

# **MisUnderstanding Dementia**

**MICHAEL CHUA, PT, DPT**

Doctor of Physical Therapy

APTA- Certified Clinical Instructor

NCCDP - Certified Dementia Practitioner

NASM - Senior Fitness Specialist



Copyright © 2017 Michael Chua

All rights reserved.

ISBN: 9781521109496



## DEDICATION

To Puppen, my wife and my best friend.

*It is hard to believe we've been together so long already. You are a blessing and gift from God to me. Master Shifu of Kung Fu Panda said. "Yesterday is history, tomorrow is a mystery, but today is a gift. That is why it is called the Present." You epitomize my past, present and future. I love you very much!*

And to my children, Alyssa, Akeisha and Izaiah

*It is difficult to find words how much I truly love you all. You girls inspire me to be a better father and a better person. Thank you for being such a good inspiration not only to me and your mother, but as well as to other children.*



## Table of Contents

DEDICATION .....	4
CHAPTER 1 INTRODUCTION .....	8
CHAPTER 2 STAGES OF DEMENTIA .....	10
CHAPTER 3 COMMUNICATING WITH DEMENTIA ..	14
CHAPTER 4 BEHAVIORS .....	22
CHAPTER 5 WANDERING.....	26
CHAPTER 6 INCONTINENCE .....	32
CHAPTER 7 AGITATION .....	36
CHAPTER 8 PERSEVERATION .....	40
CHAPTER 9 PARANOIA .....	44
CHAPTER 10 SUNDOWNING.....	48
CHAPTER 11 NUTRITION .....	54
CHAPTER 12 BATHING .....	60
CHAPTER 13 DRESSING .....	66
CHAPTER 14 HALLUCINATIONS AND DELUSIONS .	70
CHAPTER 15 INAPPROPRIATE SEXUAL BEHAVIOR.	74
CHAPTER 16 VERBAL OUTBURST .....	78
CHAPTER 17 SHADOWING .....	82
CHAPTER 18 DIFFICULT BEHAVIORS .....	86
CHAPTER 19 KEEPING YOUR PATIENT ENGAGED .	90
CHAPTER 20 CARING FOR THE CAREGIVER.....	92
ABOUT THE AUTHOR.....	96



# CHAPTER 1

## INTRODUCTION

Taking care of a loved one with dementia poses a lot of challenges for the spouse, children, and caregivers.

Patients with dementia due to Alzheimer's disease experience difficulty in remembering things. They are unable to think clearly and communicate. They also cannot take care of themselves. Additionally, patients can have behaviors, such as mood swings and change in personality, which could lead to confusion and frustrations for their care providers.

Both patients and caregivers may experience the Kubler Ross Stages of Denial, Anger, Bargaining, Depression and Acceptance. In my practice as a physical therapist, I have seen patients who are in denial stage and continue to drive around. I know in my mind, that they are not supposed to do such an act because they are in the denial stage. I have also seen patients and family members who are in the anger stage.

Patients take some time to process information. They have what we call the 90 seconds rule. This means that it takes them 90 seconds to process information any information fed to them. When we bombard

these patients with multiple questions, they get easily agitated. It is very crucial, then, to ask closed-ended questions, instead of open-ended ones.

In the bargaining stage, the patient will try to bargain with you, family member, priest, pastors or any higher being. And of course, the last stage will be the acceptance stage, wherein the patient or family accepts the situation. Family members and patients need to progress to the Acceptance Stage in order for them to apply the strategies in this book.

Dementia is not a disease in itself. Rather, it is a broad name referring to a long-term and gradual deterioration of a person's mental ability. The condition can be severe enough to obstruct the sufferer's daily life. Dementia occurs when the brain cells stop working as they should, affecting the person's ability to think, remember, and communicate. Its usual symptoms include the difficulty of reasoning and thinking, gradual memory loss, and deteriorating communication skills. The most common type of dementia is caused by Alzheimer's, which accounts for 60 - 80% of the cases.

In this book, we will discuss the different stages and some strategies on how to take care of our patients and loved ones.

## CHAPTER 2

# STAGES OF DEMENTIA

Global Deterioration Scale for Assessment of  
Primary Degenerative Dementia (GDS)  
(also known as the Reisberg Scale)

### **Stage 1: No Dementia; No Cognitive Decline**

In this stage, the person functions normally. He has no memory loss and is mentally healthy. People with NO dementia would be considered to be in Stage 1.

### **Stage 2: No Dementia; No Cognitive Decline**

This stage is used to describe normal forgetfulness associated with aging. For example, the person experiences forgetfulness of names and where familiar objects were left. Symptoms are not evident to loved ones or the physician.

### **Stage 3: No Dementia; Mild Cognitive Decline**

This stage includes increased forgetfulness, slight difficulty concentrating and decreased work performance. The individual may get lost more often or have difficulty finding the right words. At this stage, his loved ones will begin to notice a cognitive decline. Average duration: 7 years before onset of dementia

### **Stage 4: Early Stages; Moderate Cognitive Decline**

This stage includes difficulty concentrating, decreased memory of recent events, and difficulties managing finances or traveling alone to new locations. People affected with the early stage of dementia have trouble completing complex tasks efficiently or accurately. But they may deny about their symptoms. They may also start withdrawing from family or friends because socialization becomes difficult for them. At this stage, a physician can detect clear cognitive problems during a patient interview and exam. Average duration: 2 years

### **Stage 5: Mid Stage; Moderately - Severe Cognitive Decline**

People in this stage have major memory deficiencies and need some assistance to complete their daily

activities (dressing, bathing, preparing meals). Memory loss is more prominent and may include major relevant aspects of current lives. For example, they may not remember their address or phone number and may not know the time or day or where they are. Average duration: 1.5 years.

### **Stage 6: Mid Stage; Severe Cognitive Decline (Middle Dementia)**

People in Stage 6 of dementia require extensive assistance to carry out daily activities. They start to forget names of close family members and have little memory of recent events. Many of them can remember only some details of earlier life. They also have difficulty counting from 10 and in finishing their tasks. Incontinence (loss of bladder or bowel control) is a problem in this stage. Ability to speak declines. Personality changes, such as delusions (believing something to be true that is not), compulsions (repeating a simple behavior, such as cleaning), or anxiety and agitation may occur. Average duration: 2.5 years.

### **Stage 7: Late Stage; Very Severe Cognitive Decline (Late Dementia)**

People in this stage have essentially have lost their ability to speak or communicate. They require assistance with most activities (e.g., using the toilet, eating). Most of them have lost their psychomotor skills, like the ability to walk. Average duration: 2.5 years.

## CHAPTER 3

# COMMUNICATING WITH DEMENTIA

When I first came here in the United States, I encountered a lot of dementia patients.

I did not know how to handle them.

They were reluctant to receive care. They refused to undergo therapy. They refused virtually anything I offered them. But with patience and persistence, I succeeded in gaining their trust. I learned that good communication skill is the key to building a relationship with dementia patients. A relationship that is founded on trust. Once you have developed it, caregiving becomes less stressful.

And when I say communication skills, it involves both the verbal and nonverbal language. Let me share with you some of the techniques that I have learned from my research and practical application in caring for dementia patients. I have proven these to be effective.

Positive attitude. First and foremost, you need to have a positive mental and emotional attitude. Patients are very sensitive. They can detect how you feel towards them through your speech and nonverbal

expressions. So, it is important that you establish a positive atmosphere around them. A soft and kind tone of voice and a sincere smile can do a lot to help them feel comfortable.

Be sensitive. Dementia patients have difficulty expressing themselves. You need to use all your senses in observing their nonverbal expressions. Is your patient frowning? Does he maintain an eye contact with you and the other people around him? Is he staring at something? Did he smell reeked? Listen, listen, and listen well. Try to decipher what the person is trying to say or convey.

Limit external distraction. Persons with dementia are easily disrupted by noise, light, and other glaring visual objects. So, when trying to get the patient's full attention, make sure to limit unnecessary external distractions. Turn off the radio or TV, and close the curtains or door in his room. And if you need to move some of his belongings, you must ask for his permission first.

Gentle approach. As dementia progresses, the patient's vision becomes limited. Make sure that he recognizes you easily. Approach him from the front. Before speaking, position yourself at an eye level with the person. Identify yourself to help him recognize

you easily. Maintain an eye contact with him throughout the conversation.

