. For more information contact Laurie Frasier, Senior Daybreak of Hilltop, 970-241-7798.

**211 Western Colorado Resource Phone Line:** By simply dialing 211 or 244-8400, callers can obtain information and options on local services and resources. An Information and Referral Specialist will assess one's situation, help find answers to one's questions, and provide options and information for a multitude of services such as free/low cost health and dental care, food-clothing-shelter, counseling and support groups, employment services, crisis intervention, elder assistance and disability services, substance abuse services, mental health services, transportation, legal assistance, parent education, and more. This service is free.

**Mesa County ADRC:** ADRC stands for Aging & Disability Resources for Colorado. ADRC provides a coordinated and streamlined access point to long term care services and supports for adults age 60 and over, or age 18 and over living with a disability, and their caregivers. ARDC can help a person find programs and/or services, can assist with determining preliminary qualifications for programs that pay for long-term care, and can assist with application processes for programs. ADRC can provide referrals and options for transportation (medical and grocery shopping), handyman services/light home repairs, yard work, advocacy, long term care options and benefits counseling, information and assistance, connection to local services, respite assistance, grant application assistance, assistance finding in-home services, veteran's programs. Call 970-248-2746.

**Alzheimer's Association:** The association offers 24 hour telephone support, family counseling, support groups, education classes, information and referral, and a MedicAlert/Safe Return program for persons or families dealing with Alzheimer's disease or dementia of any type. Most of these services are free or have a minimal cost. The Alzheimer's Association is a national organization with chapters in each state. The Colorado Chapter headquarters is in Denver with a local regional office in Grand Junction that serves 9 counties on the Western Slope. Regional Office, 970-256-1274, 2232 N. 7<sup>th</sup> St. Suite B1, 24-7 Helpline-1-800-272-3900. [www.alz.org](http://www.alz.org)

**Geriatric Care Managers:** These individuals can help families with a variety of services. Generally they provide education, counseling, resources and referral, and assessments. They can provide on-going support as needed by the family or client to include family liaison for care management, assessment and safety planning, downsizing and /or relocation assistance, handyman assistance, transport to appointments, accompanying and advocating at appointments, securing assistance and services, provide supervision with bill paying or secure bookkeeping services. Some can help with getting medical power of attorneys or guardianships in place. A geriatric care manager could help a client who has no local family member to provide support and assistance. There is a fee for the services of a geriatric care manager.

Recommended Geriatric Care Managers: Hilltop Home Care Geriatric Care Manager, 970-208-1345, [www.htop.org](http://www.htop.org). Elder Quest, Paula McCormick, 970-985-5950.

**A Place for Mom:** An Eldercare Advisor from this franchise referral service can assist families in finding a variety of senior care services. The list of services may not be all inclusive, as A Place for Mom will only refer to those organizations who have contracted with A Place for Mom to be on their referral list. Care options can include assisted living communities, retirement communities, skilled nursing homes, residential care homes, home care services, respite and hospice. This service is free to the client. Find a local contact at [www.aplaceformom.com](http://www.aplaceformom.com)

**Home Health Care Agencies:** Offer a range of services in the home from assisting with daily tasks, personal care assistance, meal preparation, medication management, light housekeeping, companionship, or skilled nursing care. An agency will send out a personal care provider (PCP), or certified nursing assistant (CNA), or a registered nurse (RN), who will come to the home on a part-time basis for an agreed upon amount of time for agreed upon tasks. Fee is usually based on an hourly rate. Names of agencies can be found in the phone book under “home health care”. Recommended Agency: Hilltop Home Care, 1620 Hermosa Ave., #62, Grand Junction, CO 81506, 970-208-1345. [www.htop.org](http://www.htop.org)

**Private Caregivers:** Private caregivers are difficult to find, and are usually found by word of mouth. Attending support groups, elder care community conferences or health fairs, and making contacts with other caregiving families is the best way to find a knowledgeable, caring caregiver. Private caregivers charge an hourly rate which is usually less than the hourly rate charge of an agency. However, private caregivers do not usually have liability insurance.

**Adult Day Care Programs:** Adult day care programs offer stimulation and socialization for participants. Caregivers can get a much needed break while their loved one is attending the program. Day programs provide a variety of activities to meet all ability levels to include thinking/talking activities, physical activities, pampering and entertainment. They also assist participants as needed with activities of daily living such as eating, toileting, and walking. Medicaid and the Department of Veterans affairs will pay for this service for those participants who qualify, otherwise a family must private pay. Recommended Adult Day Care Program: Senior Daybreak of Hilltop, Laurie Frasier, Director, 970-241-7798. [www.seniordaybreak.org](http://www.seniordaybreak.org)

**Elder Law Attorneys:** The caregiver becomes responsible for getting financial and legal affairs in order so as to be prepared for what the future brings to a person with dementia and/or Alzheimer's disease. Frequently an attorney is needed to provide the necessary advice and legal paperwork. A person with dementia should have a person designated as their health proxy to make medical decisions on their behalf when they are no longer able. A person with dementia should have a person designated to handle finances and assets on their behalf when they are no longer able, especially if they are likely to run out of money to pay for their care and would qualify to apply for Medicaid. The legal documents appointing these individuals are called Power of Attorney. Appointing these people, usually family members, and making plans and decisions and getting documents in place early on is critical. Elder Law attorneys can draw up these legal documents and advise caregivers on the best way to legally protect their assets but still qualify their loved one for Medicaid. Recommended Elder Law Attorneys: Billie M. Castle, LLC, 970-255-7488 and Brown & Brown, 970-243-3558.

**Medicaid Planning and Qualifications:** Mesa County Department of Human Services (DHS) administers the Medicaid program and services for Mesa County. Persons with dementia and their caregivers must meet very specific health, income and asset financial criteria in order to qualify. Families must complete an application, meet with a DHS eligibility worker, and provide all requested documents showing proof of income and assets and health issues in order to determine eligibility. Once a person has been approved for Medicaid they will be assigned a DHS Case Manager to oversee their Medicaid-paid-for needs and services. These services can include home health care, adult day care plus transportation to and from the program, and assisted living or nursing home placement. Contact DHS to speak with an eligibility worker or to pick up an application, 970-248-2888. Or, contact an Elder Law Attorney who specializes in Medicaid qualification who can prepare this application with knowledge and strategy for protecting the assets of the spouse.

**Veterans Administration:** The Veterans Administration (VA) provides a wide range of benefits to a person if they are a:

- Veteran, Veteran's dependent
- Surviving spouse, child or parent of a deceased Veteran
- Uniformed service member
- Present or former reservist or National Guard member

With regards to a person with dementia, these benefits can include payment for adult day care, home care, or long term facility care. To determine which benefits a person is entitled to one may contact a social worker at the local VA Medical Center at 970-242-0731.

**Aid & Attendance Benefits:** Veterans and surviving spouses may be eligible to receive a monthly income through the Veterans Administration Aid & Attendance pension benefit. Pension is a benefit paid to wartime veterans who have limited or no income, and who are age 65 and older (or if under 65 who are permanently and totally disabled). Veterans who are more seriously disabled, such as with Alzheimer's, may qualify for "Aid and Attendance" or "Housebound" benefits that are paid in addition to the basic pension rate. Generally, a person may be eligible if they were discharged from service under conditions other than dishonorable, served at least 90 days of active military service 1 day of which was during a war time period, their countable income is below a yearly limit set by law, and they are age 65 or older, or, they are permanently and totally disabled, not due to their own willful misconduct. Individuals are encouraged to speak privately to their local Veterans Service Officer as each application is evaluated on a case-by-case basis. Contact the local VA Medical Center at 970-242-0731 for the current officer.

**Mesa County Human Services Respite Funds:** Mesa County Human Services Department has a Respite Assistance Program (RAP) which offers an annual grant to caregivers of \$500 for in-home respite care of not more than 5 consecutive days. Qualification is based on need, not income. Call 970-683-2614 or 211 for more information and an application.

**Ombudsman:** The Ombudsman program is affiliated with the Area Agency on Aging. The Ombudsman office is a resource for finding the right assisted living or nursing home placement. They also provide problem solving, mediation or investigation of concerns and complaints by nursing home or assisted living care center residents, family members or staff. They can assist anyone in the community looking for guidance or help with long term care issues. The local Ombudsman is Marilyn Richardson. Her office is located at Colorado Legal Services, 200 N. 6<sup>th</sup> St., Suite 203, GJ, CO 81501, 970-243-7940.

**Assisted Living Care Facilities:** Assisted living facilities provide individual apartments with light housekeeping, nutritious meals, transportation, laundry services, cable TV, activities and outings, and medication assistance. The amount of assistance provided is tailored to the needs of the individual. Some assisted living facilities have special wings or units for people with dementia. Some offer respite care. There are approximately 16 assisted living facilities in Mesa County. A list can be obtained from Senior Daybreak, Laurie Frasier, 970-241-7798, or 211-Western Colorado, or the Ombudsman, 970-243-7940. (*See handout, page 152, When is it time?*)

**Nursing Home Care Facilities:** Nursing Home Care Facilities offer 24 hour skilled nursing care to residents in private or semi-private rooms. Services include ongoing health care treatments and assessment, meals and snacks, medication management, laundry, and activities. Some offer speech, physical and occupational therapy, respite care and secured units for dementia. Some are private pay only, some take Medicaid, some are for veterans. There are 7 nursing homes in Mesa County. A list can be obtained from Senior Daybreak, Laurie Frasier, 970-241-7798, or 211-Western Colorado, or the Ombudsman, 970-243-7940.

**Hospice:** Hospice organizations provide end of life care for those with a terminal illness. After an assessment of needs of the patient, their focus is patient comfort and pain management offering 24 hour service to both the patient and their family members. Hospice eligible patients often experience: increased visits to the doctor, hospital or emergency room, difficulties dressing and bathing, treatment side effects with little or no health improvement, decreased appetite, weight loss, depression or withdrawal from loved ones. Hospice will care for a person in their home, at a nursing home or assisted living facility, or at the Hospice Care Center. A patient can be in Hospice for weeks, months, and sometimes years, depending on the individual situation. A patient can be referred by their physician, or a family can contact the hospice directly and request an assessment. Each patient is assigned a Hospice team which includes a Doctor, Nurse, Social Worker, Certified Nursing Assistant and a Chaplain to provide end of life support and medication management. Hospice services are paid for by Medicare and can provide medications and medical equipment and supplies, usually at no cost to the family. There are two hospice organizations in Mesa County: Hardin Hospice (formerly Alpine Hospice), 970-245-0188, and HopeWest Hospice (formerly Hospice and Palliative Care of Western Colorado), 970-241-2212. (This hospice program also offers a “Transitions-palliative care program” for those with a serious illness that have a life expectancy of longer than 6 months.)

**Support Groups:** Support groups offer caregivers the opportunity to talk, vent, and share with others who are traveling a similar caregiving journey. It is empowering to learn that others are dealing with similar issues, stress, and emotional turmoil. These groups usually meet once a month on a regular schedule. There are currently three support groups specifically for dementia in Mesa County: Hilltop/Senior Daybreak's caregiver group held monthly, with a Brainbooster Group held simultaneously for individuals diagnosed with early dementia. For location and time contact Laurie Frasier, 970-241-7798. The third group is a caregiver only support group held at Aspen Ridge Alzheimer's Care Center facilitated by Gail Hansen, 970-254-1233.

**Medical Supplies and Incontinence Products:** As the disease progresses, special products and tools will be needed and can help make caregiving easier. The old adage, "the right tool for the job", definitely applies to caregiving. Researching and discovering what tools are out there, (and there are many that one has probably never even heard of), is an important aspect of caregiving. Medical supply stores are very helpful and can advise caregivers on products they have that might solve a problem. Grand Mesa Medical Supply, 970-241-0833, Walker Discount Medical Supplies, 970-243-5111, Walgreens, and Sam's Club and Wal-Mart are all good resources.

**Colorado Life Trak (Project Lifesaver):** Colorado Life Trak (previously known as Project Lifesaver) is a tracking program designed to find persons with dementia, who still live at home and who are no longer driving, who have wandered off and are lost. Since 60% of Alzheimer's patients are likely to wander and get lost, this program gives caregivers and families peace of mind. A bracelet equipped with a small transmitter, which emits a signal, is worn by the person with dementia either on the wrist or the ankle. Average recovery time of a lost individual is under 30 minutes. Volunteers change the battery once a month. This program is provided by the Mesa County Sheriff's Department with no cost to the family. 970-244-3500

**The Aetrex GPS Shoes:** These innovative shoes feature the latest GPS tracking technology embedded in the base of the heel with location coordinates sent to a central monitoring station. When a person with dementia is wearing the Aetrex GPS Shoes, their caregiver will have the ability to quickly track and locate them at any hour of the day using the interactive tracking website service (contingent upon enrollment in a separate monthly tracking plan – approximately \$35/month). Price: approximately \$300/pair.

**Senior Companion Program:** Senior Companions are seniors who volunteer their time to help other frail seniors. They offer companionship and support with errands, and usually are able to give 3 hours per week to each client. If the client has dementia, this companion time gives the caregiver a break. St Mary's Hospital sponsors the local Senior Companion Program. This service is free. 970-263-9092

**Alzheimer's Store:** This online store offers a huge selection of products especially for caregivers and persons with dementia. Products range from activity materials to clothing to safety devices and everything in between. [www.alzstore.com](http://www.alzstore.com) or phone 1-800-752-3238

**Colorado State Infusion Project:** Colorado State Infusion Project provides for the purchase of high calorie drinks (called Two-Cal @ 495 calories per can) for patients who are not getting enough nutrition through the regular meal and snack process. These are the same drinks given to cancer patients by doctors and hospitals. 970-243-3411

## **Books**

Learning to Speak Alzheimer's, Joanne Koenig Coste, First Mariner Books, 2003  
The 36-Hour Day, Mace, Nancy L. MA & Rabins, Peter V. MD, Johns\_Hopkins Press Health Book, 1981,1991,1999.  
Voices of Alzheimer's, Petersen, Betsy, Da Capo Press,, 2004  
Broyles' Playbook for Alzheimer's Caregivers, Broyles, Frank, University of Arkansas, Razorback Athletic Director - [www.alzheimersplaybook.com](http://www.alzheimersplaybook.com)  
Aging with Grace: The Nun Study, Bantum Books, May 2001  
Finding the Joy in Alzheimer's, Avadian, Brenda, North Star Books, 2001  
Wilfrid Gordon McDonald Partridge, Fox, Mem, Kane/Miller Book Publishers, 1985  
Losing My Mind, De Baggio, Thomas, Free Press, 2002

## **Pamphlets**

Free pamphlets on all dementia & Alzheimer's topics, Alzheimer's Association - 1-800-272-3900, local office 256-1274, 2232 N. 7<sup>th</sup> St., Suite B  
"When Death is Near - A Caregiver's Guide", Hope West Hospice & Palliative Care of Western Colorado, 241-2212

## **DVDs**

The Alzheimer's Project: A 4-part Documentary HBO series, [www.hbo.com](http://www.hbo.com)  
Complaints of a Dutiful Daughter, Deborah Hoffman, [www.wmm.com](http://www.wmm.com), \$25  
Understanding Alzheimer's and Safety, Alz Assoc., [www.alz.org](http://www.alz.org), \$24.95  
Bathing Without A Battle, [www.unc.edu/ordering.htm](http://www.unc.edu/ordering.htm), \$57  
Accepting the Challenge, [www.alznc.org](http://www.alznc.org), \$190  
Your Time to Care: Basic Skills for Caring for Individuals with Alzheimer's Disease and Related Dementias at Home, [www.alz.fdn](http://www.alz.fdn) \$34.95  
The Family Guide to Alzheimer's Disease, 5 volume set, hosted by Leeza Gibbons, \$99.95  
Savvy Caregiver Program, [www.hcinteractive.com/savvy](http://www.hcinteractive.com/savvy), \$57

## **Websites:**

[alz.org](http://alz.org) - Alzheimer's Association - National Site  
[alz.org/co](http://alz.org/co) - Alzheimer's Association - Colorado Chapter  
[alzfdn.org](http://alzfdn.org) - Alzheimer's Foundation  
[alzpoetry.com](http://alzpoetry.com) - Alzheimer's Poetry Project  
[alzstore.com](http://alzstore.com) - Alzheimer's Store - supplies and products for caregivers  
[care4elders.com](http://care4elders.com) - educational materials for professionals  
[dementiaguide.com](http://dementiaguide.com)  
[bestdementiavideosandbooks.com](http://bestdementiavideosandbooks.com)  
[youtube.com](http://youtube.com)



# WAYS TO HELP

**To be completed by the caregiver. Use this list to help you think of specific ways people can help. Make copies and give to people when they offer to help.**

- ☐ I would like for somebody to stay with my loved one while I get away by myself for a couple of hours on an “every once in a while” basis.
- ☐ I would like for somebody to stay with my loved one while I get away by myself on a regular schedule: 1, 2, 3, 4, 5, 6, 7 times a week for 1, 2, 3, 4, 5, 6+ hours a day.
- ☐ I would like for somebody to come take my loved one out to lunch, movie, mall, concert, walk, which would give me a break and give him/her some mental stimulation.
- ☐ I would like for somebody to go with me and help take my loved one out to lunch, movie, mall, concert, walk, which would make it more fun for us and allow us both some social interaction.
- ☐ I would like for somebody to help with chores around the house: cleaning, lawn, laundry, cooking, paying bills, washing car, walking pets,  
\_\_\_\_\_
- ☐ I would like for somebody to come visit our house and just sit and talk and keep us company.
- ☐ I would like for somebody to call me on the phone (how often \_\_\_\_\_) to check on us and just chat and give me a reality check.
- ☐ I want someone to listen to me vent and cry about every hard and absurd thing that is happening in this crazy world of dementia.
- ☐ I would like for someone to stay with \_\_\_\_\_ for \_\_\_\_ days and nights while I go out of town.
- ☐ Other: \_\_\_\_\_
- ☐ Other: \_\_\_\_\_
- ☐ Other: \_\_\_\_\_

## When is it time to place my loved one with dementia in a care facility?

The decision to place a loved one in a care facility is extremely difficult and emotional. While it is great to have input and support from other relatives, the primary caregiver should ultimately be the person to make the decision. Some people with dementia are kept at home until they pass, while others are placed in a care facility early on. There are many factors to consider and each family situation will be unique.