Call the person by his first name, if he so prefers it. It helps you get his attention and as a sign of respect, address him according to the profession he was once engaged in, such as Doctor, or Sir or Ma'am if he were a serviceman. Speak slowly using simple words in short sentences. If, at first, he does not understand what you were saying, repeat it over again using the same words as when you first said it. You may use hand gestures or other body languages to reinforce your words.

But, just a word of caution, though: be careful in using nonverbal language. It might run contrary to your words. A crossed arm, for example, may send a message that you are impatient.

Typically, a dementia patient has a slow response time. It may take him up to 30-90 seconds to process any message or information he receives. It matters, then, that you exercise more patience when you don't get a quick response. And while he is processing the information you feed him, do not distract him. Refrain from raising your voice, unless the patient is hard of hearing. It would help the patient if you could visually demonstrate your point. For example, when

instructing him to raise his arm, you may show him how to do it.

Mention the proper names of people and specific places. Avoid using pronouns as these would only confuse the person with a cognitive problem. You would also make things easy for him if you use close-ended questions answerable by either Yes or No.

Use short sentences and direct to the point. When explaining an activity, keep your sentences short. Break down the information or the process by which the activity is to be carried out.

One step at a time.

There are two kinds of problems with dementia has in communication. One is having difficulty in expressing himself and the other one is difficulty in understanding what the other person is saying. He may understand more than he can say or express. Make sure to not make assumptions about what he understands.

Some patients have occasional difficulty in finding their words. They may have trouble remembering names. Most of the time they substitute words such as wall or wheel, or pie or tie. Sometimes they also

change words with related meaning like book for read, or circle to ball, radio to television.

Sometimes patients are able to ramble on quite fluently and it seems like it is a lot. But if you will try to decipher them, it will not make sense.

In my experience, I don't just tell my patient that we were going to the bathroom. Instead, I would start by instructing him to lean forward. Then, as soon as he had done so, I'd proceed to tell him to push up from the arms of his chair, before further instructing him to stand up. Once the patient starts walking, I would tell him what is going to happen next.

The most important point here is to make your patient feel safe with you. And make sure, you get his approval before you proceed with the entire activity.

Be supportive and friendly, It's normal for the dementia patient to become agitated. This occurs when he is anxious or confused. He gets confused over his past experiences and with reality itself. When the person in your care is agitated, let him know that he got your full attention and support. Give particular attention to his feelings. Empathize with him.

Don't argue when he insists, for example, that the present time is the 1950s. If it helps, you may suggest

that you take a walk together so that his attention may get redirected.

Dementia patients retain their Long Term Memory while practically lose their Short Term Memory. They remember the events that occurred 30 years back, but could not recall what had happened in the past 30 minutes. When your patient starts talking about his life, show your interest in knowing what had happened like 15 - 30 years ago. And as you converse, you may apply other forms of communication, such as a smile or a touch.

Maintain a sense of humor. The comic actor, Charlie Chaplin, once said, "A day without laughter is a day wasted." It makes sense. Apply humor when dealing with your dementia patient whenever appropriate. But, of course, humor should not be at his expense. After all, laughter is said to be the best medicine.

To sum up all these, I should say it takes both expressive and receptive communication to make caregiving stress-free. A healthy relationship between the person with dementia and the caregiver is founded on trust.

Here are some more ways to improve your communication with your dementia patients:

- Check their hearing levels. Make sure they hear you well. Majority of your patients/dementia will have hearing problems. Check their hearing aide. Talk a little bit louder, but not too loud that they think you are shouting at them.
- Talking about talking loud, make sure to talk in a nice low tone. A raise tone is a nonverbal sign that make dementia patient upset. I don't like being shouted at either.
- Use short phrases, simple sentences. Avoid or minimize complex explanations. Instead of saying, “We will go to the doctors office tomorrow when i am not busy and probably after having my car fixed.” Say this instead, “We will go to your doctor tomorrow.”
- Last but not the least, i have learned this in a hard way, make sure to speak slowly and wait for the patient to respond. Wait. Wait. Wait.

If you are living with a patient with a dementia, you have probably learned their non-verbal signs and cues when they are happy or upset. You know what, same thing with them. They still recognize (depending on their stage) your own non-verbal signs. Here are some

additional ways to improve your non-verbal communication signs with your dementia patients.

- Make sure to remain calm and pleasant. Even if you feel upset your body language, your facial expression is seen by your patient.
- Smile, smile, smile. Even if you don't feel like it.
- Look directly at the patient, eye level. Not over, not under. But eye level. If they are in a wheelchair, kneel down and be at their eye level.
- Use other cues, in rehabilitation. We use different cues such as pointing, touching and visual cues. Make sure to point what you want and describe it in the most simplest way.
- Limit complex reasoning for the patient. Your dementia patient is no longer able to process information properly.

Even when you patients are unable to communicate, they all still need love and affection. I remember one of my end stage patient, her daughter continues to hug and kiss her every time, all the time! I wonder how or what the patient feels inside when her daughter kisses her and hugs her.

## CHAPTER 4

# BEHAVIORS

One of the issues I encountered among dementia patients is their varied behavioral patterns.

Every now and then, they would demonstrate hostile acts and refuse to receive any care. At times, they may hurt their caregivers both physically and emotionally. Their violent speech and actions can be stressful and a drain for the care provider.

But you should understand that these sudden outbursts may be triggered by different factors. They might be experiencing physical discomfort and poor communication. They may also have been distracted by certain environmental stimulants, like visual, verbal, and tactile sensation.

Certain behaviors may also be caused by medications. There are medical treatments that may precipitate hallucinations and incontinence on the patient. In this case, you better consult with the person's physician and nurses regarding the side effects of the drug administered to him.

There are also instances when patients behave on purpose. I have dealt with patients who just wanted to

keep folding their clothes. They do this to keep themselves busy.

Nevertheless, for whichever reason your patient may be behaving, you must remain calm. Exercise patience. Do not take his behavior personally. Instead, try doing different approaches. Although some techniques may work, I admit that other recourse would not. Be flexible, more understanding, and show compassion. Be creative with your strategies. The best way to ease the tension in dealing with difficult patients is to instill humor.

Look at the situation from a positive perspective. Always remember that you cannot change the person. Otherwise, you would just end up frustrated as the patient mounts resistance. Instead, try to accept the behaviors as a reality that come with the disease. Work through this reality. Do not argue or convince him into doing the thing you think is better for him. When, for example, your patient wants to take a walk. Do not stop him from doing so. Or, if he insists on sleeping on the floor, manage to put a mattress on which he may lay down. And if the patient wants to cook, provide him with something to mix his ingredients in.

Dementia patients can be very demanding and appear very self centered. This is very hard to accept when

the person seems to be in the early stages. If you feel this is happening, step back, relax and analyze the situation. Is their behavior intentional or accidental? Are they manipulative? Often, they cannot control their emotions. As patient with dementia progresses, they are more focused on themselves. If you know the Maslow's Hierarchy of needs. That is what they are experiencing. Some demanding behaviors are reflections of feeling of fear, loneliness or loss of independence. When a patient is unable to remember time and date, their means of adaptation or excuse is to get mad if you ask them what day is it. Some patients gets mad if you leave them for a short period of time and thinking you have left them for the whole day.

Some patients get mad if they cannot remember when they last took a bath and maybe insulted if you ask to take a bath.

Focus on the good and pleasant things you are having. When going to the bathroom, make sure the bathroom smells good. When asking a patient to go eat, make sure the kitchen smells good too. Always take the road of least difficulty. Avoid arguments and accept whatever compromise will work.



## CHAPTER 5

# WANDERING

Once the person with dementia experiences memory problems and is still able to walk, he is likely to wander.

He will walk aimlessly as he becomes disoriented or confused. And the challenge here is that he most likely forgets even his name or address. This symptom could happen even in the early stage of the disease.

Admittedly, identifying the triggers to wandering is quite difficult. But you can plan for this situation. Be keen in observing for signs of the person's behavior. Does your loved one try to fulfill former obligations, like going to work? Does he insist on "going home", even when he is at home? You may also notice his difficulty in finding his bedroom, the bathroom, or the dining room. These are few of the signs that you should look out for.

As his caregiver, you may apply these strategies to minimize the person's chances of wandering.

Identify which time of the day he often wanders. Plan a pleasant activity or schedule his regular exercise

during this period. Activities and exercise help reduce the person's restlessness as his mind gets occupied.

Reposition or install new locks at home. A person with dementia does not likely look beyond eye level. So, it would be wise to install the lock high or low on the door. Or, you may add a slide bolt at the top or at the bottom. But don't forget the fire and safety concerns of the other members of the household. See to it that the locks are accessible to them and are easy to open.

Set up a barrier or camouflage doors. Set up a removable screen or curtain over the doors. Or, paint them with the same color as the walls. Use child proof knobs. You may also want to put up a sign on the door that says something like "Stop" or "Do Not Enter".

Create an impassable illusion. A person with dementia is likely to mistake a black thing for an impassable hole. Capitalize on this misconception by placing a black mat at the outer side of the doors and porch.

Supervision is a must. Whether he is at home, at a care facility, or inside a car, never leave a person with dementia alone without supervision.

Notify your neighbors. Inform your neighbors that you have a member with dementia who has the tendency to wander. Leave your contact numbers with them. Request them to call you in case they see your loved one alone.

Use a monitoring device. Lessen your worry about your loved one wandering into places they should not be. Know where the dangerous areas near or around your home. Areas like open stairwells, bodies of water, tunnels, dense foliage, and roads with heavy traffic pose hazard to the person. Avail of any of the tracking devices specially designed to monitor persons with dementia, Alzheimer's, and other conditions.

If your loved one does wander, make an immediate search in your surroundings, especially in those dangerous areas. Immediate means not later than 15 minutes from the time of the person's disappearance. Keep a list of possible places where he may wander. The person might have gone where he used to work or live, went to his favorite restaurant, or place of worship,

Have your loved one wear an ID jewelry. In case your loved one does strays, his ID bracelet or jewelry should alert your neighbor's or anyone who sees him about his condition. A dementia medical ID is also meant to notify professionals, such as first-aid

personnel, medical practitioners, and rescuers of the appropriate action to take in the event that the wearer is involved in an emergency.

Always keep a recent and close-up photograph, and an updated medical information of your loved one. You will need these items to present to the police in case of his disappearance.

Keep the person's essential items out of sight. If your loved one is not likely to go out without his coat, eyeglasses, or favorite wallet, don't let him see these items. Put them away and all other items that might tempt him to leave.

Remember that if the patient is still able to read and follow instructions, a pocket card may help him. Write very simple instructions like, "Stay Calm," "Don't walk away," "Call Home," and put your telephone number on it.

If you are planning on putting your patient/loved ones in a daycare center. Make sure to put them in the early stages of their disease. When putting them in a Daycare center, make sure to have them stay short visits on the first few visits. Like start with 2 hours for the first day, and 4 hours on the second time and so on and so forth so they get used to it. Also on those first few days, make sure that a familiar caregiver is

with them. Another thing to consider is that the actual caregiver at the Daycare Center visits them at your home before the transition. Leaving your patient/loved one who has dementia alone to adjust may add to the patients agitation and continue to wander around.

The stress that the families and caregivers experience when their dementia-suffering member wanders can be overwhelming. It is important, then, that you make the necessary precautions and plans to minimize his wandering.



## CHAPTER 6

# INCONTINENCE

Incontinence refers to the involuntary release of urine from the bladder or bowel movement.

Most people with dementia experience this situation especially in the later stages of the disease.

It can be caused by many factors, including:

- Failure to recognize the need to use the toilet
- Obstacles on the way to the toilet, like clutter or some furniture
- Forgetting where the bathroom is located
- Difficulty in removing one's clothing
- Stress
- Medication side effects
- Certain physical disabilities

When incontinence occurs, extend your support to the person and apply these tips.

Watch out for nonverbal cues. Be keen to observe certain behaviors, such as tugging on clothing, pacing, restlessness, hiding behind furniture, or sudden silence. These cues may indicate that the person needs to use the toilet.

Reassure your loved one. Instead of reprimanding him, speak kindly to the person when he accidentally wets himself. You may say, “It’s Ok, accidents do happen.” Take note if there is a pattern for his incontinence. If, for example, the accident happens every two hours, remind the person to use the toilet before that time. Many people with dementia do well if they have a fixed schedule for emptying their bladder and bowels.

Make the toilet easy to find and use. Make sure that nothing obstructs between the toilet and the person. Remove clutter, furniture, or other things that make it difficult for him to walk. Leave the bathroom door open, so he could readily see the toilet. Place a sign with illustration on the bathroom door.

Never withhold fluids. Some drinks have more diuretic effects, like beer, coffee, or tea. You may limit the person’s intake of these fluids, if necessary. But, do not attempt to control the person’s accidents by not giving him enough water to drink. It will only cause dehydration, which can lead to other problems. He might develop a urinary tract infection and become more agitated. His incontinence might also worsen. You may, however, limit his water intake before bedtime.

A commode or urinal may help. Leave a commode or urinal in the person's bedroom in case he needs to empty himself at night.

Easy to unfasten clothing. Let your loved one wear loose and easy to remove clothes. Make sure also that these clothes are easy to wash.

Incontinence products. For the convenience for both of you and the person with dementia, consider using incontinence products. Put waterproof mattress covers and incontinence pads on his bed. Or, let him wear adult briefs or padded undergarments. You may also ask his urologist for the appropriate product to use.

When incontinence starts occurring, consult with the person's physician. He might be suffering from urinary tract infection or medication side effects that need immediate attention. It also helps if you encourage him to tell you when he needs to use the toilet.



## CHAPTER 7

# AGITATION

It is common for persons with dementia to be anxious or agitated.

It does occur as the disease advances. Agitation covers a range of behaviors, like irritability, sleeplessness, and verbal or physical aggression. Such behaviors may be due to varied factors.

Medical condition, medication, fatigue, fear, and some environmental circumstances can trigger or worsen their ability to think. Also, the person also experiences a profound loss of his ability to process stimulus and new information. He feels that his sense of control is being taken away from him.

It is when he is most agitated that you, as his caregiver, should exercise your utmost patience. Don't take his offensive behaviors personally. Stay calm and apply these tips to ease the person's anxiety.

Set a calm environment. Remove the stimulants. As much as possible, minimize the noise, glare, background distractions, and clutter in his room. Limit the number of persons coming and going around him. Also, reduce the person's caffeine

intake. When applicable, you may even try some soothing rituals with the patient.

Simplify tasks and routines. Make the person's daily tasks as simple as possible. Use low lighting or put on night lights to ease his anxiety. Do not rearrange the furniture and other household objects around him. Otherwise, he would get more confused. It also helps if you put familiar objects and photographs within his sight. These items may provide him a sense of security and bring in pleasant memories.

Check for physical stimuli. Perhaps, he is hungry, thirsty, or needs to use the bathroom. He may also be feeling cold, or the environment he is in is too warm. Make sure that his room is at a comfortable temperature. Pain, fatigue or skin irritation may also make him anxious.

Make exercise a daily routine. Exercise helps reduce stress and anxiety. Encourage the person to go for a walk or help you in some gardening chores. If he loves dancing, you may play his favorite music and dance with him.

Engage the person in activities. Introduce him to some simple activities to divert his focus from the anxiety. Let him do things by himself. Support his independence and ability to care for himself. But,

even as he does things by himself, make sure you keep an eye on him. Keep dangerous objects out of his reach.

Provide reassurance. When he is agitated, back off a bit and ask permission to talk with him. Do not raise your voice. Instead, use calming and reassuring words, such as, “I’m sorry you are upset.” or “May I help you?”. Acknowledge his anger and let him know you understand his situation. Give him a gentle touch as you speak in a reassuring voice. If it helps, let the person listen to soothing music, or invite him to go for a walk or a car ride with you.

Do not ignore, restrain, criticize, or argue with the agitated person. These reactions from you can only worsen his anxiety.

If you cannot stop the agitation on your own despite the interventions you employed, see the person’s physician. He might be reacting to medication-related side effects or any physical triggers, especially when the symptoms occur suddenly. In which case, he must undergo a thorough medical check up. Symptoms can be minimized with proper treatment and intervention.