- **physical health of the caregiver:** Does the loved one need a lot of physical assistance with mobility or toileting or bathing, and is the caregiver physically able and strong enough to provide this assistance without getting hurt?
- **emotional health of the caregiver:** Is the caregiver emotionally overwhelmed with the stress of caring for their loved one? Do they *want* to keep their loved one at home? Is the stress affecting their ability to stay healthy? Are they getting respite (breaks) that allow them to rejuvenate and relax?
- **ability of the caregiver to get adequate sleep:** Is the caregiver getting enough sleep or are they suffering from sleep deprivation because their loved one is frequently up during the night?
- **safety of the current living situation:** Is the loved one exhibiting wandering behaviors and/or other safety issues (such as falls) that cannot be resolved in the current living situation?
- **medical needs of the person with dementia:** Does the loved one have medical needs that cannot be met at home, even with the assistance of home health care or hospice?
- **financial situation:** Can the family afford the cost of assisted living or nursing home care, or do they have financial assistance in place with Medicaid or VA or long term care insurance?

When considering placement, families should visit care facilities to determine which is the best fit for them and their loved one. Care facilities are very different in many ways: physical appearance, size and layout of rooms, total number of rooms, staff training and philosophy, price, levels of care, types of entertainment and activities, food, and proximity to the family. Care facilities assess potential residents on a case-by-case basis and may or may not accept a person based on their ability to meet that person's unique needs.

If placement is a probable likelihood, families should start researching facilities early on, before a crisis situation develops.

Feelings of guilt, mixed with feelings of relief, are natural and common emotions that accompany the placement of a loved one in a care facility.

## CARE FACILITY DEFINITIONS

**Assisted Living:** a care facility that provides a combination of housing, personalized supportive services and health care designed to meet the individual needs of persons who need help with the activities of daily living, but do not need the skilled medical care provided in a nursing home. The *Activities of Daily Living* are generally considered to include eating, bathing, dressing, getting to and using the bathroom, getting in or out of bed or chair, and mobility. Assisted Livings vary in their ability to care for persons with dementia and will assess potential residents on an individual basis. Some facilities will only accept people in the early stages of dementia. Others will accept all levels of dementia.

**Nursing Home:** A place of residence for people who require constant nursing care and have significant deficiencies with activities of daily living. Residents include the elderly and younger adults with physical or mental disabilities. Residents in a skilled nursing facility may also receive physical, occupational, and other rehabilitative therapies following an accident or illness. Nursing homes vary in their ability to care for persons with dementia and will assess potential residents on an individual basis.

**Secure Facility:** The whole facility or a wing of a facility has a locked door system preventing the resident from leaving at will. The purpose of a secure facility is to prevent a person with dementia from wandering out and getting lost. Both assisted and nursing facilities can have secure wings.

**Wander Guard:** The facility has a special alarm system installed that allows for residents and families to go in and out the door at will. However, the resident at risk for wandering wears a special bracelet and if the person wearing that bracelet goes out the door an alarm signals the staff.

**Licensing:** Each state licenses its assisted living and nursing homes, making them subject to the state's laws and regulations. The public can view inspection reports of each facility by going to [www.cdphe.co.us](http://www.cdphe.co.us), then selecting "Assisted Living Residences" or "Nursing Homes", then selecting "Inspection and Occurrence Findings".

**Medicare and Medicaid:** *Medicare* is the federal program primarily for the aged who contributed to Social Security and Medicare while they were employed.

Medicare does not pay for adult day care or long term placement in a care facility or nursing home. Medicare will pay for nursing home services for 20 to 100 days for beneficiaries who require skilled nursing care or rehabilitation services **following a hospitalization of at least three consecutive days**. The program does not cover nursing care if only custodial care is needed — for example, when a person needs assistance with bathing, walking, or transferring from a bed to a chair. To be eligible for Medicare-covered skilled nursing facility (SNF) care, **a physician must certify** that the beneficiary needs daily skilled nursing care or other skilled

rehabilitation services that are related to the hospitalization, and that these services, as a practical matter, can be provided only on an inpatient basis.

*Medicaid* is the federal program implemented with each State to provide health care and related services to those who are "poor." Each State defines poverty and; therefore, Medicaid eligibility. Those eligible for Medicaid may be aged, disabled or children.

Medicaid offers assistance in paying for in-home care, adult day care, assisted living care and nursing home care. To qualify for Medicaid benefits, recipients must meet criteria related to their medical condition, income and financial resources. Medicaid takes into account the financial needs of married couples when one person requires long-term care and his or her spouse does not. To apply for Medicaid, a person must contact the Department of Human Services, complete an application, provide requested documentation, and meet with an eligibility specialist who will then determine whether the criteria for qualification has been met. A person could also hire an elder law attorney to help them analyze their individual situation, and possibly rearrange assets to meet criteria for eligibility, or plan ahead for qualifying in the future.

Assisted Living facilities and Nursing Homes may *choose* to participate in Medicare and/or Medicaid. If they apply and pass a survey (inspection), they are "certified" and are also subject to federal laws and regulations. All or part of a care facility may participate in Medicare and/or Medicaid. Some facilities choose not to participate because the rates for reimbursement from the government are much less than their actual costs for providing care and they could potentially lose money and not be able to afford to stay in business. For this reason, some facilities limit the number of Medicare or Medicaid beds.

## CHAPTER 10

# **HOMEWORK & PRACTICUM**



**This chapter includes the Homework Packet, which is simply a tool to help one better learn and retain the important concepts surrounding dementia care. The Senior Daybreak practicum is an opportunity for students to interact with many individuals with different types and degrees of dementia.**



## **Homework Packet**

The Homework Packet, (pages 159-181), is a review of this manual. The packet is a tool to help the learner retain and better understand the important concepts regarding dementia care. It is suggested that one first try and complete the packet from memory to see what they have already retained from reading or attending a class or work experience, then complete what they don't know by using the manual as an open book test. The questions on the homework packet are in order of the manual, not randomly mixed up, for ease in completing.

## **Daybreak Practicum**

The Senior Daybreak of Hilltop 2-hour practicum is an opportunity for students to interact with many different individuals with different types of dementia in different stages of dementia, all in one place...an adult day care program. A special memory care wing at an assisted living or nursing home is also an ideal classroom for observing and learning about dementia. Any person who is interested in a practicum opportunity at Senior Daybreak of Hilltop is welcome. Call Laurie Frasier, Director, to schedule this practicum.

Walking into such an environment for the first time can be frightening and overwhelming, which is why completing this piece of the training is so important. If one has never been in such a place, it is natural to be nervous, but a person will quickly learn that there is really no need to be nervous around people with dementia. These individuals are the same as all individuals. They have unique personalities with many endearing qualities and traits. Most students walk away from the practicum with a new found sense of compassion and caring for these individuals who were simply dealt the fate of a terrible and devastating condition which has impaired or is in the process of destroying their brain function.

The student's goal at the practicum is to interact with as many different participants or residents with dementia as possible within the 2-hour time frame by either conversing or doing a one-on-one activity with the individual. The length of time a student will spend with each participant will vary from 1-15 minutes, depending on the person with dementia's ability to communicate and interact. The student will interact and then record observations on a form. Students will be given a list of the first names of all of the Daybreak participants in attendance that day, and the type of dementia and level of dementia so that they can better understand their observations.

For liability reasons, students should not assist a person with dementia with walking or transferring or toileting or feeding during this practicum. Students should alert staff to attend to any of these needs if they arise. Students may feel free to ask questions of staff regarding an individual participant's activity ability or conversational ability, understanding that extreme confidentiality should be upheld with regards to this person's privacy rights.

A sample observation form is included on page 182, with a blank observation form following. This will give students an idea of what will be expected of them during the practicum experience.



# 1: HOMEWORK – DEMENTIA & ALZHEIMER'S OVERVIEW

1. List 7 examples of common forgetfulness that are considered typical of aging:

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2. T or F: When a person is having problems with their memory, it is sometimes difficult in the beginning to tell if it is because they are simply getting old or whether it might be the early signs of dementia.

3. Dementia is a word that describes a broad category of illnesses that affect the brain. There are different types of dementia. A person showing signs of dementia is having problems with \_\_\_\_\_, \_\_\_\_\_, and \_\_\_\_\_.

4. T or F: Dementia is not a normal part of aging as it is always caused by something.

5. List the 8 areas of cognition that are affected by dementia and circle the one that is the first and predominant area affected.

|       |       |
|-------|-------|
| _____ | _____ |
| _____ | _____ |
| _____ | _____ |
| _____ | _____ |

6. What is the leading cause/type of dementia? \_\_\_\_\_

7. List the 8 other diseases/conditions that cause dementia.

|       |       |
|-------|-------|
| _____ | _____ |
| _____ | _____ |
| _____ | _____ |
| _____ | _____ |

8. T or F: Every person who has Alzheimer's has dementia, but not every person who has dementia has Alzheimer's.
9. T or F: Persons with symptoms of dementia should see their doctor as their condition might be treatable and reversible.
10. Alzheimer's destroys the brain cells. The hallmark pathology consists of \_\_\_\_\_ and \_\_\_\_\_ which choke the healthy brain cells causing them to shrink and die.
11. What causes Alzheimer's disease? \_\_\_\_\_
12. List 8 known/probable risk factors for Alzheimer's disease:
- |       |       |
|-------|-------|
| _____ | _____ |
| _____ | _____ |
| _____ | _____ |
| _____ | _____ |
13. T or F: There are two different types of Alzheimer's disease based on the age of onset. The symptoms are the same.
14. List the 4 steps that a physician would take to reach a diagnosis of Alzheimer's disease.
- |       |       |
|-------|-------|
| _____ | _____ |
| _____ | _____ |
15. T or F: The typical progression of Alzheimer's disease is slow and gradual and can be from 3-20 years. A person is thought to go backwards in \_\_\_\_\_.
16. The stages of Alzheimer's are early, \_\_\_\_\_, and \_\_\_\_\_.
17. People with Alzheimer's will have a mixture of \_\_\_\_\_ and \_\_\_\_\_, with mysterious moments of \_\_\_\_\_ all the way until the end of their journey.
18. T or F: Every person diagnosed with Alzheimer's is very aware that they have a brain disease which is affecting their ability to function.

19. T or F: Alzheimer's is always fatal though many will die from other health issues before the disease runs its slow gradual course of destruction.
20. The number of people with Alzheimer's is rapidly increasing, especially as babyboomers enter the age of greatest risk, age \_\_\_\_ and older. Currently, 1 in \_\_\_\_ people over the age of \_\_\_\_ get AD and 1 in \_\_\_\_ people over the age of \_\_\_\_.
21. List the 4 medications currently used to treat Alzheimer's, which are of benefit to some and used in the hopes of chemically boosting a person's memory and slowing the decline.
- \_\_\_\_\_
- \_\_\_\_\_
22. T or F: Alzheimer's is always fatal though many will die from other health issues before the disease runs its slow gradual course of destruction.
23. Scientists are hopeful that we can prevent Alzheimer's by taking better care of our \_\_\_\_\_ through nutrition and exercise, because what's good for the \_\_\_\_\_ is good for the brain.
24. List the 10 early warning signs and symptoms of dementia and/or Alzheimer's:
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
25. A person with dementia often lives in a world of \_\_\_\_\_, \_\_\_\_\_, and \_\_\_\_\_.

## 2: HOMEWORK – INTERACTION, COMMUNICATION, ENVIRONMENT

1. T or F: Even though there are classic symptoms and behaviors of dementia and Alzheimer’s disease, each individual will be very different and must be cared for as a unique individual.

2. List the 5 ways that dementia can affect each person differently:

|       |  |
|-------|--|
| _____ | there can be no change or drastic change   |
| _____ | they can have few challenging ones, or many challenging ones                             |
| _____ | it can be slow or rapid  |
| _____ | these will constantly change as the dementia progresses                                  |
| _____ | these can come and go and are important to know and share with the rest of the care team |

3. List 12 unique traits that would be important to know about a person with dementia so that a caregiver can provide the best care.

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4. A caregiver can expect changes and challenges to occur with \_\_\_\_\_ and these changes and challenges will increase as the dementia increases. This will make it difficult to know if the individual's needs are being met or if they comprehend what the caregiver wants them to know and understand.
5. A person with dementia will constantly \_\_\_\_\_ the same words or phrase or story or joke. How should the caregiver respond?
- \_\_\_\_\_
6. A person with dementia might have difficulty finding \_\_\_\_\_, making it hard for the caregiver to understand what the person with dementia is trying to say. What should the caregiver do?
- \_\_\_\_\_
7. A person with dementia might have difficulty keeping up with a \_\_\_\_\_ or staying on \_\_\_\_\_. What should a caregiver do?
- \_\_\_\_\_
8. A person with dementia might have difficulty understanding and following \_\_\_\_\_. What should a caregiver do?
- \_\_\_\_\_
9. A person with dementia might say things that aren't \_\_\_\_\_. What should a caregiver do?
- \_\_\_\_\_
10. A person with dementia might say things that are \_\_\_\_\_ or \_\_\_\_\_ inappropriate. What should a caregiver do?
- \_\_\_\_\_
11. A person with dementia might become very \_\_\_\_\_ because they don't remember the actual facts or things that they have already been told. What should a caregiver do? (Hint: this is THE MOST IMPORTANT COMMUNICATION TIP)
- \_\_\_\_\_

12. A person with dementia might scramble up sentences or say words together that don't make sense. This is called \_\_\_\_\_.  
What should a caregiver do?  
\_\_\_\_\_
13. A person in the advanced stages of dementia will lose the ability to speak. What must a caregiver do if the person cannot verbally make their needs known? \_\_\_\_\_  
\_\_\_\_\_
14. Why should a caregiver not ask a person with dementia, "Do you remember me?" or "Do you remember what we did yesterday?"  
\_\_\_\_\_  
\_\_\_\_\_
15. Why should a caregiver *try* not to get their feelings hurt if a person with dementia says something to them that is rude or inappropriate?  
\_\_\_\_\_  
\_\_\_\_\_
16. \_\_\_\_\_ is very stimulating to the brain of a person with dementia, makes them feel valued and loved, and triggers old memories.
17. T or F: In the world of dementia, funny and bizarre actions and words will occur frequently and it is okay to laugh and find humor in the situation, being mindful and careful of the person's feelings. It is a caregiver's job to find and create moments of \_\_\_\_\_ and \_\_\_\_\_ for the person with dementia.
18. Everyone is affected by the \_\_\_\_\_ and the people around them. People with dementia are more sensitive to their surroundings and the actions of others. Why is this concept an important one for caregivers to understand? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

### 3: HOMEWORK – BEHAVIORS

1. T or F: People with dementia will behave in ways that can create difficulties for themselves, their caregivers, and the people around them. Dementia compromises a person's \_\_\_\_\_, leading to awkward and embarrassing situations.
2. T or F: There are classic dementia behaviors that are common and most likely to occur, but each individual will exhibit their own unique set of behaviors.
3. A caregiver's goal in the early stages of dementia is to preserve the person's feelings and dignity, and help them maintain as much \_\_\_\_\_ as possible.
4. What 5 things can a caregiver do to help a person who is in the early stages of dementia:
  - Do not point out their \_\_\_\_\_.
  - Cue and help with visual and verbal \_\_\_\_\_.
  - Answer \_\_\_\_\_ in a calm and supportive voice.
  - Avoid arguing and trying to \_\_\_\_\_ or \_\_\_\_\_.
  - Do what it takes to help the person save \_\_\_\_\_ and feel \_\_\_\_\_.
5. T or F: Typical behaviors in the early stages are the same as the early warning signs/symptoms of dementia.

Complete the blanks on the following probable/possible challenging behaviors that may occur as the dementia progresses:

6. \_\_\_\_\_ is when a person with dementia follows their caregiver and is afraid to let them out of their sight.
7. If a person leaves the safety of their home and caregiver on foot or by car with the likelihood of being unable to find their way home it is called \_\_\_\_\_. 60-70% of people with Alzheimer's will do this.