## CHAPTER 8

# PERSEVERATION

Perseveration refers to the repetition of a certain word, phrase, or gesture.

Dementia patients often repeat a word, question, statement, or activity over and over.

They repeat what they say or do because they do not remember that they have just asked a question or completed a task. They ask because they may be trying to seek help or express a specific concern.

This repetitive behavior is due to the deterioration of the person's brain cells that consequently affects his ability to make sense of the world. Certain environmental elements can also trigger the symptoms or make perseveration worse. Repetition may also be the individual's way of coping with frustration, insecurity, or anxiety. Perseveration does not pose a threat to the patient with dementia. But, it can be irritating and stressful for his care provider..

As his care provider, therefore, you must keep in mind that it is the disease causing the behavior, not the person. When your loved one gradually loses his ability to communicate, it is important that you regularly monitor his comfort and anticipate his

needs. You can help ease the situation of perseveration by applying the following tips.

Identify the reason for the repetition. When does the repetition usually occur? Is there a certain time of day when the person behaves this way? Or, does the repetition occur around specific surroundings or people? Instead of focusing on what he is doing, try to figure out how he is feeling. It would be easier for you to respond more effectively if you take notice of the emotion and need behind his behavior. Be keen on his nonverbal cues and behavior. An act of pulling at his clothing may indicate a need to use the bathroom.

Provide an answer or memory aid. It's not easy to be asked the same question or to be told the same story again and again. But, you have to put up with the person. Recognize that your loved one may be repeating himself because he needs a certain kind of response. Perhaps, he just needs to communicate and feel close to someone. If this is the case, try changing the topic to something that you find more interesting. This way, it would be easier for you to stay talking with the person.

If for example, the person keeps on asking the time, you may install a large clock. Or, if he frequently asks for certain information, you may provide a notebook or a diary that contains what he keeps asking for.

Turn his action or behavior into an activity. When you see that your loved one keeps on folding the edge of her clothing, she may be bored and needs something to do. Engage her in a pleasant activity. You may ask her to help you with the folding of her other clothes or some other chores.

Also, take note of the subject that the person keeps on talking about. It might represent a need that he has at the moment. For example, recalling about a key achievement in the past might have been making him feel wanting. In this case, organize a meaningful activity from which he can achieve something.

Respond with affection and reassurance. Speak to the person with a voice and gentle touch. Sometimes, a hug and praise are all he needs when he is confused. Do not argue or employ logic.

Perseveration may suggest the person's need for information. It could also mean an emotional need. As his care provider, therefore, it is important that you accept the behavior as a reality of the disease. And you have to find ways to work with it.



## CHAPTER 9

# PARANOIA

A person with dementia finds it difficult to remember things and remain in the current moment.

This condition is due to the glitches in his brains that cause memory problems and change in personality. As a consequence, he develops a certain level of paranoia, which can be his way of projecting fear.

Paranoia is usually a result of delusion or a firmly-held belief in things that are false. As the disease advances to the middle and late stages of dementia, the person's paranoia may focus on suspicions. He is likely to be suspicious of anything and anyone, especially those around them. For example, the person with dementia has forgotten where he left his coat, and a new care provider has just started visiting him. He may simply assume that the new visitor stole his coat. He may also accuse a loved one of infidelity when the latter suddenly comes to visit him.

Although the suspicion may seem a real experience for the dementia patient, never attempt to argue with him. Do not take offense on the accusations. Rather, take to heart that it is the disease that causes him to act in such a manner. As his care provider, you can

help ease the situation, no matter how difficult it may seem.

Do not take offense. Remember, it is the illness talking, not the person. Try putting yourself in his shoes and figure out what might be the reason behind the accusation. Listen to what might be troubling him, and understand the reality. And then, give the person your reassurance.

Do not argue or try to convince. Allow the person to express his ideas and opinions. Never say, “Why would I do that?” or “Don’t be silly.” These statements can only make him more confused and agitated or even angry. He would think you are not listening to him or considering his point of view.

Duplicate the “stolen” item. If he suspects that his money has been stolen, allow him to keep a small amount in his pocket. Or, if he keeps on looking for a lost wallet, buy at least two of the same kind.

Help him “search” for the missing item. Assure him that you are going to help him locate the “stolen” object. Identify the places where he usually puts his things. If you have a simple answer, share it with him. But, do not give him lengthy explanations and do not argue with him. And, even as you “search” for the

missing item together, try to distract and redirect his attention to a pleasant activity. You may also switch the person's focus even before you start searching for the "missing" object. Say, "Before we start looking for your wallet, why don't we have some snacks, then we will look for it afterward?"

Explain the situation to other household members. It's important that everyone in the house understands the changing behavior of the person. You should make it clear with every member of the household that false accusations and suspicions are brought about by the illness, and not a reflection of them.

Be generous of your non-verbal reassurance. A gentle touch, a firm hold of his hands, or a hug may do wonders to ease the person's feeling of fear and agitation.

See the person's physician. In case the person is showing a severe delusion and you fear he might hurt himself, talk to his doctor. A medical evaluation may be needed to ease the problem.

Understand that a person with dementia tries to make sense of his world - the world with diminishing cognitive ability, confusion, and fear. As his caregiver, you should be able to explain to every member of the

household how patience, love, and understanding can help the person with dementia.

## CHAPTER 10

# SUNDOWNING

Research shows that some people with dementia experience restlessness, agitation, disorientation and other troubling behaviors towards the end of the day.

While others may experience a disruption in their body's sleep-wake cycle. They may become restless and sleepless during the night. Experts call this syndrome sundowning.

Sundowning is a symptom of dementia, usually occurring from the middle to the advanced stages of the disease. It is associated with the changes in the person's internal biological clock. Other factors that are believed to contribute sundowning include:

Disorientation. A person with dementia is unable to separate dreams from reality. Non-verbal cues from the people around him. The person may be affected by the nonverbal cues of frustration from his care provider, who may be exhausted from work. Reduced lighting and increased shadows. He may misinterpret what he sees, making him afraid and confused.

As his caregiver or a family member dealing with a dementia sufferer, you can help reduce sundowning. First and foremost, try to identify what triggers the

person's confusion and agitation. For example, environmental distractions, like noise, TV, loud music, or children playing around him may upset him. To help you identify the triggers, keep a record of his daily activities, behavior, and the environment. Check the patterns of activities and environments that seem to worsen his symptoms. And then, apply these simple tips to make him calm down.

Help the person relax. If commotion around the house makes him upset, try taking him to a quieter area. If the cause of his agitation is hunger, serve his food earlier than usual, or give him a little snack or something to drink. If he makes unrealistic demands or keeps arguing with you, let him know that you are listening to him. Speak in a calm and reassuring voice.

Sometimes, too, a gentle hand massage, a stroke on his arm or a hug might be what he needs.

As much as possible, minimize the person's stress in the evening hours. Let him engage in simple activities that are not frightening or challenging. You may play soft music to make him relax, or allow him to snuggle with his pet animal.

Create a comfortable and familiar environment. For a dementia patient, the world is a scary place. So, it is important that you create for him a comfortable and

familiar surrounding to help him cope with the difficult situation.

Whether the person stays at home, move into a hospital, or transferred to an assisted living facility, furnish his surrounding with some of his cherished items. A family photo by his bedside table or his favorite coat may ease the transition and control his sundowning syndrome. Make sure, also, that his sleeping area has a comfortable temperature.

Maintain a routine. Dementia makes it hard for the person to remember new schedules. He might get confused when you introduce new things and places. It's rather advisable that you adhere to the same schedule every day. Set a regular time for his waking up, going to bed, and his meals. This will make him calmer, and have a restful sleep at night.

Organize more daytime activities. Help the person stay active during the day to promote a good night's sleep. Discourage afternoon naps. Allowing him to rest most of the day would only make him awake at night. You may go for a walk together in the park, a car ride, make him dance to his favorite music, or schedule a visit to the doctor. Encourage him to exercise daily.

Adjust his dinner portions and avoid stimulants. Refrain from giving your loved one large dinners. This will only worsen his agitation and make him awake at night. Instead, give him a light meal or healthy snack.

You may give him large meals only during lunch. Also, do not serve him alcohol and nicotine. Restrict his sugar, caffeine, and other stimulants consumption to the morning hours.

Keep the person's room well-lit. Persons with sundown syndrome need adequate lighting to minimize agitation. So, as a care provider of someone with the condition, you may put a full-spectrum fluorescent lamp about a meter away from him for a couple of hours every morning. Turn this lamp on while the person is doing some of his daily activity. This can help in getting his biological clock back on track.

Take good care of yourself, too. The sundowning syndrome can be exhausting for both the person with dementia and you. As his care provider, you must also take good care of yourself. Eat a well-balanced diet and make sure you get enough sleep at night. Take a good daily exercise, too. There is no better position to care for a loved one than a healthy and well-rested body.

You may also ask other family members to take turns with you in attending to your loved one. So, you can take regular breaks. Or, you may consult your doctor about respite care or other similar professional support services.

Seek the doctor's advice. You may discuss with the person's physician about his sleep disturbances. He may be suffering from another ailment.

Research shows that 1 out of 5 persons with dementia is susceptible to sundowning. But, this syndrome can also happen to older individuals who do not have the disease.



## CHAPTER 11

# NUTRITION

Persons with dementia do not require a special diet.

Just like everyone else, they follow the same basic rules of proper nutrition. The only difference is that the latter's deteriorating cognitive function makes eating independently and mealtimes challenging.

Why is eating and mealtimes difficult for dementia patients?

When tending to a loved one with dementia, you must acknowledge the following factors that might cause his loss of appetite.

A decrease in appetite. This situation is normal for any aging person. But dementia patients may feel less hungry because of his deteriorating body signal. He may also have difficulty in chewing or swallowing.

Inability to recognize food. As his condition deteriorates, the person may no longer recognize the food you serve him.

A decrease in sense of taste and smell. The person may not feel like eating because the food does not taste or smell as good as it was.

Poor fitting dentures. When communicating becomes difficult for your loved one, he could not tell you if his dentures are hurting him. Instead, he would just refuse to eat. Make sure, therefore, that his dentures fit well. Bring him to the dentist regularly.

Mind the medication. There are certain medications that may affect the person's appetite. Report to his doctor whatever change you may notice in your loved one's eating habits. Some dementia medications can cause constipation. Likewise, there are food and drinks that may keep his medicines from working.

Lack of exercise. Not having enough physical activity may lead the person to lose appetite and to constipate. Ensure that your loved one does simple exercises daily, like going for a walk, gardening, or any simple chores to keep him active.

Building a meal plan for your loved one with dementia

Once the person has dementia, his ability to prepare meals and eat independently becomes too difficult. And, this situation can be frustrating not only to him. But also to his care provider.

To make things easier, you can build a meal plan for your loved one to keep him well-nourished. Just remember the basics of nutrition.

Feed him with a variety of foods. Whole grains, low-fat dairy, lean protein, fruits, and vegetables are highly recommended for a balanced diet.

Control his intakes of high saturated fat and cholesterol, such as fried foods, fatty meats, solid shortening, butter, and lard. Remember, not all fats are good for the heart's health.

Reduce the person's consumption of refined sugars. Know that refined sugar does not contain vitamins, minerals, and fibers. What it has, instead, is calories. In case your loved one wants to have some sweets, you may give him fruits or juice-sweetened baked products.

Refrain from serving your loved one with too much salt. Too much sodium consumption affects his blood pressure. You may season his food with herbs and spices instead.

Let him drink plenty of water. A person with dementia has the tendency to not drink enough water. This is because his body's signal system for thirst is no

longer as strong as it was before the disease. Some medicines, too, can dry his mouth.

Watch for weight loss. Since the person with dementia tends to lose appetite or less thirsty, he is at risk of losing too much weight. And this may lead to other health problems. To prevent this situation from happening, help your loved one get enough nutrition.

Prepare foods that are easy to pick up, chew and swallow. Bite-sized foods like fish sticks, tuna sandwich, chicken nuggets, orange slices, and steamed broccoli or cauliflower are some of the items that are easy to handle. If chewing and swallowing are difficult for him, serve him soft foods like scrambled eggs, cottage cheese, or applesauce. Or, you may grind his meals. Also, take into consideration his personal food preferences. And be ready when he suddenly develop new food choices and reject those he used to like.

Serve the person some snacks or smaller meals more often. Consider that he may not remember when or if he has eaten and so he might continue asking for breakfast. In this case, serve him several breakfasts-one at a time. You may start by giving him juice. Then, give him a toast, and followed by a cereal. Allowing your loved one to eat 5 or 6 times a day may be easier than serving him the same amount of food in three meals.

Eat together. It is more enjoyable to be eating in the company of others. Make his mealtime a social event so that he may look forward to it.

Make sure that your loved one is comfortable with the utensils or dishes he is using. A spoon with a big handle and a bowl may be easier for him to use than a fork and plate. Or, perhaps, he's more comfortable eating with his hands. Don't worry about the mess he may make.

Allow the person to eat independently as much as possible. But, be ready to help when needed. Give him enough time to eat, even if it means an hour or longer to finish his meal. Tell him to chew and swallow his food carefully.

Give him a daily dose of multivitamins. But, make sure that these supplements are under the recommendation of his physician.

Poor nutrition is likely to cause or increase behavioral symptoms among dementia patients. As a caregiver, you must be keen on their eating patterns. The above nutrition tips can help boost the health of both your loved one and you.



## CHAPTER 12

# BATHING

Bathing is a private and personal matter.

It is a necessity for people, in general. But, for a person with dementia, it is the most dreadful thing to do. He often refuses, withdraws, or fights when bath or shower time comes. Many professionals and care providers claim that bathing a person with dementia is the most challenging part of their job.

Most often than not, the reluctance to bathe may be associated with some environmental or circumstantial factors, many of which can be controlled. The person might feel like losing his dignity being naked in front of others. He may find the assistance as an intrusion into his privacy. He might be afraid of falling, or of the water itself. The temperature in the room might also be a cause for him to refuse to bathe.

During the earlier stages of the disease, the person may only need a reminder to bathe. But as dementia advances, he needs more assistance. And here is where the problem arises. Having another person telling him what to do or assisting him inside the bathroom makes him feel like being tampered. And so, his initial reaction is to resist the instruction to bathe. He will either claim to have just showered or

that he will do it later. But, in many cases, the person with dementia will outright refuse to take a bath. As he is defiant, you can expect him to argue and cry.

Admittedly, trying to convince the person to bathe rarely works. But, as his care provider, you can try various techniques in getting your loved one to the water. You just have to exercise lots of patience. And most important, you should not take his offensive behavior to heart. Always remember that it is the disease that makes him behave the way he does, not the person.

Here are a few tips that might help ease the struggle in bathing a person with dementia.

Determine which kind of bathing he enjoyed in the past. If he is used to a shower, do not insist on using the tub. And if he used to go down the tub, do not attempt to give him showers. And if he so prefers it, you may allow him a sponge bath at the sink once in awhile.

Suggest bathing at the time of day the person is most cooperative. Determine when he is in good mood or most relaxed. Although, there are occasions when you are more successful inviting him to bathe in the afternoon, most persons with dementia cooperate well when their bath is done in the morning. Probably

because they are made to change clothes once for the day.

When the person refuses to bathe, do not be too anxious. Wait for a while and try again. Give him a choice before taking him to the bathroom. You may ask him something like, “Do you want to bathe now or in 15 minutes?” Don’t force him to do as you wish. It could be dangerous for both of you.

Once you have established the best time to bathe, make it his routine time for bathing. Otherwise, he might get confused when you change the schedule.

Make the bath area appear familiar, comfortable and non-threatening.

If the person is in a care service facility, try to replicate or change the shower or bathing environment to look and feel like home.

Install grab bars, a handheld shower head, and put non-skid mats on the bathroom floor.

Place a shower or bath chair that can be adjusted to different heights.

Make sure that the room temperature is tolerable for the person. It should not be too cold or too warm for him.

Check the water temperature. He may withdraw if he feels the water is too cool for him.

Or, he may not sense that the water is too hot.

Pad the shower chair and other cold surfaces with a towel.

Prepare the bathroom and all bathing supplies in advance.

Remove clutter.

Cover or remove the mirrors in the bathroom to dispel his suspicion of a stranger in the room.

Keep the razors and electric dryers out of the person's reach.