8. A person who constantly cries and is overwhelmed with sadness is said to exhibit the behavior of \_\_\_\_\_.
9. Exhibiting behavior that is rude or embarrassing or sexually inappropriate is called \_\_\_\_\_.
10. \_\_\_\_\_ is the universal phenomenon commonly seen in people with dementia who get more anxious, agitated and confused in the late afternoon.
11. When a person with dementia picks up items and hides or moves them to other places this is called \_\_\_\_\_.
12. People with dementia often “want to go \_\_\_\_\_”, even when they are already there.
13. The behavior of getting up at 3:00 am and getting dressed or wandering around the house is called \_\_\_\_\_.
14. Being anxious and irritable with no apparent cause other than the confusion from the dementia is known as \_\_\_\_\_.
15. \_\_\_\_\_ is the name for the behavior when a person is not able to sit calmly and relax and feels the innate need to be on the move.
16. A person may make the same odd sound or say the same word over and over and this is known as \_\_\_\_\_.
17. When a person with dementia has false paranoia and suspicions that others are stealing or cheating on them this is called \_\_\_\_\_.
18. A person is having \_\_\_\_\_ when they see people or things that are not really there.
19. A person with dementia may have \_\_\_\_\_, which are also considered as “quirks”, when they constantly worry about certain items over and over.



20. Some people with dementia will talk to their own reflection in the \_\_\_\_\_ as if they were talking to another person.
21. A person with dementia may exhibit \_\_\_\_\_ and \_\_\_\_\_ due to their impaired social graces and falsely perceived ideas.
22. Most commonly seen with bathing or dental care, a person with dementia may be uncooperative or fearful, also known as \_\_\_\_\_
23. A person with dementia may exhibit \_\_\_\_\_ as they go backwards in time, in both voice and action.
24. For reasons other than “letting it all hang out”, people with dementia might do this if they are hot or feeling restricted or have forgotten the social norms, \_\_\_\_\_.
25. This happens when a person with dementia is unable to figure out how to get out of a room or closet, \_\_\_\_\_.
26. When a person with dementia forgets how to operate the washing machine or lawn mower they may try to “fix” it resulting in \_\_\_\_\_ to household tools or equipment.
27. When a person with dementia no longer has control of their bowel or bladder, resulting in the need for adult protective briefs it is called \_\_\_\_\_. When they can’t remember how to use or recognize a toilet they may \_\_\_\_\_.
28. Dealing with challenging behaviors requires creative problem solving, flexibility, and patience. There is no magic \_\_\_\_\_!
29. People with dementia are often inconsistent and \_\_\_\_\_.
30. The first step when faced with a challenging behavior is to decide if \_\_\_\_\_ is really necessary.

31. If a behavior is compromising the \_\_\_\_\_, \_\_\_\_\_, or \_\_\_\_\_ of the person with dementia, or others, then it is necessary to take action to try and stop the behavior. Give an example of such a behavior: \_\_\_\_\_  
\_\_\_\_\_
32. The second step when faced with a challenging behavior is to analyze the environment and the physical needs of the person with dementia for \_\_\_\_\_.
33. List 12 triggers that could be influencing the behaviors of a person with dementia:
- |       |       |
|-------|-------|
| _____ | _____ |
| _____ | _____ |
| _____ | _____ |
| _____ | _____ |
| _____ | _____ |
| _____ | _____ |
34. The third step when faced with a challenging behavior that calls for intervention is to try one of the 9 Caregiving \_\_\_\_\_.
35. \_\_\_\_\_ is the technique used that takes advantage of the loss of short term memory. Knowing the individual's history, family, likes and dislikes, happy buttons and upset buttons gives a caregiver lots of material for this technique.
36. People with dementia will often automatically say "no" when *asked* to do something. If this happens more frequently than not, a caregiver should employ \_\_\_\_\_, which involves physically leading or guiding them without asking.
37. \_\_\_\_\_ is the strategy used to preserve the person with dementia's feelings over all the losses they are experiencing. It can also be used to coax a person to accomplish a task.

38. Everyone needs the opportunity to vent and have their feelings understood. This makes a person feel reassured and can calm them. The technique for listening with empathy and expressing words of understanding to the person with dementia is called \_\_\_\_\_.
39. A person with dementia needs constant \_\_\_\_\_ from their caregivers as they struggle with the world of confusion. This strategy can alleviate their fear and is often needed every single minute of every day.
40. The \_\_\_\_\_ approach takes advantage of old social tapes and often gets a positive reaction from the person with dementia. The caregiver will greet the person with dementia with enthusiasm and joy at seeing them.
41. The old saying, "Out of sight, out of mind" describes this strategy known as \_\_\_\_\_.
42. When tasks are too complicated, resulting in confusion, the strategy of \_\_\_\_\_ should be used, all the while praising the person with dementia for their effort.
43. Some times there are no strategies that are effective. When this happens, a caregiver needs to \_\_\_\_\_. This is not failure...just part of the challenge.
44. T or F: All people with dementia will eventually turn angry and violent.
45. List the 5 rules of thumb for dealing with an upset and angry dementia person:
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
46. When is it appropriate to use behavior modifying medications on a person with dementia? \_\_\_\_\_
- \_\_\_\_\_

47. The goal of using behavior modifying medications is to \_\_\_\_\_ , not “drug” the person with dementia into a lethargic state. The \_\_\_\_\_ is in charge of the \_\_\_\_\_ , with input from the observations of those who care for the person.
48. There are several types of medications that can help alleviate behavioral symptoms. List 5 types:
- |       |       |
|-------|-------|
| _____ | _____ |
| _____ | _____ |
| _____ | _____ |
49. T or F: People with dementia still have the same need for sexuality and intimacy as those without dementia. Sexually inappropriate behaviors can occur as the dementia damages one’s social filters, and it is not uncommon for a person with dementia to show signs of attraction to a person who is not their spouse.
50. What steps should be taken if a relationship develops in a care facility between two persons with dementia?
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
51. If a person with dementia makes sexual advances towards a staff person they should remain calm and do not \_\_\_\_\_ , even if the behavior is upsetting, shocking, or embarrassing. Why?
- \_\_\_\_\_
52. T or F: Caregiving teams should share information on residents and clients with each other about which specific behavior strategies work and don’t work for a particular individual for the purpose of providing successful and individualized care.

## 4: HOMEWORK – SAFETY

1. There is a delicate balance to preserving a person with dementia's sense of \_\_\_\_\_, privacy, and dignity while keeping them safe.

2. List 10 safety issues that need to be addressed when caring for a person with dementia:

|       |       |
|-------|-------|
| _____ | _____ |
| _____ | _____ |
| _____ | _____ |
| _____ | _____ |
| _____ | _____ |

3. T or F: Driving is a complex skill, and early on people with dementia will lose the ability to drive safely and remember the rules of the road.

4. All safety issues are of concern, but \_\_\_\_\_ is one of the biggest challenges as it will often happen when the family least expects it. The Alzheimer's Association cites that 6 out of 10 people with dementia will do this, often resulting in injury or death.

5. List 5 ways to wander-proof the environment:

|       |
|-------|
| _____ |
| _____ |
| _____ |
| _____ |
| _____ |

6. List 7 ways to plan ahead in the event a person wanders:

|       |
|-------|
| _____ |
| _____ |
| _____ |
| _____ |
| _____ |
| _____ |
| _____ |

## 5: HOMEWORK – PERSONAL CARE

1. List 8 personal care activities that a person with dementia will need assistance with, especially as the dementia progresses:

|       |       |
|-------|-------|
| _____ | _____ |
| _____ | _____ |
| _____ | _____ |
| _____ | _____ |

2. A general rule for personal care is to encourage and cue the person to do as much as possible for themselves, but be ready to \_\_\_\_\_ when needed.

3. List 11 personal care general tips:

|       |
|-------|
| _____ |
| _____ |
| _____ |
| _____ |
| _____ |
| _____ |
| _____ |
| _____ |
| _____ |
| _____ |
| _____ |

4. What could you do if a person with dementia insists on wearing the same outfit every day. \_\_\_\_\_  
\_\_\_\_\_

5. \_\_\_\_\_ is often the most difficult and challenging personal care activity that caregivers face. Knowing the individual's routine, ability level, and current feelings with regards to this task is the most important step in accomplishing a successful experience.

6. T or F: The caregiver will need to assume increasing responsibility for maintaining good dental care for the person with dementia, as they will forget the importance of good hygiene and how to perform the task.
7. Most women with dementia will respond to pampering and not mind having their \_\_\_\_\_ and \_\_\_\_\_ and \_\_\_\_\_ done. Most men with dementia will need help with \_\_\_\_\_, and gloves should be worn in case he is accidentally nicked or cut.
8. People with dementia will gradually become unable to toilet independently, and will become \_\_\_\_\_ of both bowel and bladder.
9. When a person wears adult protective briefs, keeping them as dry and clean as possible will prevent \_\_\_\_\_.
10. Adult protective briefs, a.k.a. "Depends", should never be called \_\_\_\_\_.
11. List 3 toileting issues that are common with the elderly and can increase problems with incontinence.  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## **6: HOMEWORK – NUTRITION & DEMENTIA**

1. The portion of the brain that interprets the signals for \_\_\_\_\_ and \_\_\_\_\_ are often affected by dementia, leading to poor food and liquid choices and intake.
2. The \_\_\_\_\_ must ensure that a person with dementia gets the nutrition and hydration they need without compromising their dignity and independence.

3. The best way to keep a person nutritiously fed and hydrated is to \_\_\_\_\_ and diligently monitor their food and beverage consumption with \_\_\_\_\_ and \_\_\_\_\_.
4. Caregivers should not treat people with dementia like \_\_\_\_\_ when it comes to eating. Do not say, "If you clean your plate you can have dessert."
5. It is important for people with dementia to drink plenty of \_\_\_\_\_ to prevent dehydration and constipation.
6. T or F: People with dementia will never lose the ability to ask for a drink when they are thirsty.
7. List 3 ways a caregiver can assist a person with eating.  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
8. When actually feeding a person with dementia, it is necessary to be very familiar with their ability to \_\_\_\_\_.
9. List 5 signs that indicate that a person is choking:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
10. If choking is occurring, the Red Cross recommends a \_\_\_\_\_ approach to delivering first aid.
11. Some people with dementia are unable to sit still long enough to eat or be fed. These people are "pacers" and may have to be \_\_\_\_\_, and this is okay!



## 7: HOMEWORK – MEDICAL ISSUES

1. When it comes to medical issues, most dementia patients cannot explain their \_\_\_\_\_, cannot remember instructions, and can be resistant to therapies or treatments.
2. It is important for a caregiver to communicate with \_\_\_\_\_ on behalf of the person with dementia, and must do so with \_\_\_\_\_ and \_\_\_\_\_ so as to not make the person with dementia feel inadequate or inferior.
3. What is the document called that appoints a trusted family member to make health decisions on behalf of a person with dementia?  
\_\_\_\_\_
4. T or F: A person with dementia should go to a doctor appointment by themselves without the accompaniment of the caregiver because of HIPPA laws.
5. Why should a person with dementia not be left alone in the hospital?  
\_\_\_\_\_
6. A caregiver should make a list of all \_\_\_\_\_, that a person with dementia takes, and keep this list handy for doctor visits and in case of emergencies.
7. \_\_\_\_\_ occurs in people with dementia for two reasons: the degeneration of the brain cells, and the realization by the person that they have a chronic dementing illness.
8. List 3 types of bacterial infections:  
\_\_\_\_\_  
\_\_\_\_\_
9. Caregivers need to be able to monitor blood sugar levels since the dementia patient usually cannot and may not even remember or know they have \_\_\_\_\_.

10. High blood pressure is called \_\_\_\_\_.
11. Artherosclerotic heart disease is common in the elderly and also known as \_\_\_\_\_.
12. \_\_\_\_\_ can result in the need to quit smoking and have respiratory therapy.
13. Anti-inflammatories, heat and physical therapy are useful in treating \_\_\_\_\_.
14. \_\_\_\_\_ is a disease that weakens bones over time and puts a person at risk for breaking a bone.
15. \_\_\_\_\_ attacks are usually referred to as light strokes.
16. Patients with mild to moderate dementia can generally report the symptoms of \_\_\_\_\_, but those with severe dementia may not be able to.
17. The use of \_\_\_\_\_ drugs is sometimes used to control challenging behaviors in people with dementia, but may have serious side effects and should be used only as a last resort.
18. \_\_\_\_\_ are common in the elderly and common in dementia patients resulting in fractures.
19. List 3 toileting issues that are ongoing and challenging to deal with when caring for persons with dementia:  
\_\_\_\_\_  
\_\_\_\_\_
20. Which sense is the last to go when an individual is dying? \_\_\_\_\_

## 8: HOMEWORK – ACTIVITIES

1. Who is responsible for planning activities for the person with dementia, and why can't the person plan their own activities? \_\_\_\_\_  
\_\_\_\_\_
2. For the person with dementia, \_\_\_\_\_ becomes an activity.
3. T or F: There is no magic list of activities that is specifically designed for people with dementia as each person is different and will be unique in their ability level and likes and dislikes.
4. Figuring out \_\_\_\_\_ or unusual things a person with dementia will do can often be intriguing and fun, as people with dementia will do tasks that are not considered "traditional" activities. List 3 examples of this type of activity:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
5. The \_\_\_\_\_ does not matter. It is the enjoyment while doing the activity that counts.
6. T or F: It is more difficult to find activities that a person can and will do as the dementia gets worse.
7. Caregivers must find tasks and activities that fit the person's \_\_\_\_\_ of \_\_\_\_\_, and focus on what the person can still do, not what they can't do.
8. Almost every task can be broken down into smaller \_\_\_\_\_, thus simplifying a complex task for the person with dementia.
9. Discovery of successful tasks and activities for the person with dementia is made through \_\_\_\_\_ and \_\_\_\_\_ and experimentation.

10. An activity is successful if:

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11. Often a person with dementia can keep a task going on their own if they have that initial \_\_\_\_\_ to get started.

12. List 7 things a caregiver may have to do to get a person with dementia started on an activity or task:

|       |       |
|-------|-------|
| _____ | _____ |
| _____ | _____ |
| _____ | _____ |
| _____ | _____ |

13. Activities should be appropriate for \_\_\_\_\_, not geared for children, and appropriate for the \_\_\_\_\_, based on their likes and dislikes.

14. When playing traditional games with a person with dementia such as cards or dominos, you may have to \_\_\_\_\_

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15. T or F: You should never force a person with dementia to do an activity, but encouraging and cajoling and employing gentle guidance is okay. It is sometimes better not to ask them and give them the opportunity to say no.

16. All activities should be geared for \_\_\_\_\_, so that no one feels stupid or inadequate.

17. Being responsible for planning another person's activities can be emotionally and physically \_\_\_\_\_. List 5 resources caregivers can use to help entertain their person with dementia:

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18. What are the two benefits of adult day care centers?

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19. List 14 activity idea categories:

|       |       |
|-------|-------|
| <hr/> | <hr/> |
| <hr/> | <hr/> |
| <hr/> | <hr/> |
| <hr/> | <hr/> |
| <hr/> | <hr/> |
| <hr/> | <hr/> |
| <hr/> | <hr/> |

20. List 10 activities that you personally like to do that you would enjoy and could potentially do with someone with dementia:

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## 9: HOMEWORK – FAMILY SUPPORT

1. T or F: Caring for and watching a loved one with dementia decline is one of the most stressful challenges a family can face.
2. List 5 feelings a family member will experience when watching a loved one with dementia decline.

|       |       |
|-------|-------|
| _____ | _____ |
| _____ | _____ |
| _____ |       |

3. List 7 helpful ways that you/staff can support and interact with family member s who have a loved one with dementia:

|       |
|-------|
| _____ |
| _____ |
| _____ |
| _____ |
| _____ |
| _____ |
| _____ |

Families will face many tough decisions and landmarks when caring for a person with dementia. Fill in the blanks.

4. What dementia \_\_\_\_\_ should the physician prescribe, how to pay for them, when to stop them?
5. When is it time for the person to stop \_\_\_\_\_ due to impaired reaction time, perception, and memory with regards to signage?
6. When is it no longer safe to leave the person \_\_\_\_\_ because they need supervision and oversight?
7. How does the caregiver get time off from caregiving, known as \_\_\_\_\_ or taking a break.
8. What kind of \_\_\_\_\_ is the best and what if they don't like the current one they have?

9. When is it time to \_\_\_\_\_ in a \_\_\_\_\_, and how much does it cost, how will we pay for it, what kind, and how much should we go to \_\_\_\_\_ once they are there?
10. What to do if the loved one is exhibiting \_\_\_\_\_ that are a problem for other residents in the care facility?
11. How do they \_\_\_\_\_ themselves and pay for care for their loved one?
12. What \_\_\_\_\_ steps need to be taken with an elder law attorney?
13. How will they handle the emotions when their loved one no longer \_\_\_\_\_ who they are?
14. What should they do when very little time is left and their loved one is near \_\_\_\_\_?
15. Good \_\_\_\_\_ is the best way to help a child or teen deal with the changes that are happening when someone they love has dementia.
16. List 5 components that a caregiver must learn to balance to be a good caregiver and survive the stress:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
17. List 8 resources that are offered **at Hilltop** to help families care for a loved one with dementia:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

# HILLTOP DEMENTIA TRAINING

## HANDS ON PRACTICUM OBSERVATION FORM

Name \_\_\_\_\_ Date \_\_\_\_\_

Your goal is to interact with at least 6 different participants with dementia, by either conversing or doing a one-on-one activity with the individual. Length of time with each participant can range from 1 - 15 minutes.

1. Participant Laurie

Activity: string beads

What did you observe or learn about the participant and their level of dementia:

Laurie had limited conversation ability and repeated the same phrase over and over. She was able to string beads independently. She smiled a lot and was very engaged in the activity.

2. Participant Jack

Activity: we talked while he walked around

What did you observe or learn about the participant and their level of dementia:

Jack was talkative but asked over and over how he was getting home, not retaining any information for longer than 2 seconds. He was pleasant and friendly. Did not want to sit down or participate in any activities.

3. Participant Joni

Activity: ate lunch at her table

What did you observe or learn about the participant and their level of dementia:

Joni was very quiet. She needed assistance cutting up her food into smaller bites. She said a few fragments of sentences that did not make sense. She smiled when I smiled at her first.



# **HILLTOP DEMENTIA TRAINING**

## **HANDS ON PRACTICUM OBSERVATION FORM**

Name \_\_\_\_\_ Date \_\_\_\_\_

Your goal is to interact with at least 5 different participants with dementia, by either conversing or doing a one-on-one activity with the individual. Observe their personality, memory, communication abilities, activity abilities, and behaviors. Length of time with each participant can range from 1 - 15 minutes.

1. Participant \_\_\_\_\_

Activity: \_\_\_\_\_

What did you observe or learn about the participant's level of dementia:

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2. Participant \_\_\_\_\_

Activity: \_\_\_\_\_

What did you observe or learn about the participant's level of dementia:

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3. Participant \_\_\_\_\_

Activity: \_\_\_\_\_

What did you observe or learn about the participant's level of dementia:

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4. Participant \_\_\_\_\_

Activity: \_\_\_\_\_

What did you observe or learn about the participant's level of dementia:

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5. Participant \_\_\_\_\_

Activity: \_\_\_\_\_

What did you observe or learn about the participant's level of dementia:

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6. Participant \_\_\_\_\_

Activity: \_\_\_\_\_

What did you observe or learn about the participant's level of dementia:

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What did you learn in general from this experience: \_\_\_\_\_

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## CHAPTER 11:

# **SARAH'S STORIES**



**Sarah Phillips Fenley**  
*December 1, 1930 - June 4, 2003*

# **Sarah's Stories**

by Laurie Fenley Frasier, December 2014

I wanted to share these stories about my Mom's journey with Alzheimer's in the hopes of helping other families or professional caregivers gain some insight into the crazy and challenging world of dementia. I have told these stories numerous times in my dementia training classes, but am now spent from the telling. It is time for me, 11 years after Mom's death, to close this chapter of my life. Not that I want to forget Mom, or the stories, I just can't tell them anymore. I know that my Mom would be okay with me sharing her stories, and that she would most certainly be thrilled if the small pieces of her journey helped others to better cope and understand.

Some of these stories were recorded as they happened in a spiral notebook. Others were pulled from my memory. I was surprised and pleased at how much I remembered once I started writing because I worry daily about my own memory. My writing has not been professionally edited, and I have an affinity for using ellipsis (...) which is probably annoying to those who like proper punctuation.

Every family's journey with Alzheimer's is different, but here is mine and Sarah's...

## **THE BEGINNING – EARLY STAGE**

### **AUNT MARGIE**

My great Aunt Margie, my mother's favorite aunt, was diagnosed with Alzheimer's disease. I was a teenager at the time and didn't really understand what was happening to her as we didn't see her too often. We just knew that whenever we were around her she was always looking for her purse. "Where's my purse? Where's my purse?" Unfortunately, this kind of became an inside joke between Mom and myself and my sister, Gail. Whenever we couldn't find our purse, or our keys, or whatever, we would call each other Aunt Margie and jokingly say, "where's my purse... where's my purse?". Karma. Boy did this come back to bite us in the butt when my Mom was herself diagnosed with Alzheimer's disease...many years later.

### **THE DOORBELL**

I think the first sign of my Mom's Alzheimer's was her claim that some mysterious person was ringing her doorbell in the middle of the night. This claim went on for months and months. We (me and the relatives) all speculated that it might be Gail, my sister, who was estranged from my mother at the time. We couldn't imagine, though, why she would go to so much trouble. One of Mom's friends set up a video camera in the window (Neil). Another friend spent the night watching the house (Don). I thought my mother was dreaming or had invented the whole story to get attention. She insisted that it was happening, and in her mind it probably was.

### **WHEN DAD PASSED AWAY**

My Dad passed away from lung cancer and several years later my Mom was ready for a change. 3660 Warick Drive, Dallas, Texas, was a wonderful home, filled with laughter, patio pool parties, delicious food, and amazing memories, most associated with Bob, my Dad. Mom worked with a realtor and found a lovely little condominium to move to in Carrollton. I helped my Mom move out of the house she had lived in for 25+ years. Within days of moving, Mom complained and complained about the new condominium, repeating over and over that she never should have moved. The transition was difficult. She stressed and obsessed over taking care of the hot tub in the new place, even though the old house had a swimming pool which was much more complicated and time consuming to care for. She insisted on driving 5 miles back to the old neighborhood to the old Tom Thumb for groceries, even though there was a nice Tom Thumb close to her new place. I remember this irritated me immensely. The move was her idea, after all. Finally, though, she settled in and for the most part she seemed to be getting along fine. She had a very busy social life. She was even dating by answering and placing personal ads in the newspaper! Shari was her best friend and they spent a lot of time traveling and hanging out together. They acted like two teenagers and it was nice to know that my mom was having fun and starting a new chapter of her life. During this time the hot tub stress/obsession blossomed. I wrote maintenance instructions down for her but it didn't matter, she couldn't follow them. She complained, stressed, complained, stressed, complained, and stressed some more. I told her to get rid of the hot tub and she finally gave it away to the guys who cut her grass. What a relief for us both. Looking back, this was the beginning.

### **HELPLESS**

Mom had always had what my sister, Gail, and I called her "helpless" routine. It seemed to be getting worse and more magnified with time. I attributed this to her drinking. I knew she drank wine, but I never really paid attention to exactly how much she drank. I lived 800 miles away. I saw her maybe twice a year. I was not happy that my mom was "getting old"! I later learned to attribute this magnification of helplessness to the onset of dementia.

### **MAKING COFFEE**

Mom was a huge coffee drinker and for as long as I could remember had started each day with a pot of bubbling hot coffee. She came to visit me in Colorado and one morning she asked me to help her make coffee. I remember being very perplexed by this and thinking, "how on earth could she not know how to make coffee?" I was totally irritated. Then she went to work with me and sat in my office all morning. At lunch she went next door to get her hair done. She walked back and couldn't remember where my desk was. She stood in the front office of Pyramid Printing until someone asked her what she was doing. She said she was waiting for me. I was working ten steps away in my office where she had been all morning and she could not find me. I was embarrassed and irritated. I worry now that my irritation made her feel bad...she must have been so scared.

### **PACKING FOR A TRIP**

Mom went on a trip with Uncle Robert and Aunt June. She packed 4 bras, 1 shirt and no pants for a long weekend. Odd, we thought, what kind of packing was that?

## **THANKSGIVING**

Mom was a phenomenal cook, and my sister and I looked forward to the great Thanksgiving feast that she would prepare. One year we arrived in Dallas and learned that Mom wasn't going to cook. She had gone to the grocery store and bought traditional Thanksgiving dishes that were already prepared. "This is different", I thought, "but okay, I guess she just doesn't feel like cooking this year." On Thanksgiving morning we discovered that she had thrown all of that store bought food in the trash. She wanted to go out to a restaurant instead. Perplexing at the time.

## **THERE'S SOMETHING WRONG**

Relatives and friends started to call. "There's something wrong...maybe...we're not sure." No one wanted to mention the big "A" word...Alzheimer's. Aunt Margie had Alzheimer's. No...it had to be the drinking or that she was just getting old. Oh, it felt good to live in the land of denial!

## **THE DIAGNOSIS**

Denial was no longer an option. Mom knew something was wrong. I knew something was wrong. Friends and family knew that something was wrong. I desperately wanted to believe that my mother's forgetfulness and sometimes strange behavior was attributed to the wine, but, being familiar with the words "Alzheimer's disease" because of Aunt Margie, I feared the worst. Mom had been to her primary care doctor by herself and he had run a gamut of tests. Then he referred her to a neurologist for further testing and I flew to Texas to accompany her. The neurologist tested Mom's reflexes and administered the mini mental cognitive exam. I remember being shocked and surprised at her inability to answer some of the questions...who was the president...what month was it...what season were we in...what was the year. He then asked her to say as many words as she could that started with the letter "F". She froze for a few seconds, then rapidly fired off words including ones I wasn't familiar with that she knew from her years of being an avid crossword puzzle fanatic. When she finished she laughed and explained that she froze because the only word she could think of at first was "fuck"...the official "f" word! The neurologist finished the rest of his tests and delivered the verdict. I knew in my heart what was coming. He diagnosed her as being in the early stages of dementia, probably of the Alzheimer's type. I felt like I had been hit in the gut. We shed a few tears, but Mom was so brave. She said she wasn't going to give up on life and she would fight this dreaded disease with all her might. We laughed and laughed the rest of the night over the "F" word test. I cried later when I went to bed and she probably did, too.

## **LIVING ALONE**

Mom would continue to live on her own in Dallas for several years after diagnosis. She had help from friends and family, and my son and I made frequent visits to Dallas to check on her. She knew she had Alzheimer's and discussed it with everyone and was not opposed to the attention and support. She was happiest when she was busy and socializing. She still drove herself to the hairdresser and her best friend Shari drove them every place else. Her sister-in-law, June, spent a lot of time with her, and nephews fixed things around the house. She had strong friend/family support which made it possible for her to live on her own during this time. Even so, now that I understand dementia, I shudder to think of the risky things that probably happened when she was by herself.

### **GOLD BRACELET**

Persons with dementia are frequently losing things, even in the very early stages, and Mom was no different. Mom had a beautiful gold bracelet that she had bought herself on one of her many trips. I came to visit her in Dallas with the intention of starting conversations about her moving to Colorado. Upon arrival I learned that she was very distraught because she had lost this bracelet. I searched her house high and low. I looked in every pocket of every item of clothing. I looked in every purse. I searched couches and dresser drawers to no avail. Then, lo and behold, I was in the kitchen making her a cup of coffee, pulled down the sugar bowl from the cabinet, and there was the gold bracelet in the sugar bowl. Of course Mom had no memory of placing it there and wanted to know who had put it there! We were both very happy the bracelet was found.

### **EYE MEDICINE**

I noticed on one of my visits that Mom's house was becoming more and more cluttered. She used to be an impeccable housekeeper. Everything was always tidy and organized and labeled in totes... and you could probably have eaten off the floor. Not so much...I noticed on this visit. I observed in the bathroom that she had several tubes of a prescription eye medicine, and she was diligently putting this medicine frequently in her eye. I examined the ointment and saw that the prescription was almost a year old and for some type of eye infection. Her eye looked perfectly healthy. Then I discovered more and more tubes of the same stuff. I don't know how she had been able to refill the prescription so many times. I explained to her that the prescription was old, her eye was no longer infected, and that she needed to stop putting it in her eyes. She did not agree. We got in a huge argument. Finally, after going around and around, I convinced her that she no longer needed the medicine and I threw all the tubes in the trash. I felt triumphant. Twenty minutes later..."Laurie, do you know where my eye medicine is?" She had no recollection of our discussion/argument. Defeat. I had not learned the importance of not arguing with a person with dementia!

### **CALLING 911**

On another one of my visits to Dallas, Mom and I were surprised by a visit from the police. They knocked on her door and asked why we had called 911. We were perplexed. They said someone had called 911 twice from our number and that all the 911 dispatcher could hear was heavy breathing. Then it hit me. Mom had been using the phone earlier and I had noticed that she was having a little difficulty. I realized that she must have kept hitting the speed dial for 911 inadvertently. I explained this to the very hot looking police officers, and they were very polite and glad there was no real emergency. When they left, Mom laughed and laughed at herself and said she should probably do that again to get those good looking policemen to come back.

### **RESTAURANTS**

Mom and I had always loved to go out to eat and we frequently did so. I began noticing that whatever I ordered, she would say, "I'll have the same thing", even if it was something I knew she didn't particularly like. I found myself getting annoyed by this. Later, looking back, I realized that something as simple as making a decision about what to eat off of a menu was becoming too difficult for her.

## **SKIPBO**

One Christmas, after Mom's diagnosis of dementia, we went to visit my grandmother, Mamo, in Oklahoma. The three of us tried to play the card game Skipbo, which we had played numerous times, all of my life. Mom could not play. I restated the rules and told her what to do at least 3 million times. I remember thinking to myself, "What a life. Here it is a Friday night and I'm playing Skipbo with a mother with Alzheimer's and a 94 year old grandmother. I was directing and telling each how and what to play, though Mom more than Mamo. One year later we played again. Mom did better this time for some odd reason. Was it the Aricept that helped? I was surprised.

## **EARLY TO MIDDLE STAGE**

### **MOVING TO COLORADO & HOOKING UP THE CD PLAYER**

As Mom declined it became apparent that it was no longer safe for her to live on her own. When I had first suggested she move to Colorado to be with us she was very resistant. Then I got tricky. I helped her grandson, Caleb, who was 6 years old at the time, write her a letter telling her how much he wanted his Nana to move to Colorado to be close to him. Score! She couldn't say no to her only grandson! I was able to rent and move my Mom into the house next door to me, which was truly a blessing. Cleaning out her stuff, and packing it all up for the move from Texas to Colorado, however, was quite the ordeal. I had originally thought she would be able to help pack, but quickly learned it was way too overwhelming and confusing for her. Her house had become a cluttered mess, with all kinds of stuff stuck in inappropriate places. I cleaned out and threw out as best I could. As I sorted through her things I would place the items to be donated to the Salvation Army in the garage. Every time I wasn't looking she would go out to the garage and bring stuff back in! And she got really mad at me for getting rid of some of her things, despite the fact that she never used them. I had to actually get a little mean to prevent her from undoing my hard work! Then, when we arrived in Colorado, her boxes had to be stored in my garage for a short period of time until her house next door was ready. When we finally were able to start carrying boxes over, she would get confused and would carry the boxes that I had just carried over to her house back to my house! OMG! When I would stop her and point her in the right direction she would laugh at herself. We finally got all of her boxes carried over and unpacked. It was really nice having her next door, despite the fact that I was a single working mom with a 6 year old child and I shopped for both mom and myself, paid bills for both of us, cleaned both houses (4 toilets), took care of 2 cats (one was Mom's) and a dog, and entertained all of us. At times it was quite exhausting, but it was really a wonderful opportunity to be together and for her to spend time with her grandson. I clearly remember the moment when I hooked up her stereo system and I plugged in one of her favorite CDs. She hugged me exuberantly and thanked me profusely. She told me I was a genius! Something so small had made her so happy...and that made me happy and so glad to have her close to me.



## **CALEB & NANA**

Mom so loved her grandson, Caleb, and he loved her. He was 4 years old when she was first diagnosed with Alzheimer's. She would make him a giant nest out of pillows for sleeping when we visited her in Dallas and he never forgot this. He was 6 years old when she finally agreed to move to Colorado and he could hardly wait to be with her. To my dismay, after only 8 weeks of her living next door, he was starting to lose patience and tolerance for her. Everything she said began to irritate him. I had to constantly remind him that "she can't help it." His acts of love and affection towards her were becoming fewer and fewer. When he was snotty to her she was mean back. When he went next door to watch cartoons on her TV, they fought. I always had to buffer and intervene. In the beginning he was a lot more patient...and so was I. It was a transition for all of us but we persevered.

One day Caleb said to me, "Mom, do you know what I love about Alzheimer's?" I couldn't imagine. "Nana does so many humorous things that are really funny – not that I'm making fun of her – but she makes me laugh." Pause..."I hate everything else about Alzheimer's." Wow.

Another day Caleb went to work with his Dad instead of staying home with Mom. When I picked him up he said he missed her. When he saw her he gave her a big hug and told her how much he missed her. It was a very sweet moment. Understanding that your grandmother has a brain disease is not so easy for a little boy, for anyone for that matter.

I found a journal entry that I wrote during this time. "I let Caleb stay with Mom at our house while I worked over the Christmas holidays. They actually got along well for the most part. He bosses her around, making her work puzzles or build leggos and such with him. She seems happy to do it. One day she went to the mail box and never returned. She forgot she was staying with Caleb at our house and went to her house instead. Caleb called her a half hour later to find out why she never came back over. She got mad at him and said she had only been gone 5 minutes."

*Another entry:* "My mom tattled on Caleb. She was like a kid trying to get another kid in trouble. He told me he only watched TV for 1 hour. She said he watched all day. They argued back and forth. Knowing her memory was unreliable...I believed Caleb."