Make sure the temperature in the bathroom is warm and well-lit.

Arrange the soap, shampoo, washcloth, towel, robe, and clean clothes in sequence. These items should be within your reach. If needed, you may consider using

a towel warmer and towel blanket to wrap him in after bathing.

Let the person get into the bathtub with only 2 to 3 inches of water in it. Fill it up only after he gets comfortable in it or after he is seated. For his safety and yours, make sure that it's easy for you to get your loved one out of the tub after his bath.

Undress him gradually. If he uses the toilet before bathing, take the pre-existing opportunity to start undressing him. While he is sitting, remove his clothes that are already partly off first.

Simplify the steps of bathing or showering. Do not rush. Give the person a role in the process, like letting him hold the shampoo bottle or the washcloth. Just be sure the bottle is unbreakable. Use the washcloth to cover his eyes to prevent stinging.

Be gentle in washing the person. Do not scrub if his skin is very sensitive.

Adjust the spray on the shower head so that its pressure is as soft as possible on his skin.

Keep the person's privacy and dignity in mind. Use the curtains to let him know you respect his privacy. You may also cover him with a bath towel while undressing. Let him hold a towel in front of his body

in and out of the shower if he so prefers it. It would also help if a familiar person of the same gender assists him in bathing.

Dry the person while he is seated. Drying him while he is seated reduces the fear of falling. It's also safer for you, as well. Do not rub him with the towel. Instead, pat him dry to avoid hurting his sensitive skin. Then, start the dressing process.

Give praise. Compliment the person on how good he looks and how nice he smells after the bath. You may even offer a reward, like a ride in the car or his favorite food.

If bathing is a constant battle, you don't have to bathe the person every day. You can give him a sponge bath on the days between bathing.

You may also be interested in towel bathing as another option for giving a bath. Refer to the book *Bathing Without a Battle* (details in the Recommended Reading section below).

## CHAPTER 13

### DRESSING

As dementia advances past the early stages, choosing what to wear and putting them on can be a challenging task for the person.

He may have forgotten how to dress or may be confused over the choices of clothing. His deteriorating motor skill in fastening buttons may also pose a problem for him.

Nevertheless, it is still important that the person should be given the freedom to choose what to wear for as long as he can. Letting him choose his clothes retains his sense of personal style and identity. But when he does need assistance, you must offer it with utmost tact and sensitivity.

Here are some tips that might help you plan when dressing or grooming your loved one with dementia.

Ask for his choice. When possible, ask the person what he wants to wear. This way, he feels a sense of dignity and importance. If he finds it difficult to choose, you may suggest his favorite color or clothes. Or, offer him a choice of only two options.

Limit his choices. If the person has a lot of clothes, remove those that are not frequently used. He may panic seeing so many clothing choices.

Organize the dressing process and encourage independence. As much as possible, allow the person the freedom to dress.

Choose simple and comfortable clothing. Shirts and cardigans with the buttons in front are easier to work. It is even more comfortable for the person if he wears loose fitting clothes.

Arrange his clothing in the order that each should be put on. Make sure that the background where you place his clothing on is non-patterned to avoid confusion.

Undo zips, buttons, and fasteners before he starts dressing.

Ensure that all the items are not inside out.

Hand him one piece of clothing at a time. And give simple, direct, and step by step instructions. Instead of telling him to “get dressed”, you may say, “put your arms in the sleeves”. It helps if you use gestures as you give the instructions.

If he makes a mistake in putting an item on the wrong way or position. Be patient and tactful in correcting him.

Help him stay comfortable.

Make sure that the temperature of the room where he gets dressed in is comfortable. The room's lighting levels should also be suitable for him.

Ask the person if he wants to use the toilet before getting dressed. If the person has a balance problem, make him sit on a chair with arms.

Observe privacy. Close blinds and curtain in the room. Also, see to it that no one walks in and disturbs him as he dresses.

If he insists on wearing the same outfit over and over, buy duplicates or offer similar options. Do not mind even if his outfit is mismatched. Just focus on the fact that he was able to get dressed and had kept good personal hygiene. This is more important than developing a urinary tract and other infections from poor sanitation.

Allow him if he wants to wear several layers of clothing. But make sure he does not get overheated.

When going outdoors, make him dressed for the weather.

Let him wear a non-slip and comfortable shoes.

Your loved one should change his clothes regularly. A person with dementia would sometimes refuse to change his clothes or may be reluctant to undress. To persuade him to change his clothes every day, you may apply these tips:

Tell the person you love seeing him wearing something new.

Encourage him to dress for certain occasions.

Put away dirty clothes and put clean clothes in its place when he is in the shower or when he goes to bed.

Make dressing a positive experience for the person with dementia. Compliment him on the way he looks. Encourage him to take pride in his appearance.

## CHAPTER 14

# HALLUCINATIONS AND DELUSIONS

Hallucinations and delusions are two conditions that may occur as dementia progresses, particularly in the later stages of the disease. These happen due to the changes in the person's brain.

Hallucination is the state of seeing, hearing, or feeling things that other people do not perceive. A person with dementia may see, hear, feel, taste, or smell something that is really non-existent. For example, he may insist seeing an insect crawling on his leg.

Delusion, meanwhile, is a false belief or idea firmly maintained due to a misinterpretation of a situation. For example, the person with dementia may suspect that a loved one is cheating on him, or a family member is stealing his money. This kind of delusion is sometimes called paranoia.

Remember, however, that not all hallucinations are scary. Likewise, not all delusions should be equated with paranoia.

When your loved one experiences hallucination or delusion, be cautious in dealing with him.

See his doctor. The best way to start is to consult with the person's physician. It's important that you coordinate closely with his doctor to help determine the appropriate intervention to make. His behavior might be caused by certain conditions like bladder or kidney infection, pain, or dehydration. A history of serious mental illness, like schizophrenia, might also have something to do with his hallucination or delusion.

It could also be that a medication he is taking causes his hallucinations or delusions. In this case, you may ask his doctor to evaluate the person to determine whether a medication needs to be adjusted, added, or reduced. Also, have the person's eyesight and hearing checked regularly.

In whichever case, and if the doctor prescribes a new medication, watch for any reaction and side effects on the person. Report any reaction you may notice, such as tremors, over-sedation, or heightened confusion.

Non-medical solutions. There are cases when the hallucinations or delusions are not due to any of the above-mentioned medical problems. In which case, try to assess whether or not the hallucination or delusion upsets the person. Does his behavior lead

him to do something dangerous? It could be that a sight of some unfamiliar faces frighten him.

Respond with caution. If the person does not cause a problem for himself, for you or other family members, you may just ignore his hallucination or delusion. Do not intervene unless his behavior becomes dangerous.

Find out the feeling behind his hallucination or delusion. You may respond by saying something like, “It sounds like you are worried.”

Act calmly and quickly. Be supportive. You may give words of assurance, such as, “Don’t worry. I’m here to take care of you.”

Give him a gentle touch. A simple gesture of patting his hand may divert his attention from the hallucination as he turns his attention toward you.

Do not argue with the person about what he sees, hears, or believes.

Distract the person. You may invite him for a walk together. You may also suggest that he does some activities, like listening to music, looking at a family photo album, or gardening. Or, you may invite him to another room where there are some other people.

Usually, a frightening hallucination or delusion diminishes in well-lit rooms. But make sure that the lighting does not cast shadows or distortions on the floor and walls.

Remove or cover mirrors with a cloth to dispel his belief that a stranger is watching him.

Check for sounds that might cause a misinterpretation, like a noise from the air conditioner or the television.

Be honest. When he asks for your confirmation, like, “Do you see it?”, avoid getting involved in an argument. Instead of giving him an outright “No”, you may say something like, “I know you are seeing something, but I don’t see it.”

Remember that the person suffering from dementia is trying to make sense of his world. And so your patience, support, and love are profoundly needed in this most challenging phase of his life.

## CHAPTER 15

# INAPPROPRIATE SEXUAL BEHAVIOR

Some persons with dementia may display inappropriate sexual behavior at any stage of the disease. Although it is not widespread, the conduct is potentially disruptive to the family, caregivers, and the patients themselves.