*And yet another entry:* "Caleb and I have a new bond. We give each other "the look" when mom says or does something weird or repeats herself for the 20 millionth time."

As the days and years of caregiving for Sarah stretched on, Caleb grew up. He was a tremendous help in caring for Mom, and I believe he learned a valuable lesson on compassion and taking care of family. All of my stepkids and husband and numerous friends helped take care of Mom as well. Somehow we found a balance between caregiving and living a normal life, but I am forever grateful that all of our kids and family and friends were so compassionate and sweet towards Mom.

**CALEB'S POEM** *(written after Mom died)*

Most kids grow old with grandparents close by  
Who raise them like the world depends on it  
They teach them how to think and how to fly,  
Or all 'bout girls or simply how to spit.  
But I was born with one already left  
But Nana my dear grandma cared for me  
But when I barely knew her was the theft  
of Alzheimer's which drowned her in the sea.  
So now she's finally gone and now I can't  
Remember her the way that she once was.

**THE BIG SEARCH**

*Journal entry:* "I unpacked and decorated Mom's whole house. She loves it. I simplified and assigned a place for everything. She keeps it pretty tidy so far and it helps that she has a lot less stuff. Today I just realized that for several days she hasn't gone on The Big Search. What a relief. She spent the first few days searching for certain items: jewelry, clothing, books, etc. She hasn't obsessed over finding things which usually end up being in plain sight. Her visual ability doesn't jive with her brain."

**MOM'S LAST DRIVING EXPERIENCE**

Mom was still driving in Dallas before the move to Colorado, but I noticed quite a few new dents and scratches in the car, which she denied having any knowledge of how they happened! I drove her car from Texas to Colorado and wanted to take it to a mechanic to be checked out and tuned up so we could sell it. Thinking that she was still able to drive, I drove my car and had Mom drive hers, with instructions to follow me closely to the auto shop which was only a few miles away. At the last second I decided to have Caleb ride in the car with her, so she wouldn't be alone, but what was I thinking? I regretted this decision immediately. Mom's driving was terrifying as I watched in horror in my rearview mirror. She was driving erratically, weaving, and going very slow, so cars were whipping around her. We finally arrived at the shop. Caleb told me that Mom had somehow turned the heat on high and then was fumbling around trying to figure out how to turn it off. I never allowed my Mom to drive again. She never asked to drive again. I sold her car. I think she was greatly relieved.

**THE CAT BOX**

Mom emptied the cat litter box out and didn't refill it. I don't know why she did this because I was usually the one who changed the litter once a week. The cat then went to the bathroom in the sink because she didn't have her usual place to go. Actually, I thought that was pretty considerate of the cat rather than using the floor. When I asked Mom why she emptied the box she said she didn't do it.

## **THE MAILBOX**

When Mom first came to live next door to me she was able to stay home during the day by herself while I went to work. Since her new house was decluttered and simplified she could spend the day reading, relaxing and doing chores that I would write on a dry erase board for her each morning. A sample list might be: dust, vacuum, wipe off kitchen counters, eat a sandwich for lunch, work your crosswords, read your book, Laurie home at 4:30. I have no idea if she followed the list or not...it really didn't matter...it was just a way to help her remember things to do and give her something to refer to if she got confused. It wasn't until after I moved her to assisted living that I learned from the neighbors that they had seen her go to the mailbox at least 10 times a day. She would obviously forget that she had already checked the mail. This was a recipe for disaster and thank goodness she always remembered how to find her way back to her house. I did quickly discover, however, that operating the microwave was too much for her, even though I had purchased the most basic simple model I could find. She burned numerous TV dinners that I noticed in the trash and probably went without eating that day until I got home. I then got wise and learned to leave sandwiches and cold finger foods for her in the refrigerator. I also paid a friend and a home health care agency to come in several times a week to take her to lunch or for outings so she didn't get so bored on her own. As time went by and she declined, I tried taking her to Grand Valley Senior Daybreak, the adult day care program that I am now the director of! She did not like it and after taking her twice, she refused to go again. I didn't push the idea and deferred to her wishes. Now I know that I should have continued taking her, as the stimulation and being in a safe place would have far outweighed her resistance.

## **GETTING SICK**

During the time Mom lived next door, I was sick off and on for a week with vertigo, a condition I had struggled with in the past. I remember thinking, "I can't get sick. I have two people who depend on me." I woke up violently ill puking my guts out and could not get out of bed without the world spinning. Mom came over to take care of me. She emptied the vomit out of the puke pan several times and then sat in the living room and read all day in case I needed her. She checked on me all day. Later that evening, though, I managed to crawl out of bed and fix her dinner, as this was a task that was now beyond her ability to accomplish.

## **THE COLORADO FAMILY REUNION**

After Mom moved to Colorado, I wanted to do something special for her that would make her very happy. I decided to have a family reunion in Colorado in her honor. My mother had 2 brothers and 1 sister, with the accompanying sisters and brothers-in-law and a passel of nieces and nephews and their kids. There were 28 total. I made phone calls. I sent letters. Would they all be willing to come to Colorado for a big surprise family reunion in honor of Mom, knowing that time was now a precious commodity? They all said yes. They all arranged their lives and work schedules to be able to come. For most it was an 800 mile journey. Some would drive, some would fly. One cousin would be flying in from Florida with her 5 year old handicapped daughter and all the accompanying paraphernalia – power wheelchair, oxygen, medications, etc. This would be a miracle in itself. I kicked into major planning mode. I made arrangements. This reunion was to be a 4-day extravaganza like no other.

We have always had a very close family, but as time passed and everyone grew older and spread out to various parts of the country, the time spent together had become less and less. Phone calls were rare and infrequent. The reunion gave everyone a new sense of purpose. The reunion gave everyone a reason to call and to email...we were doing this for Mom...we were doing this because we were family.

The big weekend in June finally arrived and so did the family. The next 4 days were remarkable. The big event of the first night was the Memory Presentations. Each person had come prepared with a story, a song, a poem – something special to be shared and remembered in front of all – a special memory of Mom or of my Dad and grandparents who were no longer with us. Tears flowed pretty freely during the Memory Presentations. The poignancy of it all was overwhelming. We all watched and listened to each other, in awe of the moment, in awe of the memories.

The time sped by over the next three days...we ate, we drank, we laughed, we cried. We talked about Mom's deterioration when she wasn't close by. We watched Leila drive up and down the street in her power wheelchair with the rest of the kids on rollerblades, hanging on to her like a train. We crammed into vehicles and drove over the Colorado National Monument, playing tourist, posing for each other's cameras, delighted by the beauty of the scenery and the fact that we all looked so spiffy together in our matching commemorative reunion t-shirts. We played dominos and Skipbo, a family tradition and cheered Aunt Kaye when she won the domino tournament. We laughed when my two cousins, who were sisters, got in a cat fight and called each other a bitch. We ate catfish in memory of Pappy, my grandfather. We had Cousins-Night-Out-On-The-Town-While-The-Old-Fogeys-Stay-Home-And-Babysit-The-Grandkids Night. Two of my cousins, Angela and Cynthia, got a little wild and had a memorable walk down Main Street back to the hotel. We went river rafting, a new experience for most, and we were entertained by and sang along with Lloyd, a fabulous singer and guitarist friend of mine who put on a special concert for us on the front lawn. Uncle Kirk sang "Hey Good Looking" which surprised me as I had never heard him sing before. Uncle Robert and Mom, formerly and fondly known as Dude and Sarah sang their famous duet, one we all knew well. Uncle stated it was the last time it was to be sung...and it was. Uncle Butch and Uncle Robert sang. Jim sang. Julia sang. Caleb sang. Spencer sang. Dustin sang and played percussion with 2 rocks. Leila and Cyndi sang. It was all amazing and delightful. The weekend ended with a goodbye brunch and awards ceremony.

Leila, my cousin's little handicapped girl, passed away shortly after the Colorado reunion, which made us cherish the time all the more, knowing we were truly blessed with her presence on those 4 very special days.

Those 4 days changed my life. Those 4 days taught me that there is nothing stronger and more precious and uplifting than the love and support of family. The ugliness of Alzheimer's had brought all of us together for a 4 day feast of bonding and reconfirmation of love. We all felt it. We all thrived on it. Mom was in bliss, surrounded by so many people who adored her.

## THE CRUISE

After the family reunion, Caleb and I took my Mom on a Carnival Cruise to the Caribbean. We were accompanied by her sister Kaye, sister-in-laws June and Linda, my cousin Sarianne and her daughter Mellanie, so there were 8 of us. This was a wonderful adventure for all and I believe that Mom really enjoyed herself, though several days after the cruise she didn't remember that we had even gone, which was typical of dementia and to be expected. The memories that were created for the rest of us, though, and the pictures we took were priceless! We had barely been on the boat when Mom cut her arm because she didn't pull it out of the way of the elevator door. It was a minor injury, but something that probably wouldn't have happened to a person who had the wherewithal to pull their arm in out of the way. I won \$300 at Bingo. Mellanie, 11, and Caleb, 10, discovered the *true* meaning of a topless deck after exclaiming to me, "Look, Mom, there's no roof on this deck...it's a topless deck...OMG they're not wearing any tops!" Mellanie learned the slang meaning of the word "cock" and shouted out during one of the Las Vegas type entertainment shows, "Look, guys, I can see his cock!" Much laughter was incurred by all on this amazing trip. The most memorable event, however, was Mom getting lost in Cozumel. Cozumel was one of the stops and we all got off the boat to explore the town. It was Kaye's turn to be in charge of Mom for awhile, which was such a welcome break for me. Caleb and I went off to explore Mayan ruins. We returned later that afternoon to a very distraught Kaye who told us the tale of Mom's harrowing adventure. Mom and Kaye were shopping and fingering souvenirs. Aunt Kaye told Mom, "sit right here while I pay for our purchases." Mom sat down 6 feet away from Kaye. Kaye paid, turned to Mom, and Mom was gone. She searched the store. No sign of Mom. She ran outside. No sign of Mom. She somehow enlisted the help of a young couple who were bilingual in Spanish and English and helped find and explain to a policeman what had happened. Everyone searched for Mom. Twenty minutes or so later they found her walking along the edge of the very busy boulevard, with cars and motorcycles whizzing by within inches of her. She was oblivious. Kaye grabbed her and said, "Sarah, where have you been? You scared me to death!" "Oh, hi" said Mom with a flat affect. She had no idea of the panic and havoc she had caused. I think Aunt Kaye lost a few years off her life that day from the stress of the ordeal. She was very happy to see me and relinquish babysitting responsibility for the rest of the day!

## THE OKLAHOMA TRIP

Travelling with a person with dementia can be challenging. We took a trip to Texas so Mom could meet up with friends and family that she hadn't seen for awhile since her move to Colorado. The plan was to spend one night in Dallas then rent a car and drive to Oklahoma. We arrived in Dallas, picked up our luggage, and drove to Shari's house for the night. At Shari's house it was discovered that we had left Mom's suitcase at the airport. I was so focused on getting myself, Mom, and Caleb through the airport that I totally spaced out her bag. My cousin Cyndi and Tim were with us, too, and none of us realized that we did not have it. Mom no longer had the wherewithal to keep up with her own bag nor the ability to notice that we didn't pick up her bag from baggage claim. We had to drive back to the airport early the next morning to get her bag before heading to Oklahoma. The funny part about this was that when we got on the plane to get from Grand Junction to Dallas, the flight attendant announced that the plane was carrying too much weight and several bags were going to have to be left behind and sent on a later plane. (I had never had this happen before, and have never had it happen since.) Out of a whole plane full of people they

randomly announced that it was my specific bag, and my cousin Cyndi's bag, that were to be left behind. I made a bit of a scene about this and loudly explained to the whole plane that it was important we have our bags as we were driving to Oklahoma from Dallas and would not be able to make a trip back to the airport to claim our delayed luggage. I was quite vocal. A few minutes passed and they then announced that their calculation of the total weight was off because they hadn't allowed for the lesser weight of a child on the plane, so the bags could stay on afterall. Caleb was the only child on the plane. So...as it turned out...our bags made it with us to Dallas because of Caleb, but because I left Mom's bag at the airport, we did in fact have to go back to the airport to retrieve her bag after I had made such a big deal that this was not something we would be able to do. It was a weird set of coincidental events!

### **TIM**

Tim and I had started dating just prior to Mom moving to Colorado. Tim was never daunted by the fact that dating me meant dating my mom with Alzheimer's. Tim bent over backwards to help care for Mom and she quickly fell in love with him, as did I! At our wedding, mom beamed because she was so happy for us and surrounded by so many of her beloved family, her sister Kaye and brother in law, Kirk, her nieces Sarianne and Julia, great niece and nephew Mellanie and Christopher, and even her best friend, Shari. Aunt Kaye and Shari were in charge of getting Mom ready for the wedding and keeping an eye on her. Mom looked so beautiful. I had painstakingly shopped for her to have the perfect dress, and it was. She danced with me at my wedding and did really well on this special day, with the help and support of her assigned babysitters! I was grateful.

### **THE RAVEN**

Tim and I would frequently take Mom for drives because that was something she still really enjoyed doing. We drove through the beautiful Colorado countryside and she oooohed and awed at the splendor of the scenery. One day as we were driving she saw a black crow sitting in a tree. She recited the poem, "The Raven", by Edgar Allen Poe, word for word, verse after verse. We listened in amazement. How could a woman whose brain was so compromised with dementia still have the capacity to remember a poem from her school days? My brain, not ravaged by dementia, was never able to recite poems from memory.

Once upon a midnight dreary, while I pondered weak and weary,  
Over many a quaint and curious volume of forgotten lore,  
While I nodded, nearly napping, suddenly there came a tapping,  
As of someone gently rapping, rapping at my chamber door.  
"Tis some visitor," I muttered, "tapping at my chamber door –  
Only this, and nothing more."

Ah, distinctly I remember it was in the bleak December,  
And each separate dying ember wrought its ghost upon the floor.  
Eagerly I wished the morrow; - vainly I sought to borrow  
From my books surcease of sorrow – sorrow for the lost Lenore –  
For the rare and radiant maiden whom the angels named Lenore –  
Nameless here for evermore.

## **THE RECIPE**

Mom and Tim and I went to The Wagon Wheel restaurant in Mesa, Colorado and I ordered a very delicious bowl of green chili. Mom had always loved to cook and she said, "Oh, I have a wonderful green chili recipe." I thought, "Great, maybe she can still remember how to cook a few things and I can write the recipe down". I asked her to tell me the ingredients for her green chili. "You know..." she said, "you just take a bunch of stuff and put it in a bowl and mix it around and you have green chili." That was the extent of her memory for the recipe at this point.

## **THE DEAD COW**

Mom had a large repertoire of favorite phrases/sentences that she repeated over and over because of her dementia. "Look at that beautiful blue sky. Look at those rain clouds, I think it's going to rain tonight. Look at that green grass. Is that a forsythia bush? No room at the inn. Is the Pope Polish? I need to pee. Look at those healthy cows." One day Tim and I were driving in the car with Mom on our way to Oklahoma. As was typical, she saw a field of cows and said, "Look at those healthy cows." At that exact moment we passed a dead bloated cow, which Tim and I saw at the exact same time, and in perfect synchronization we said together, "EXCEPT FOR THAT ONE!" We laughed and laughed at the absurdity of the incredibly coincidental timing.

## **FEAR**

*Journal entry:* "Mom has a lot of FEAR now. She was afraid to step off of a curb in Silverton. When she is afraid my protectiveness kicks in. She tries not to be afraid, but she can't help it."

## **SCRABBLE**

Mom wanted to play Scrabble with me, Savannah, and Travis. It was a nightmare for me. She kept saying, "I have horrible letters," but she didn't. She would put partial words on the board like "reb" for "rebel". After allowing her several attempts at her turn, I spent the rest of the game walking over to her and figuring her play out for her. I should have had more patience and just let her play whatever, but I was so angry, frustrated, and annoyed because playing Scrabble was always our thing and it was painful to accept that she could no longer play. I won the game...she came in second...ha ha.

## **CROSSWORDS**

Mom was always a crossword puzzle whiz/addict. This task required long term memory, so she was able to continue working the puzzles and did so quite voraciously for quite a long time after diagnosis. I do remember her commenting at some point, that they were "getting too hard". Ever once in a while she would say things like, "I'm deteriorating," or "I'm probably only going to live 2 more years". Other times she seemed to have no clue that she was experiencing difficulties.

## **CHRISTMAS**

Christmas was always a big deal for Mom and myself. We loved to shop together. We loved to wrap presents together. I took Mom shopping and discovered that she had lost the ability to shop. She just stood next to me and didn't know what to do. She was also unable to wrap the presents. She could not remember how to cut the paper the right size, could not remember how to fold up the edges, could not remember how to pull off a piece of tape, could not remember

how to tape on a bow. I was devastated at yet another loss of something we used to love doing together.

*Journal entry:* We went to a Christmas Eve party at Tim's sister's house. I'm starting to get embarrassed at some of the things my Mom says and does. She interrupts others' conversations to interject something about herself. Or, she repeats the same phrases over and over. "I believe they're going to impeach Clinton. Maybe he'll learn to keep it in his pants. How's the Frasier kids? We need to buy me some snow boots." Over and over and over again.