A sexually active individual in the past remains active during his early stage of dementia. And so, he continues to enjoy the experience. In other cases, an emotional distress that the person went through in the past may cause him to sexual withdrawal and feelings of inadequacy, or anger and resentment due to sexual problems. Another factor that causes his inappropriate sexual behavior is physical discomfort.

As the dementia advances, the person may forget how to make love anymore. He may become less considerate of his partner's needs. Thereby, he may demonstrate aggressive and inappropriate sexual activities. He may also forget that he has just engaged in a sexual activity and demand more relations. And if denied, he might get angry, confused or disoriented. The person may undress or attempt to undress in public, fondle, and masturbate in unsuitable places.

He may even expose his private parts and try to have sexual acts with other than his partner. Or, he may direct his sexual desires to his own children, professional caregiver, and other persons due to confusion.

## **HOW TO HANDLE AN INAPPROPRIATE SEXUAL BEHAVIOR?**

As a care provider, you must understand that the inappropriate sexual behavior in your loved one is due to the damage in the frontal and temporal lobes of his brain. Such damage disrupts his ability to control responses.

Admittedly, there is no single best solution in adjusting to the changing behavior of a loved one with dementia. But there are effective ways of handling inappropriate sexual behavior.

Stay calm and be patient. Do not argue with the person. If the act is done in a public place, lead him to a quiet area. If the inappropriate behavior occurs at home, guide him to the bedroom. But tell him gently and firmly that his actions are inappropriate. Hugging or holding his hands gives the person an assurance that he is being loved and cared for.

Determine the triggers. You can do this by keeping a record when his inappropriate sexual behavior occurs. Take note of his regular use of the toilet. Check for signs of urinary tract infections or constipation. These may be causing him discomfort.

Distract or redirect the person's attention. Employ distraction and redirection tactics. Ignore his behavior and lead him to more meaningful activities and change the topics. You may invite him to take a walk, eat some snacks together, or look through some photos to reminisce fond memories.

Specially-designed clothing. Buy specially-designed shirts that close at the back to make disrobing difficult for him.

Be also aware that the person may blurt out crude sexual remarks at you or at anybody else around. Thus, your understanding and patience are important in handling your loved one's inappropriate sexual behavior. You must also educate others that the behavior is due to the damage to the person's brain in order to avoid misunderstanding and confrontations.



## CHAPTER 16

# VERBAL OUTBURST

Ninety percent of people with dementia are likely to exhibit verbal outburst in the later stages of the disease.

They may throw a fit due to a frustrating situation or for no apparent reason at all. They curse, argue, and threaten anyone when angry or stressed out. This behavioral psychiatric symptom is found to be the most challenging and distressing effect of dementia. Because of this worsening condition, families of the dementia patient may now entertain the idea of moving him to a residential care.

The most common intervention to ease the verbal outburst is to administer medication. Pharmaceutical treatments can significantly reduce or stabilize the symptoms. But sometimes, medications can rather cause an increase in the symptom being treated. Thus, putting the patient at greater risk.

Fortunately, there are non-pharmaceutical options that work much better. These types of interventions have been proven to have fewer side effects.

Physical evaluation. Conduct a physical evaluation on the person. If he has just been given a new medication

or taken off one that he has taken for a while, there will certainly be some reaction on his part. Constipation, infection, injury, pain related to arthritis, or other medical problems may also cause his agitation.

Identify the trigger. Most often, a person with dementia reacts to certain environmental alterations, such as:

- The presence of house guests
- Change in his living arrangements
- Alterations in his routine
- Hospitalization
- Travel
- A new caregiver

Bathing and being asked to change clothing can also trigger agitation and anger. Likewise, under-stimulation can be a problem for the person.

Redirect the person's attention. Do not disagree, argue, or be confrontational with your loved one. Instead, look for ways to divert his attention from his disruptive behavior. You may apply any of these strategies:

Play a soft and relaxing music, especially during meals or bathing. Employ pet therapy. Give him a massage.

Allow the person to look through photographs of family, or familiar people and places

Allow enough rest in between stimulating activities.  
Provide adequate lighting to lessen confusion and restless nights

Assess the caregiver. Whether he is in a long-term care facility or in a home environment, the dementia patient can be affected by the disposition of his care provider. If the caregiver is feeling stressed or not in a good mood, he will surely pick up on this as well.



## CHAPTER 17

# SHADOWING

Shadowing refers to the situation when the person with dementia constantly follows his care provider around.

He may mimic him and go wherever he goes. He may peer down at the caregiver while he sleeps. He becomes worried when his caregiver spends time away from him. He may even tip-toe lightly and peer around corners to make sure that his care provider is always in sight.

This behavior occurs during the later stages of the disease. It happens due to the person's feeling of uncertainty and anxiety. He feels like his caregiver is his one safe refuge. Like a small child to his mother, the person with dementia becomes totally dependent on his caregiver. The moment the latter is out of sight, he becomes upset and angry.

While shadowing is not as challenging as the other behaviors that the patient exhibits, it can be a problem on the part of the caregiver. The caregiver may find it annoying, leaving him with a feeling of claustrophobia and without privacy. He can no longer do his personal matters, like going to the bathroom without interruption.

## Coping up with shadowing

Although it may be difficult to be always followed around, you must always remember that the person you are tending to is afraid and anxious. Recognize that his shadowing behavior is a reaction to confusion and anxiety.

To ease your frustration, you may apply some strategies in dealing with your loved one.

Give him a sense of security. With reassuring words, tell him something like, “You are safe.” “Everything is going to be alright.” “Don’t worry, I am here to protect you.” Say these words every day in a calm and loving voice. Make sure your words are simple, short, and the same.

Organize predictable daily routine. Keep your loved one busy with familiar and uncomplicated activities in a calm environment.

“Cereal therapy” or “gum therapy”. Divert his attention from constantly following you by giving your loved one some food to snack on or a gum to chew. Just make sure the snack you give is not likely to cause choking.

Play music. You may give the person headphones from which he can listen to his favorite music. It has been proven that music tremendously benefits people with dementia.

You may also make a recording of your own voice speaking reassuring words to him. Familiarity can be calming and relaxing to your loved one.

Set a timer. When you need to go to the bathroom or spend some alone time, you may set a timer. Set it for as long as you want to be in the bathroom or at rest. Let the person hold the timer and make him wait for it to ring. Return within your loved one's sight when the timer goes off.

Find a way to escape periodically. No matter how dedicated, loving, and patient a caregiver you are, you also need some time off. You need to take a break to keep your emotional well-being, and to be relieved from stress. Ask other family members to tend to your loved one while you are away. You may also ask a neighbor, whom you trust and who is familiar to the dementia patient, to take a walk with him for a couple of hours.

If necessary, make an audio tape of your voice for him to listen to while you take a break. The tape should contain some short and meaningful stories

from your loved one's past. Again, the tone of your voice must be reassuring and calm.

Keep in mind, however, that what strategy works today may not work tomorrow. And what didn't work yesterday may work perfectly well the next day. Just be patient and creative in finding ways to distract the person from following you all the time.

## CHAPTER 18

# DIFFICULT BEHAVIORS

When the person enters the later stages of dementia, his behaviors become more difficult to handle.

He can act in an agitated and aggressive manner. You usually encounter these problems during bath or shower time, or in reaction to an overstimulation in the environment.

Other triggers to problematic behaviors include physical discomfort, frustration over not being able to communicate or do something he pleases, and alterations in his routine. Sometimes, too, the patient exhibits certain behaviors, like refusing help and hoarding. He would just refuse any help or he may only accept help from a specific person. It is also not uncommon for him to hoard food or other items, keeping them underneath mattresses, inside jars, or in dresser drawers.

As his caregiver, remember that his sense of reality may now be different from yours, but it is still real to him. Usually, the environment you create around him can make a huge difference. While you cannot change him, you can employ some strategies to ease any behavioral problems.

Examine the behavior and validate his feelings. Remember that the person has a deteriorating brain function that shapes who he has become. Instead of attempting to control him, try accommodating his behavior. If for example, he insists on getting the car keys, you may say something like, “Yes, you will surely have it as soon as the mechanic is done with the car.” Don’t answer him with a flat “No.”

Also, look at the behavior from a different perspective. You may want to try putting yourself in his shoes so you may better understand his feelings. Remember, you cannot change the person’s behavior. But you can change your own behavior or the physical environment around him.

Introduce pleasant stimuli. You may suggest looking through an old photo album and relive the good memories he had. You may let him listen to his favorite songs, or give him some food to snack on. The important thing here is to divert his attention from what upsets him.

Consult the person’s physician. In many cases, behavioral issues have something to do with the person’s feelings or discomfort. He may be in pain or having an adverse reaction to the medication he has been taking.

Determine the proper approach. Sometimes, his refusal to accept help from other persons is just a matter of how he is being approached. If you are the reliever of his caregiver, you must carefully explain your presence. Tell him when his caregiver is coming back. You may say something like, “Your regular caregiver is coming back in a little while. In the meantime, I’ll help you out until she returns.”

If the person is worried about upcoming activities, like a visit to his doctor, and does not want to cooperate, you must refrain from giving him advance notice about it.

Sometimes, too, the dementia patient refuses to cooperate because he feels like losing control over things. In this situation, it may be helpful to give him a task to do.

Adapt to his behavior. When a patient keeps on hoarding food and things, do not confront and correct him. Instead, try adapting to it. Limit the number of hiding places by locking drawers, cabinets, and closets that are not frequently used. Check the places where he usually hides food and other items, including the trash and laundry bins.

There is no doubt that caring for a person with dementia is a challenging job. Dealing with the

different extreme behaviors can be stressful. But even then, care providers must understand that these actions are coping tactics of a person with deteriorating brain function. You must be equipped with patience, understanding, and enormous love for the person if you are to be an effective care provider. After all, the life of a dementia patient is a journey in which you are his trusted companion.

## CHAPTER 19

# KEEPING YOUR PATIENT ENGAGED

Your dementia patient/loved ones will eventually lose the ability to participate in their hobbies and lose interest in doing things.

Inactivity, not exercising and decrease in mobility will eventually result in behaviors, agitations and decrease in quality of life. Here are some tips you can use to increase their participation level.

- Identify your patients current level of function or stage. Are they in early, middle or end stage of mobility or activity level. Early stages mean, they can complete simple task with minimal cues. Middle stage is they can do task with cues, one step at a time. End stage means, they only respond to certain cues and feedback such as visual, sound and touching cues.
- Activities doesn't have to be complicated. You can start an activity by doing everyday task such as making a sandwich, combing hair, fixing the table, washing hands. Etc....

- Find the right activity for your dementia patients. The simpler the better. Find a physical therapist or an occupational therapist to make things for you. Some patients are unable to read books, maybe start with reading a greeting card. Some patients are unable to do complicated puzzle, try using 10 piece or 5 piece puzzles.
- Always provide a structure routine and environment. Make a morning routine, a lunch, evening and sleeping routine. The more structured it is, the more they are relaxed.
- Also take into consideration on patients past interest. The more they are familiar with it, the more they will likely enjoy the activity.
- Try doing half-done activities, like when making sandwich, finishing puzzle and setting the table. Empower your patients, include them in simple decision making skills.
- Don't be too tight. There is no right and wrong in activities. It is not about finishing or completing these activities. It is about initiating and enjoying the time with your loved ones.

## CHAPTER 20

# CARING FOR THE CAREGIVER

I have seen so much caregivers got burned out from taking care of their loved ones.

One thing I always tell them is that, you cannot give what you do not have.

You cannot give money, if you do not have money. You cannot give love, if you don't love yourself. You cannot give care, if you don't take care of yourself first.

I remember, when riding in an airplane, the stewardess will always tell us to help ourselves first just in case there is a change in cabin air pressure. They will tell us to put our oxygen mask first before putting or helping other people. Caring for yourself is also very important and is one of the most forgotten things we do as a caregiver. When you take care of yourself, you take care of your loved ones too!

We are now seeing more and more caregivers who are putting their health and wellbeing at risk. If you are a baby boomer and have assumed a caregiver role for your spouse, parents or sometimes children. You will simultaneously try to balance work and family. You will face a higher risk of depression, sickness and

decrease in quality of life due to this new situation you are having.

I have been actively engaging myself in some of the dementia groups in Facebook and have seen caregivers who complained about unable to sleep, poor eating habits, failure to exercise and failure to basically take care of themselves resulting to being sick themselves.

We cannot really stop the progression of dementia. But there is something you can do, take responsibility for your health and well being.

Most of the time, we have beliefs and barriers that is in our way in taking care of our loved ones. Sometimes we think that, i would rather take care of mom or dad than take care of myself. However, as a caregiver, you must always ask yourself. “How can i take care of mother or father if i become sick?” Sometimes, we have to accept some truth to remove these barriers we see in ourselves.

Remember that, it is not selfish to focus on your own needs and desires when you are a caregiver. Here are some things you can do to improve your self. Learn to exercise, meditate, do yoga or tai chi. Take care of your health! Go to your doctor. Get proper rest and nutrition. Get plenty of fluid, exercise and sleep! Take

time off. Get some help. Take your family to daycare. Accept and seek the support of others. Read a book. Learn learn learn more about dementia. Seek counseling. Talk to your pastor, friend or counselor. Focus on the good and not on the bad. Focus on what you have and not what you don't have. Remember what Henry Ford said, whether you think you can, or you think you can't, you are right!. This is also goes in taking care of our dementia patients and loved ones. If you think you can't change their lives, you are right. But if you think you can change and impact and touch and improve their lives, you are right!

Again, caregivers are at high risk for depression and use of tobacco, drugs and alcohol. It can be an emotional roller coaster ride. Your life will go up and down. Fast movements and slow movements. But what matter is keep moving forward and just enjoy the ride.

But on the other hand, caring for your loved ones also demonstrates commitment, love and patience and can be a very rewarding experience and can be a story that can be told to your future family. I would like to encourage you today that this test that you are encountering, is actually a testimony for other people. That this story or situation you are going through can be a good testimony. You can share your story to other people and help them how to cope up with

other family that are also encountering this horrible disease. Remember that every time you encounter a big challenge. Be encourage that, the bigger the challenge in dementia, the bigger the victory in caregiving. That every setback in dementia caregiving is actually a setup for more understanding on this disease. That every stumbling block in dementia caregiving is actually a stepping stone to further understand this disease. And that hopefully, someday we can really ~~Mis~~Understand Dementia.

## ABOUT THE AUTHOR

Dr. Michael Chua is a physical therapist practicing in Home Health, Skilled Nursing Facilities and Acute Care Hospital.

His clinical interest involves pain management, geriatrics and dementia management. He enjoys treating patients and bringing out the best in them using positive treatment approaches, his dynamic work setting in a rural area provides an opportunity to treat a wide range from geriatrics to orthopedics.

He is also the Chief Inspirational Officer for [TN Therapy Outsource, LLC](#) and the author of [MisUnderstanding Dementia](#)

Dr. Michael is also a Certified Dementia Practitioner that helps bring out the best in his dementia patients and their caregivers. Dr. Michael helps them clarify their goals in life, prioritize task and establish new behaviors not only for his patients, but as well as for the caregivers so they can achieve their highest and maximum functional potential towards their care and in LIFE.

Dr. Michael has experienced several challenges in life while treating dementia. His first experience with a

dementia patient was his grandmother. He had a hard time managing and taking care of his grandmother. He didn't know what to do. He didn't know what was going. So he decided to be in the medical field. Researching how and what causes this disease. As of now, there is no treatment for this disease. What we can do for now is to continue to care for them and educate the caregivers on bringing out the best in them.

He received his Bachelors of Science in Physical Therapy from University of Perpetual Help Rizal 1999 and his Doctorate in Physical Therapy at University of Incarnate Word at Texas 2014 wherein he graduated *Cum Laude*. He is a Certified Clinical Instructor, a Certified Dementia Practitioner and a Senior Fitness Specialist. He is a member of American Physical Therapist Association, Tennessee Physical Therapy Association, National Council of Certified Dementia Practitioners, International Council of Certified Dementia Practitioners, Academy of Filipino-American Physical Therapist and National Academy of Sports Medicine. Michael stays up to date with the latest physical therapy and dementia redirection techniques by attending various continuing education seminars to provide an evidence based and cost effective treatment.

Dr. Michael is married to Puppen and are proud parents to Alyssa, Akeisha and Izaiah. Currently, Michael and his family lives in Martin, Tennessee.