### **THE CHUCK MANGIONE CONCERT**

Mom had always loved going to plays and concerts, and was game for any adventure for that matter. She loved to get out and go, which made her a fabulous mother! I took her on as many outings/trips as I could during the year that she lived next door to me when she was in the early to middle stages of dementia. We went camping, on numerous drives, out to eat hundreds of times, to two reunions, back to Dallas to visit, my grandmother's 100<sup>th</sup> birthday party in Oklahoma, to Denver to visit a friend and go to the IMAX, rafting twice, to the Senior Center, three times to the Memory Walk, to Arches in Moab, to the symphony twice, Glenn Miller concert, Tommy Dorsey concert, a production of Annie, numerous movies, two plays at the college, and on a cruise. Taking her places got gradually more difficult and sometimes embarrassing. Wherever we went I had to constantly hold her arm and propel her in the right direction. Her steps became more cautious and more unsure and she moved very slowly. If I didn't hold on to her she would lag 10 steps behind me and I had to constantly look back to see if she was following. I had just about reached the point where taking her places was no longer fun for me. Then Chuck Mangione came to town. Mom and I both loved Chuck Mangione. I told her about the concert and bought tickets and several other couples were going with us as well. Then I changed my mind about taking her. I selfishly didn't want to take her to the concert because she might embarrass me by something she said or did, and she would have difficulty maneuvering the stairs. I thought she would forget about it, but she kept hearing advertisements on the radio and kept asking me about it. Even though I had already bought tickets, I tried to lie and told her that Tim and I had something come up that would prevent us from going. She looked as if she would cry. Major guilt. I waited a few minutes until she had forgotten my lie, then told her we were going. She lit up like a Christmas tree. We went to the concert. I had bought the tickets for everyone and had misplaced them at the last moment (stress makes you do really stupid things), so had to convince the Avalon to let us in and fortunately they did. (I found the tickets several months later stuck in an envelope in my bill paying tote). Our seats were way up high in the balcony and I carefully guided Mom up the stairs, never letting go of her arm. The concert began and I noticed that she was not paying the least bit of attention to Chuck. She didn't appear to be listening or watching, she was just kind of gazing around with a blank stare. At intermission she announced that she had to pee. We navigated down the stairs to the bathroom in the basement only to discover a long line of ladies waiting. We waited, too, inching closer and closer to a stall and finally made it in. By now it was our routine to go in to the stall together as Mom was no longer able to handle toileting by herself. I sat her down and she stated, "I don't need to pee." "Oh, yes," I said, "you will pee!" She complied. I never took her to another concert or play after that.



### **THAT'S WHAT I WAS THINKING**

*Journal entry:* Mom often repeats what I say and then says “that’s just what I was thinking,” or “that’s right.” It drives me insane for some reason. It’s like she has to steal my thoughts because she has none of her own.

### **SWEETAHOLIC**

*Journal entry:* “Mom is a sweetaholic. When I take her to the grocery store she is like a kid. She wants cookies, candy, and pop. I try to buy her healthy stuff and she doesn’t eat it. It goes bad in her refrigerator, but the sugar stuff is scarfed down. Do you deprive someone of life’s simple pleasures when they have Alzheimer’s even though you know a poor diet is bad for them?”

### **THE BROKEN FOOT**

During the year that Mom lived next door to me in Colorado, she kept in close contact with her best friend, Shari. They wanted to take a little trip together as they missed each other terribly! They decided to fly and meet in Phoenix. It was a direct flight for Mom from Grand Junction so navigating airports would not be an issue. Shari made the reservations and planned the trip and would pick mom up at her gate. They were having a wonderful time shopping and eating out until Mom slipped on some stairs at the hotel and broke her foot. Mom had always been a tad clumsy, but the Alzheimer’s definitely impaired her coordination and spatial judgment. Paramedics were called and Mom arrived back in Colorado, wheeled off the plane in a wheelchair and delivered to me, sometime on a late Sunday evening. At the airport, I realized we now had a problem. Since Mom couldn’t walk on her broken foot, and we would have no wheelchair once we left the airport, how was I going to get her out of the car and into the house? How would she go to the bathroom if she couldn’t walk? So, I had to quickly find a walker or wheelchair, and I had to fill a prescription for her. There was only one pharmacy open at that hour and they had no walkers or wheelchairs for us to use, but a kind stranger offered to loan us a walker and we followed this woman to her house before heading home. It was difficult for Mom to figure out how to use the walker and not put weight on her foot as she was tired and confused but somehow we got her into the house. Within a few days she was in a soft boot cast, and fortunately the break was minor. Putting the boot off and on to sleep and bathe was a challenge for her, and the broken foot became the straw that broke the camel’s back for me. The extra stress of this broken foot ordeal, on top of the daily stress made me realize that a year of caring for Mom living next door to me was becoming more than I could handle. Even with the loving support of family and friends...I was fried emotionally. The time had come to consider placement in an assisted living. (As a sidebar: I took Mom to a followup doctor appointment to check on her foot. Sitting in the waiting room, I looked down and realized that something was very amiss. I exclaimed in a very loud and incredulous voice, “OMG your boot is on the wrong foot!” Thank goodness it was a minor fracture that was apparently healing quickly!)

## THE PANTY CLIP

I agonized over the decision to place mom in a care facility. She was so happy living next door to us, and had no clue of the emotional stress I was dealing with as her caregiver. Shortly after I researched facilities, Bright Star Homes, a small assisted living, called to say they had an opening and this place was my first choice. Even though I thought it was time to place her for my own sanity, I wasn't ready, and all I could do was cry. I was afraid to tell Mom and I put it off as long as possible. I finally forced myself to walk over to her house and tell her. Stabbing myself in the leg would have been easier. I decided to tell her a lie. My heart told me there was no other way to make her understand the necessity of the move, and I wanted to lessen the pain and the anguish it would cause. Though I hated to lie, I felt this was the best plan. (I later had to explain to Caleb that a lie is not evil if it is told out of love to lessen the pain of the truth for a person with Alzheimer's disease). I told Mom that her landlord was selling the house she was renting and that she would have to move. That was a lie. The rest of what I told her was the truth. I told her I had found a wonderful place for her to live where she would be with others all day long instead of home alone while I worked. She did not understand and she was upset. She irrationally asked why she couldn't just stay in the living room and let the people who bought the house live in the rest of the house. Then she asked if she could move back to Dallas and rebuy her old house. I tried to gently explain that she could no longer live on her own due to Alzheimer's but she was beyond comprehending this. In her mind she was perfectly capable of living on her own. It was a very difficult conversation, but somehow we got through it.

The next day I had all the relatives and Shari call and reinforce and encourage the move. That really helped. By that afternoon Mom was fairly upbeat about the idea and joked about how she was being sent to the "pen" and the "concentration camp". She wanted to know when she could meet the other "inmates"! I told her over and over that she was not being abandoned, that Caleb and I would still see her daily. We drove by the house and saw it from the outside and she seemed pleased and relieved as it was a big beautiful ranch house in a wooded neighborhood. I explained everything about the place to her truthfully and told her it was a place for people with Alzheimer's. I did not tell her that the other people appeared more advanced with dementia than her, and I was worried that she wouldn't be able to converse or relate to the others and that this would be distressful. I had only met the other residents briefly, but couldn't really ascertain their cognitive ability compared to Mom's. Mom could be so lucid one moment, and so bizarre the next. At least she would have staff there all the time who would talk with her and keep her busy with chores and activities. This had to be better than her being home alone...or waiting for me or the home health care folks to show up.

I explained to Mom that she would still be able to call her friends and receive calls. I told her she would go on outings in a limousine on Thursdays. Musicians would come to play once a week. Her home health care gals would still take her out for outings on Tuesdays and Fridays. I would take her out on Mondays and Saturdays. She would get her hair done on Wednesdays. I would come by every day for lunch. She would have all of her meals cooked and laundry done. She would never have to be alone, unless she chose to be alone in her room. The hardest part, though, was the idea that she would have to give up most of her furniture and coveted knick knacks. She would only be able to take what would fit into her bedroom. I would keep as much of her things

as possible in my house so she would still see and have them when she came to my house, including her cat. I felt so guilty I couldn't stop crying.

I was very depressed and questioned myself over and over as to whether I was doing the right thing. Then Mom did something that helped me realize I was making the right decision. We had driven to Arches in Moab that day for an adventure with Caleb. Mom was very lucid and clear the whole day and I was really doubting my decision to place her, which was to happen in two days. When we got back home that evening, she stood up in the living room and announced that she had to ask me a very important question. I steeled myself. I was expecting her to ask why I was doing this to her and refuse to move. Instead she said, "Now, see how I have these panties on underneath these pants...will I need to wear a panty clip when I take these pants off?" Surprised and flabbergasted I asked, "What do you mean, Mom? What is a panty clip?" She said, "Well, you know...a panty clip! See how I have these panties on underneath these pants...will I need to wear a panty clip when I take these pants off?" She looked at me expectantly again. I couldn't help myself and started to laugh hysterically. I could not stop and I just kept saying, "What the heck is a panty clip?" Because I was laughing so hard, she started laughing. We never did figure out what a panty clip was. I thanked the universe for giving me that reality check on her state of cognition on the day that I needed it most.

Mom moved into the Bright Star Homes two days later and it was a very easy transition for her. We crammed a lot of her favorite furniture and knick knacks into her bedroom, and created a comfy beautiful space. She enjoyed all of the staff and made friends with the other 4 residents and adjusted very well. After a solid week of crying, I began adjusting, too. Did I ever really adjust? No. How does one ever reconcile with the fact that their Mom has Alzheimer's and has to be placed in a care facility?

### **THE HYMNS**

Once when I visited Mom at Bright Star a group of teenagers from a local church came to entertain by singing hymns. They had hymnals and were singing all of the verses. Their beautiful voices filled the room. I looked over at mom and to my amazement she was singing along, remembering *all* the words to *all* the verses without a hymnal. Some obscure hymn with 5 or 6 verses...and she still knew the words. This was a woman who could no longer live alone or take care of herself.

### **THE CAT BOX**

One day when Mom lived at Bright Star Homes the staff called to tell me something they thought I would find funny...and I did. They said, "You are not going to believe this, but your Mom just went to the bathroom in the cat litter box!" Way to go, Mom. At least she had the right idea! She also went to the bathroom on a piano bench...not quite so tidy!

### **VISITING FRIENDS**

*Journal entry:* "Whenever Mom gets a letter from a friend, she thinks they visited her in person. Her sense of reality is really becoming distorted. This is not necessarily a bad thing because she was quite pleased about seeing the Sanders and the Sheltons!"

## **THE PANTYLINER OBSESSION**

Mom had an obsession with panty liners. She would ask a million times a day, “Do I need to change my pad...am I wet?” If we did not go to the bathroom and check, she could not be distracted from this train of thought. One day I went to the grocery store and purchased 20 boxes. I was way beyond worrying about being embarrassed. The clerk looked at me a little strange but I did not care. I was sick and tired of the never ending need to keep her stocked up on liners. I was so relieved when this obsession finally ended. Hallelujah, peace at last.

## **FUNNY STUFF**

One time Mom said, “I think I’ve got a blubber and it pigs me off.”

## **THE LAST TRIP** (written May, 2000)

The last trip turned out to be the worst four days of my life. My mother, in her fifth year of Alzheimer’s disease, had advanced in her deterioration to the point that I knew in my heart this trip, a family reunion in Lubbock, Texas, would be her last. I predicted the trip would be difficult and I debated for weeks whether I should really take her on a 13 hour road trip, in a van with 3 kids. My mother couldn’t remember how to dress herself, but she remembered the reunion because it was so important to her. She mentioned it frequently and she was definitely looking forward to seeing her brothers and sisters, nieces and nephews. I had to take her, despite all my misgivings, despite my prediction that the trip would be difficult, because I loved her and wanted to give her some happiness. I knew that to see her in her present state of deterioration would be devastating to her brothers and sisters...and it was. I warned them. I told them that it would be the last time she would travel.

I’m not sure why I decided that we had to drive instead of fly. I think because I didn’t want to spend so much money on airline tickets. I think because I thought she might actually enjoy the sights and the time spent together in the van. I think because she had always loved road trips. At any rate, when I planned the trip it seemed like a good idea.

I tried to cover the bases. I got permission from her doctor to take extra medication...a prescription that helped her sleep. I decided that if things got rough I would medicate her. I joked about it. I joked about taking extra medication for myself. I joked about having margaritas waiting for me when we arrived in Texas.

We rented a van, loaded up, and left Grand Junction on Thursday evening, Memorial Day weekend. The plans were to drive for 6 hours and reach Pueblo the first night. That would leave us with a seven hour drive the next day. When we picked up Mom she was so happy and excited to be going on the trip. The caregiver at Bright Star homes where she lived assured me that she had already taken her meds for the evening including the sleep aid. I figured Mom would fall asleep shortly after we hit the road. Much to my surprise she was wide awake and very chatty. This was a bit unusual, as she had lost so much of her language ability and was usually pretty quiet. About a half hour into the trip Mom tapped me on the shoulder and informed me that she “had to pee”. This was a common announcement and dreaded words to me. Her need and frequency was something that I had dealt with for months, always making it difficult to take her

anywhere. These were the words I feared, and as I had been counting on the drug to take affect and make her sleepy, I cringed when I heard them. I put her off. "You can wait Mom. You just peed before we left. It's your brain playing tricks on you." Minutes later...tap tap tap on my shoulder. "I need to pee." These four words would haunt me for the next four days and for the rest of my life. I made her wait for a while and then asked Tim, my husband, to find a place to pull off. We did and she successfully went to the bathroom. We traveled on for about another half hour. Tap tap tap... "I need to pee." "You can wait, Mom. We'll stop as soon as we can. Hang in there." I repeated these phrases over and over and held her off for another half hour and then we stopped again. This pattern and scenario continued and escalated. The more I told her she had to wait the more upset and confused she became. I finally crawled into the back seat and sat next to her and put my arm around her trying to calm her down. She kept asking if I was mad at her and I kept telling her no, and telling her that I loved her but we couldn't stop every 20 minutes or we would never get to Texas. I tried to convince her to just go ahead and pee in her pants because she was wearing a depends, but she never could grasp this concept. She started trying to stand up and get out of the van and besides saying "I need to pee" over and over her sentences had become very jumbled and incoherent. Thoughts reeled through my brain. This was a mistake...I shouldn't have brought her...she'll fall asleep soon...we should turn around and go back...no, she can make it...I owe it to her...I'm going to kill her if she taps on my shoulder again. I actually squeezed my body as far away from her as I could as my frustration increased. Tap tap tap...it continued.

Tim and I had recently watched the movie Apocalypse Now. Marlon Brando's words, "the horror, the horror" kept echoing through my head.

Three miserable hours into the trip we decided to stop for the night. We were in Salida, Colorado. We found a motel room and checked in. I was disappointed because we would now be 3 hours behind schedule. This meant that the next day would be a very long 10 hour day of driving. I put Mom's pajamas on her, brushed her teeth, and put her to bed. I was relieved when she slept through the night.

Up early the next morning, I fed her a quick muffin and some juice, took her to the bathroom, and we set off again. The boys ate breakfast bars in the van as we were anxious to get on the road and make up for lost time. I thought about giving Mom her sleeping medication at this time but decided not to. I hated the idea of medicating her unless I really had to. A short ways into the trip though, the dreaded request to stop and pee reared its ugly head. The pattern for the day became: stop and pee, drive 15 to 20 miles, she would ask again, I would put her off verbally for as long as I could...usually a half hour, then we would stop at a gas station. We were stopping every 45 minutes to an hour. I am very proud to say that I never lost my temper with her and I displayed and felt amazing patience. I knew that she couldn't help what she was doing and I knew that I had to role model love and kindness towards her for the sake of the kids. It wasn't hard to do because I truly loved my Mom and I had mentally prepared myself for the difficulty I had predicted for this trip.

We stopped and grabbed a quick fast food lunch in Raton, the halfway point. Mom ate some chicken strips and drank part of a soda. I took her to the bathroom, standard procedure now, the very last thing you did before getting back in the van. Ten minutes later she requested that we stop. She also complained that her stomach hurt. We were 20 miles from the next bathroom. Not to be gross but I thought to myself, “oh no, she probably has to poop.” Dealing with her as if she were a 2 year old is something I was very used to and part of our life. I whispered my thoughts to Tim and he drove as fast as he could to the first possible bathroom which turned out to be a visitor center. I rushed her in and immediately saw that the ladies bathroom was closed for cleaning. No problem, there was a handicapped bathroom open right next to it. I took her in, pulled down her pants, helped her sit on the toilet, and waited. She was having difficulty relieving herself and immediately became frustrated. I told her to calm down, relax, and give it a little time. I assured her that we were not in a hurry (yeah, right!) I coached her through the task in my not very quiet voice and finally after about 15 minutes she had success. I talked/helped her through all the bathroom steps of wiping, washing, drying hands...my all too familiar and necessary standard procedure for our numerous trips to the bathroom. We exited the bathroom and stepped out into the lobby where much to my surprise there was a long line of people patiently waiting their turn to get into the handicapped bathroom as the other bathroom was still closed for cleaning. All eyes were averted, so I was pretty sure they had heard every word of my coaching and cueing! I was too tired and mentally exhausted to be embarrassed, but looking back now it was pretty funny. Ten steps away from the bathroom, which was already occupied by the next anxious user, Mom loudly announced that she felt like she needed to poop some more. Fortunately, the man cleaning the women’s bathroom finished up at this exact moment so I could take her into the women’s restroom...and yes, she had another successful BM! Oh, the joy of being my Mom’s mom.

We forged on (one of my Mom’s favorite sayings). Somehow we made it to Lubbock despite stopping every hour. I noticed that Mom was starting to have more and more difficulty performing the task of urinating. I wondered if the Alzheimer’s was causing that automatic function to shut down. Several times we stopped for her to pee and she couldn’t. I waited and waited with her and finally just got her back in the car. In the back of my mind I was very concerned but attributed it to the disease.

We finally arrived at my Aunt Kaye’s house, mentally and physically exhausted, but happy to see our family. It was quickly evident to all that Mom’s condition had deteriorated since they had last seen her, and the shock of her decline was apparent on their faces. Mom was happy to see everyone but was very confused and in a constant state of discomfort and unrest. She couldn’t relax, and kept asking everyone to take her to the bathroom. She paced around asking what she should do and where she should go. These questions were interspersed with scrambled words and sentences that made no sense. She would sit for no longer than 30 seconds and this behavior was making everyone a bit edgy. My cousins and aunt had prepared a huge feast of pot roast and potatoes. We ate, we visited, and exhausted we departed to my cousin Sarianne’s house for the night where we were to sleep. We were to meet back at my aunt’s in the morning for the reunion festivities. At Sarianne’s I gave Mom a bath, brushed her teeth, put on her pajamas, gave her the sleeping medication, let her pee one last time, tucked her into bed, kissed the kids goodnight,

and finally collapsed into my own bed. “What a day,” I said to myself. “That was very hard but we made it through. It can’t get any worse.” Mom thankfully slept through the night.

The next morning Mom was up bright and early and managed to find her way into my cousin Sarianne’s bedroom, where she crawled into bed with Sarianne and her husband, Marcus. According to Marcus, Mom laid down on the waterbed and said, “Ooooh, I like this.” We all got a big chuckle out of this!

We met with all the relatives and drove to the cemetery where we visited the graves of my grandparents, “Mam and Pap” (Olive and Marion, my Mom’s parents). This was a bizarre activity, but fitting for our family. Mosquitos swarmed us and it was quite windy and chilly. We laughed at the weirdness of the fact that we had come to visit the cemetery. Everyone posed for pictures as we remembered my grandmother and her famous words, “I’m just me.” I stood on their graves and told them hello. Mom didn’t really seem to have much clue of what was going on, but she was laughing and happy. We headed to our next stop, Silver Falls.

At Silver Falls we picnicked. Everyone looked through the photo albums I had brought from all the past reunions. Uncle Butch and Aunt Linda searched for the rock where 40 years ago they had carved their names and professed their love to the world. Uncle Pete and Aunt Bobbie showed up with their grandson. They are my mother’s aunt and uncle and I had heard their names for years but never met them. Mom seemed to remember them when told who they were. We ate a fabulous picnic feast and a good time was had by all. Mom did fairly well, but continued to intersperse lucid comments with not so lucid comments. She was constantly on the move, restless, and asking all she came in contact with to take her to the bathroom. The aunts and cousins were beginning to tire of this duty and I noticed that they were starting to avoid her. Perhaps it was just my perception, and my need to have a break from her.

After the picnic, plans were made to split up for the afternoon adventures. Some would go back to the house or to the motel to rest (my Uncle Kirk had just gotten out of the hospital and needed to be checked on). Some would take the kids on an outing to the Science Emporium. Aunt Kaye volunteered to take my mom, her sister, back to the house to rest so Tim and I could go off with the kids. I was relieved and happy to take her up on this offer, and the Science Emporium and Imax movie were fun and rejuvenating...just what I needed.

We all met back up for dinner at a restaurant. We ordered our food and started to eat and Mom immediately asked me to take her to the bathroom. For the first time on the trip I lost my temper in front of everyone and insisted in a not very nice voice that she wait. One minute later she asked again and I reluctantly took her. I was embarrassed and mad at myself for losing my cool and she kept asking me over and over if I was mad at her. This made me feel worse and I tried to assure her that I was not mad but it was too late. She obsessed over whether I was mad and got very angry with me. I tried to stay calm, but she kept bringing it up every minute, forgetting what I was saying to her, only remembering and worrying about my anger. I felt terrible. I had ruined the meal and the mood for everyone.

Aunt Kaye wanted Mom to spend the night at her house as all of us cousins were going out on the town and she assured me that she could handle her. Mom had slept well the past two nights, so we were fairly certain that she would sleep this night. We were wrong. She kept my aunt up all night and by 8 am the next morning my aunt called expressing extreme urgency for me to come over and take care of her as her nerves were understandably shot and she was trying to finish up food preparations for the big cookout planned for the day. I rushed over to her house to take Mom off her hands.

I was shocked when I arrived and saw my Mom. Over the night she had drastically changed. The best way to describe it is that her brain seemed to have short circuited. She was in a complete and total confused state. She had no idea who I was or where she was or what we were doing. She was alert and talking, but saying the most bizarre things. Nothing she said made sense, and I joke now that she was speaking in tongues. She was calling me Mom or Bob (my dad) and as I gave her a bath and got her dressed I kept thinking, "Oh my God, she lost it overnight. My mom is gone." To regress a bit, my Mom's grandmother had also had some form of dementia, and I had been told by my aunt that one day she could talk, and the next day she woke up and was babbling and never spoke coherently again. This is what I believed had happened to my Mom.

After her bath Mom started holding her stomach as if in pain. She couldn't verbalize to me what the problem was. I sat her on the toilet. She moaned and groaned and blurted out fragments of sentences that led me to believe she was remembering having a baby...perhaps she was reliving having me. That was a weird thought. After five attempts of getting her up and down off the toilet she was finally able to relieve herself and her distress went away. I dressed my Mom, put makeup on her, and curled her hair. This was the last day of the reunion and I wanted her to look her best. I thought to myself how bizarre it was that her family had witnessed her last day of cognitive clarity. I was thankful that they had laughed and spent time with her and witnessed a few moments of the old Sarah spark before she short circuited.

I was now operating on automatic pilot because I was an emotional wreck. All I could think of was how to get her home fast as soon as the final reunion event was over. I revised plans in my mind for getting her home. I would not let her fall asleep until we were ready to leave. We would leave 2 hours earlier than planned, I would give her a sleeping pill, and we would drive through the night while she and the boys slept. I had had a good night's sleep so I could do it.

Tim came and picked us up to take us to the barbecue. He was also shocked when he saw and heard my Mom speak. He took us to the club house where the barbecue and last day reunion activities were held. When we arrived my cousin's band was singing and entertaining and Mom sat for the longest period I had seen her sit and seemed to really enjoy the music. They sang the most beautiful version of "Somewhere Over the Rainbow," which sent me into a meltdown and I had to go outside and cry.

Mom's favorite aunt, Aunt Nell, showed up with her two daughters. Mom smiled and laughed when told who they were and said, "Aunt Nell is so sweet, she put the flog on the ceiling." That was the most coherent sentence she said all day. She babbled nonstop through the barbecue.



When time to eat I sat her down and fixed her a plate. I noticed that several of the relatives avoided her, sitting elsewhere even though there were 3 empty chairs by her and she was sitting there by herself. It made me very sad, but I understood. To witness my mom's decline and to deal with her bizarre behavior was just too much for everyone. I fixed myself a plate and sat down with her to eat, and then cousin Cyndi joined us much to my relief. Cyndi teased and talked with my Mom, making her laugh, and then Mom made us laugh with her bizarre responses to Cyndi's questions.

We celebrated Aunt Kaye's 60<sup>th</sup> birthday. Mom was oblivious. Kaye opened her present, a "sexy sixty" outfit...a thong and see through nightie given to her as a joke from her daughters. We laughed because Aunt Nell, the oldest person in the room, demonstrated that she knew the correct way to put on the thong. Uncle Kirk came in and really made us giggle by holding the thong up to his own crotch. It was a relief to laugh uncontrollably at the silliness of it all. We ate cake and homemade ice cream. The kids swam for an hour or so and then we all began cleaning and packing up. Uncle Robert announced his and Aunt June's immediate departure. A sense of sadness and gloom weighed in the air. It had been there all day, and really, it had been there all weekend and the time had come to say goodbye. The time had come to end The Last Trip. It was known by all that Mom would never be able to make another. It was way too much to bear and I gathered her two brothers and sister for the last traditional picture of the four of them. Mom was oblivious and had to be physically positioned as to where to stand. Her three siblings held back their tears the best they could. When I told everyone to smile, the three forced smiles, and Mom had a moment of understanding and she smiled, too. I snapped the picture.

We threw our luggage and kids and Mom in the van. I gave Mom a sleeping pill and put her in the front seat, leaning the seat back so she would go to sleep. I took off her glasses, told her it was bedtime, kissed her and covered her with a blanket and said goodnight. It was 2:00 in the afternoon. I jumped into the driver's seat. Tim crawled in the back to sleep himself, exhausted from lack of sleep the previous night. Mom closed her eyes and almost instantly fell asleep and I was so relieved. We hit the road and I was mentally prepared for a long night and an intense mission to get home as fast as possible.

My relief lasted for 30 minutes. Mom sat up, wide awake. I tried to coax her back to sleep as I was driving. No such luck. She was blurting out babble again. I pulled over to the side of the road and against my better judgment I gave her another sleeping pill. I simply had to knock her out so we could get home. She had now been without sleep for a whole night and most of the day and she had to be tired. She continued to blurt out fragments of sentences and I was fascinated in a sick sort of way by the things she was saying. Fragments of her past were all jumbled together. She had no clue who I was or where she was. I looked at Tim in the rearview mirror and he had a look of total shock on his face. The kids were extremely quiet as Mom's tone and volume escalated. She began holding her stomach and saying fragments like, "I'm dying," "help me Bob", "my clothes are on the fence", "should I?" The fragments make more sense on paper, but the way she was saying them made no sense at all. Her tone of voice was a question as if she was asking me for a response to her jumbled fragments. I would answer with a nonsense response. It didn't matter what I said and this crazy conversation went on for awhile. She then exhibited more

distress. She was sticking her hands in her pants and holding her stomach and groin. I wondered if she had to go to the bathroom and couldn't verbalize this. I stopped and took her into a bathroom and she was calm for a few moments after relieving herself and then back in the van it started all over again, just a few miles down the road. Once again she began grabbing and pulling on her pants. Grasping for straws I wondered if the elastic band of the depends was wadded up or cutting into her. We were on a country road and I pulled over, made her get out and stand up, and I tore off the depends telling the boys not to watch. This was still not the cause of her distress. We were now a mere 75 miles or so from Lubbock and it occurred to me that we should turn around but I wanted so badly to get her home that this option was rejected. I drove a bit further, but her distress continued to escalate. She screamed and cried.

Suddenly, and only at that moment, it occurred to me that we had a serious problem and that we needed help. It hit me like a flash of lightning that my Mom must have something else going on besides the Alzheimer's, perhaps a urinary tract infection. This seems so obvious to me now, but up until that point it had eluded me. Her need to frequently urinate was nothing new, and a problem I had been dealing with for the past 3 years. She had even been recently tested for a urinary tract infection back in Grand Junction, which showed she did not have one. Up until that moment I attributed her strange behavior to the Alzheimer's as she had been in a rapid decline for several months. Now it seemed clear that she had a UTI, and I feared that I might have overdosed her with the sleeping pills that were having a reverse reaction. I announced to Tim and the boys that we had to find a hospital. We were 6 miles from Vega, Texas and I drove as fast as I could to the town and stopped at the police station to find the nearest hospital. They advised me that the nearest hospital was in Amarillo...35 miles away...out of our way...it didn't matter. I was scared. They drew me a map and took way too long to repeat the directions to me. I ran back out to the van. Tim had walked Mom around while I was inside to try and calm her down and he got behind the wheel while I got in the back seat with her and put my arms around her. She was hysterical. I told her how much I loved her and how we were going to get her help. I continuously talked to her in a calm voice about the reunion and anything I could think of to distract her but nothing helped her distress. I told the boys to sing a song with me. We sang "America" and the national anthem as these were the only two songs I could think of. My voice was cracking and I fought back tears as I tried to sing. The boys sang along but they were frightened, too. We sang as loud as we could to drown out her cries. My son, Caleb, 10 years old, told his grandmother, "Nana", how much he loved her. He then told me what a good daughter and mother I was. Now I really had to fight back the tears. We sped to Amarillo. It was the longest 35 miles I had ever covered.

An eternity later we arrived at the emergency room in Amarillo, Texas, at 5:00 p.m. on a Sunday night, the day before Memorial Day. We got Mom inside, explained the problem to the intake nurse and after a short wait we were called into an examination room. Tim and the boys stayed out in the waiting room. Mom was suddenly and miraculously calm, and obviously unaware of where we were and what we were doing. She pointed to an electric outlet on the wall and said, "What a nice decorating job." When the doctor came into the examining room she rallied and smiled and suddenly perked up. He asked, "How are you doing Mrs. Fenley?" "Just great!" she replied. I stood there with my mouth open. They chit chatted. He asked her if she knew where

she was. "Well, no, I'm not really sure." He asked her if she had any pain. "Well, no, well, maybe in my arm." I was stunned, lost it, and launched into the doctor's face. Did the intake nurse not explain the situation to him and the fact that she had Alzheimer's? I frantically explained what I had just been through with her for not only the past few hours but the past 4 days. He looked at me like I was an idiot and kind of smirked. I told him I thought she must have a urinary tract infection and he agreed that was a possibility and therefore he would run a lab test on a urine sample. Fine. He disappeared. A nurse appeared with a urine specimen cup. I explained that would not work and she returned with a "hat", a device that fit into the toilet to catch the urine. I took my Mom into the bathroom, an all too familiar scenario, and told her to pee. She literally peed two drops which was not enough for a lab test. After God knows how many trips to the bathroom over the past 4 days, the "Pee Queen" now couldn't pee. I was incredulous. For the next hour I forced a Sprite and water down my Mom, and walked her up and down the emergency room hallway. She tried again, and barely squeezed out about 10 drops. The nurse told me once again that it was not enough but I implored her to make it work as I feared my Mom's bladder had now shut down and she reluctantly agreed to take it to the lab. She told me it would take about 15 minutes for the results to come back. We had now been in the hospital for hours and all this time the boys had been patiently waiting in the waiting room...incredible kids...incredible husband. I tried to wait in the exam room with Mom but she did not understand what we were doing and why we were waiting and was very restless so I kept walking up and down the hall with her. I saw a lady with her tongue all swollen. I saw a lady with a gash in her leg. I noticed that every time we went past the nurse's station they would all avert their eyes. Tick tock...time slipped by and another hour passed. I stopped at the nurse station on one of our treks and politely asked why the lab test was taking so long. No one seemed to know. The nurse who had originally taken it was nowhere to be seen. Another nurse called the lab...oh it appears they have not gotten to it yet. I was very close to going postal. Did I also mention that I had the cramps and was PMSing? Now I tried getting very pushy and demanding and of course this did not work. More time passed and then the doctor miraculously appeared at the nurse station. I rushed up to him and before I could say a word he asked me, "Have you gotten the lab result back yet?" I started to punch him, but before I could he opened up some binder and said, "Oh, here it is. Yes, your mother has a urinary tract infection." I was too dumfounded to do anything but stand there and nod. He prescribed an antibiotic, a medication for bladder pain, and a different type of sleeping pill to help us get back home. He quickly left. I asked the nurses to direct me to the pharmacy. They informed me that there was not a pharmacy in the hospital. It was now 10:30 p.m., Sunday night, the day before Memorial Day, and we had been in the emergency room for over 8 hours. They told me that there was only one pharmacy in town that would be open, but that it closed at 11:00 p.m. and they drew me a map. I was too tired to cry. We hopped in the van and drove to the pharmacy, actually a large grocery store. Along the way we spotted a motel and decided that we would return there after the pharmacy and stop for the night as we were all too exhausted to think about driving. I took the prescriptions in to the pharmacist. She was not able to fill them for me in liquid form (my mother was having great difficulty swallowing pills). She did not have a pill crusher. They would not take my insurance. Now I was way too tired to care and I paid cash. The pills had to be taken with food and we had not eaten in hours so I bought some sandwiches and we headed to the motel.

At the motel we requested two adjoining rooms on the ground floor as Mom was having difficulty climbing stairs, not to mention the fact that she now had not slept in 36 hours and was wobbly on her feet. There were no rooms available on the ground floor so we accepted two connecting rooms on the second floor and we managed to get Mom up the stairs. One of the rooms had not been cleaned. I went back to the desk and they gave us another room but we were not able to have connecting rooms so our three boys, Caleb (10), Lance (10), and Spencer (13), had to be sent down the hall to a room on their own. We sent them off with instructions to go straight to bed as we would be getting up at 5:00 a.m.

Tim and I took Mom into our room. I stuffed as much of the sandwich down her as I could while Tim took the pills into the bathroom and tried to crush them but without the right tool he ended up cutting them up into small chunks with a small pair of scissors I happened to have in my makeup bag. I mixed the pills with a ginger ale and the concoction immediately turned brown. I tried to get Mom to drink it but it must have tasted terribly nasty as she gagged and pulled pill chunks from her mouth with her hands. One of the pills contained a strong yellow dye which immediately covered her hands, and mine, as I picked up chunks off the floor and stuffed them back into her mouth. Finally, I forced most of the terrible potion down her throat, put on her pajamas, washed her face, and got her into bed. She got up three times but finally seemed to fall asleep. Relief...at last. Tim had long since passed out on his bed. It was now midnight.

I decided to treat myself to a hot bath to ease my nerves and cramps so that I could sleep. It was the first moment of peace I had experienced in hours. I soaked in the tub for a few minutes and imagine my surprise when the bathroom door slowly opened and there stood Mom with her pajama bottoms off. She stared at me with vacant eyes. Was this nightmare ever going to end?

I got out of the tub, put on my pajamas, put her pajama pants back on her, thought about strangling her, but got us both into bed instead. She immediately went to sleep...but the fun wasn't over yet.

The telephone rang and it was the front desk. "Are you responsible for the kids in room 229?" "Yes," I replied. "Your kids are exposing themselves out the window," she informed me. I hung up the phone in disbelief. I relayed the news to Tim and told him I would be right back. He jumped out of bed and said he would handle it. (I think he was afraid of being left alone in the room with my Mom!) He returned with the news that Spencer had full montied himself to another motel guest out the window. (I later heard the full story from Caleb who told me that Spencer had opened the blinds and was dancing around the room exposing himself to Caleb and Lance...and the more they laughed and put their heads under the covers...the more he was egged on...and when Lance pointed out that there were people outside the window Spencer decided to put on a little show.) Needless to say, Tim was not happy with the antics and harsh parental words ensued. Tim came back to our room and reported the news. We looked at each other and suddenly burst out in uncontrollable, hysterical laughter. We had just spent the very worst and most bizarre day of our whole lives, and just when we thought it was over...it wasn't.

Tim and I then agreed to sleep in till 7:00 instead of 5:00 but we forgot to tell the kids the change in plans. At 5:00 a.m. Caleb knocked on the door to say they were up, showered and ready to go. Amazing kids. We rolled out of bed and somehow managed to get Mom up and dressed and down to the van. She was pretty sleepy and that was good as we wanted her to sleep all the way home. We gave her some juice and another pill and she slept for the next 8 hours. Ever so often she would sit up and start talking, but always with her eyes closed. It was a relief to not have to stop every 45 minutes and an even bigger relief to have her asleep and not needing something from me. We drove as fast as we dared.

In the late afternoon, about 3 hours from home, Mom woke up. For a short time, she was fairly clear and lucid...much more than she had been in weeks. For that short period I felt like I had my old Mom back and it was uncanny and amazing. She then slipped back to her state of incoherency and her frequent need to urinate. We spent the last few hours stopping every 30 minutes but finally and painfully made it home and delivered her back to the assisted living. I had called ahead and warned them of her condition, and basically, I was so exhausted that I just dropped her off with hurried explanations and description of events, an apology, and a promise to be back first thing in the morning after some rest.

That night at Bright Star Homes, Mom peed all over and ruined the carpet in her bedroom, and kept the staff up all night. It took several weeks, and numerous trips to the doctor, to get the urinary tract infection under control and get Mom back to a manageable toileting routine. She did regain some of her ability to speak coherently, once the infection was out of her system.

“The Last Trip”, was as I predicted, the last trip. Other medical issues occurred after that trip which were also challenging, though none compared to the trauma of that never to be forgotten journey.

## **MIDDLE TO ADVANCED STAGE**

### **PLACEMENT IN A NURSING HOME**

After the Last Trip, Mom was no longer appropriate for Bright Star. She had lived there for over a year, but it was time to move her to a place that offered a higher level of care, a nursing home, mainly due to her extreme incontinence. I chose a place that was renowned for their Alzheimer’s wing, Family Health West, but discovered after several months that the 20 mile distance from my house made it very difficult to visit her as often as I felt was necessary. I moved her again to a different nursing home, La Villa Grande, that was closer to where I worked. Her confusion was such that she had no clue of what was happening and was not phased by either move, which was good. She didn’t even notice that her new room did not contain any of her own furniture or knick knacks. She still knew me, however, and every time I entered the wing to visit her she would stand up and announce me to the room like I was a person of royalty. “Have you all met my wonderful daughter, Laurie?” My heart melted each and every time.

## **THE RED ROBE**

Sarah lived on the secure Alzheimer's wing at La Villa Grande and this is where I first learned about "shopping". I noticed that very frequently Mom would have stuff missing from her room such as her glasses or articles of clothing. I might see someone else wearing something that I knew was hers. I might try to put her shoes on her to discover that one shoe was missing. This always disturbed me, because Mom and I both loved clothes, and I didn't want someone else wearing what I knew to be hers. One day I was thumbing through her closet and saw a hideous red robe on a hanger that I knew wasn't hers. I became incensed and ripped it out of the closet and marched down to the nurse station. I demanded to know why this ugly red robe which my Mom would never have worn in a million years was hanging in her closet and why her clothes were always showing up on other people. The nursing staff meekly told me that this robe had been given to Mom by another family whose loved one had passed and they thought she might like it. I felt really stupid and mean. They also told me that people with dementia often "shop" in other people's rooms, picking up stuff that wasn't theirs and carrying it off and leaving it who knew where. If items weren't labeled, staff might not know what belonged to who. Ohhhhhh. Now I got it. I just learned a whole new meaning for the word "shopping".

## **PAJAMAS**

One evening I came to visit Mom at La Villa. She had been freshly bathed and they put her pajamas on her a little early so she was ready for bed. She was pacing up and down the hall in her pajamas, which was no big deal and her usual activity, but the pajama top was on her backwards, so the buttons were down the back rather than in front like they were supposed to be and the higher back was cutting into the front of her neck. She looked silly and this made me mad. I asked the staff why her pajama top was on backwards and they told me they put them on her like that all the time because she fiddled and twisted with the buttons until they fell off. I promptly went to the store and bought her all new pullover pajamas that didn't have buttons down the front and I never bought her a shirt with buttons again. Communication people. Tell me these things so I can find a solution. I did not want to see my mom looking silly...ever.

## **TAKING WALKS**

The ability to converse with Mom was long past, but we could still spend time together by taking walks. Every time I visited her at La Villa, this is what we did. I held her hand and we walked and walked around the neighborhood or throughout the building if it was too cold outside. Mom was totally incontinent by this time and wore Depends, but once, before I could stop her, she suddenly pulled down her pants and Depends and squatted in the road and starting peeing. When you gotta go you gotta go. Another time, my little son, Caleb was with us. He was holding Nana's hand which was a necessity because her coordination was so impaired from the dementia. All of a sudden she tripped and fell and poor Caleb felt so terrible and blamed himself for her falling, but thank goodness she wasn't hurt. I realized that the responsibility for keeping her from falling was mine, and I never let her walk without me holding on to her again.

## **VISITING MOM**

When Caleb and I would visit Mom at La Villa, we could not say goodbye, because it was too painful for Caleb and he didn't want her to be upset. We took advantage of her lack of short term memory. When we were ready to leave we would quickly hide around the corner, she would quickly forget we were ever there, and we would quickly leave. I think it was better for all of us that way.

## **UNCLE ROBERT AND THE PICTURES**

Mom's two brothers and sister lived 800 miles away in Texas. They were all very very close. They called frequently to talk to Mom when she was still able to converse, and later when she wasn't, to check on both of us and offer emotional support. This was greatly appreciated by me throughout her 8 year journey with Alzheimer's. At one point when Mom was pretty advanced with the disease I decided to send a few pictures of her to her siblings. Uncle Robert called and told me not to send any more pictures. He just couldn't bear to see the changes that had happened to his beloved big sister. The pictures caused him too much pain.

## **FAMILY**

*Journal entry:* "Mom's brothers and sisters can hardly bear to be around her, now. It is too painful. She was always the big sister, the planner, the leader. They adored her. Now, she is a child in an old woman's body. There are small bits of the real Sarah that often surface, but they are difficult to appreciate with the obsessive, confused Sarah so overpowering. Sometimes I have to concentrate very hard to conjure up memories of how my mom used to be when she was the mom, not me."

# **ADVANCED STAGE**

## **BRINGING MOM HOME AGAIN**

Mom lived at La Villa for a year and a half. I learned that her long term care insurance would run out in a few months, something I had not realized when initially dealing with the insurance company. I believe I was misinformed, but deciphering insurance policies was like learning Greek, so I simply may not have understood. For financial reasons, and because I wanted and believed it was the right thing to do, I decided to bring Mom home to live with me once again. My grandmother was already living with us, and it just made good sense to care for them both. Mom was so advanced with dementia by this time that she did not know me and was not able to communicate or do anything for herself. She was an infant in an adult's body. We built and moved to a bigger house to accommodate both Mom and Mamo and Caleb and my two step sons. I quit my current job. My new job was to be a caregiver to my 72 year old mother with Alzheimer's and my 102 year old grandmother who was mentally intact but physically frail. We would have 4 generations in our home for the next year. The house had two stories, so the kids would be upstairs and have their own space, and the north wing of the house, which consisted of two bedrooms and a bathroom, became the geriatric wing. Mom would spend the last 10 months of her life in this house.

## **MUSIC**

Music touches people with dementia in a way nothing else can. Mom was sitting on the couch. She loved music. I put on a jazz musician who had always been one of her favorites and specifically the song “Take Five”. First I saw her wiggling her foot in time to the music. Then she very clearly said, “There’s no one like Dave Brubeck”. She was right. This from a woman who did not know who she was, where she was, or who I was, and who did not speak except for an occasional few words that usually made no sense.

## **MYSTERIOUS MOMENT OF CLARITY IN THE KITCHEN**

People with dementia will have mysterious moments of clarity. They will be enveloped in a cloud of confusion and without warning say or do something that is so normal, so with it, and so them. These moments are precious and are little gifts to the family. One of Mom’s most memorial moments of clarity happened when she moved back in with me. She was very advanced with Alzheimer’s at this point. She didn’t know me. She didn’t know where she lived or who she was. She barely spoke, and when she did the words made no sense. Her days were spent sleeping and pacing around the house. I dressed her, bathed her, fed her, changed her, and loved her. One evening I was in the kitchen standing in front of the sink preparing dinner. All of a sudden she walked into the kitchen and threw her arms around me in a warm embrace and exclaimed, “Laurie, is that you? What can I do to help?” For a few seconds, I had my mom back. It caught me off guard, but it was a beautiful moment that I will never forget. The clarity didn’t last long, but the memory of that special mysterious moment has stayed with me, forever ingrained in my heart.

## **THE FAMILY DINNER**

Eating dinner with Mom became problematic. She was unable to sit still long enough to eat with us normally at the table, and pacing had become her intrinsic driving force. She was constantly on the move around the dining room and touched the food on everybody else’s plate. This was creeping and grossing us all out, especially the kids. I started feeding her earlier than everybody else, but it didn’t prevent her from pacing and trying to touch our food while we ate. I had to do something. Then it dawned on me. Could I put her in another room while we were eating and shut the door? Was that cruel? Was confining my mother in another room like a prisoner inhumane? I tried it. She was just as happy pacing around her bedroom for 20-30 minutes while we ate as she was pacing around the whole house. She didn’t seem to notice or care. She didn’t have the ability to even turn the door knob and let herself out. Problem solved.

## **THE FALL**

One day I was vacuuming. I looked over and Mom was asleep on the couch next to the cat. I looked again 2 minutes later and she was gone. In that short amount of time she had gotten up, gone out the door to the garage, fallen down two steps, busted a gash in the back of her head, and had crawled halfway under my car. This resulted in a fun trip to the emergency room where she received staples in her head. They also wanted to do a cat scan but she could not hold still for the procedure. So, they wanted to give her Haldol to calm her down and make her lethargic. I told them absolutely not, because the last time she had Haldol, on The Last Trip, it had the reverse effect on her. They would not listen to me and insisted. Guess what? It had the reverse effect and she became even more antsy and agitated. I took her home without a cat scan.



## **THE ENEMA**

Toileting and dealing with incontinence is one of the most challenging aspects of caring for a person with dementia. Mom was totally incontinent and seesawed back and forth between having diarrhea and being constipated. There was no happy medium. I was an expert at every single kind of adult protective brief...aka “depends” and could quickly and efficiently clean up any kind of poop mess imaginable. Hospice instructed me to track Mom’s “movements” on paper and I did. After 5-6 uneventful days it was decided that an enema was imminent. The Hospice CNA performed the task with my assistance. Mom somehow found the words and literally thanked us. Not sure too many people have ever been thanked for giving an enema.

## **ON THE MOVE**

Mom lived in the land of oblivion at this stage of the disease. She slept or she paced. She often paced to the point of exhaustion. I placed chairs at strategic spots so she would sit down and rest but she would sit for only a few seconds and then pop back up, on the go once again. She was also particularly fond of pulling all the sheets off all of the beds. And, sometimes she would walk into a corner of a room and not be able to figure out how to turn around, so she would be stuck. Falling was a constant concern and I finally started tying her in a chair with an apron when she became too fatigued but wouldn’t/couldn’t rest. This is considered “restraint” in a care facility and is not allowed. I didn’t know what else to do. It was not possible for me to watch her every second and keep her from falling, so restraining for intermittent periods during the day became necessary to keep her safe. I would tie her to a chair and put a table in front of her with sensory objects for her to touch and feel to keep her occupied. I felt like a warden.

## **MOM EATING ROCKS**

One day I looked over at Mom and she looked like a chipmunk. On further investigation, I discovered her mouth was filled with rocks. Like a child, she had filled her mouth with the decorative rocks placed in a pot holding a ficus tree. Her ficus tree that I had hauled all the way from Texas.

## **FEEDING MOM**

Feeding Mom was something I disliked more than any other care task. Whenever I fed her, I thought about the time when I was a child and I was sick. I remembered sitting on my mother’s lap while she fed me pancakes that she had made especially for me to make me feel better. The role reversal made me too sad.

## **FEEDING MOM BEANS**

I had one sure fire way to make Mom laugh. All I had to say was, “Mom, these beans are going to make you fart!” It invoked a smile and a laugh every time.

### **MYSTERIOUS MOMENT OF CLARITY – THE BEDROOM EPISODE**

Mom was now in the very advanced stages of Alzheimer's. She spent most of the day asleep, and was totally dependent on me for care. She had become very weak and was no longer walking or pacing around the house. I had a baby monitor in her room so I could hear her on those nights that I didn't sleep in her room. One very early morning around 5:00 a.m. I heard sounds coming from her room and got up to investigate. Somehow she had gotten herself up out of the hospital bed and was sitting in the recliner chair next to the bed. She looked at me and as clear as day said, "I can't take this anymore." "What, Mom?" I said. "What can't you take anymore?" "This sickness," she said. This mysterious moment of clarity was like a knife stabbing in my heart. Thankfully, she went quickly back to the land of oblivion. I never forgot.

### **THE LAST BREATH**

Mom died on June 4, 2003, at the age of 73. I was 46 years old. Caleb was 13. Mom appeared to die peacefully around 11:00 p.m. Her body had gradually shut down and she was completely bedridden. She was very thin. On rare occasions I could put my cheek to her lips and she would kiss me, but her eyes were almost always closed. Her favorite piano music, Jim Brickman, played 24/7 on the CD player. She stopped taking food or water and her breathing became loud and gurgly...the "death rattle". Each day I had sat in the recliner next to her bed, and each night I had slept in a twin bed I had placed in her room...listening...waiting...watching. That night I had just fallen asleep, but I woke up because the room was so quiet. Mom had stopped breathing. She was finally free, and so was I.

## **CONCLUSION**

Caring for my Mom with Alzheimer's was the hardest thing I ever had to do. I used to think teaching elementary school was the most difficult challenge, but then I became my Mom's caregiver. There were many times when I was annoyed and irritated with Mom. There were many times when she melted my heart. There were many times when I thought I was going to have a nervous breakdown. There were many times when I felt pride over the way I handled so many responsibilities and protected and advocated for her. There were many many times when I prayed that she would just hurry up and die. There were many tears. There were many laughs. I made lots of mistakes. I had many triumphs. I made many new friends. This is no different from anyone else's life. I was just a daughter who was raised by a wonderful mother and I loved her very much.

I found a note one time that my Mom had scrawled and it said, "I don't want to be a burden to my family." Is caring for a person with dementia a burden? Yes, absolutely it is. But it is also an opportunity for those of us forced into the caregiving role to find strength, courage, selflessness, and stamina that we didn't know we had. And...through it all...become a better person for it. Thank you, Mom, for being a burden to me. And to the universe, "You suck for giving my mother Alzheimer's disease."