

PAC™ Profile: This is ME Sheet

(Add a current photo/head shot)

Preferred Name: _____ **Language Skills:** (native tongue) _____

GEMS® State: _____ **Hearing:** Deaf HoH 1:1-OK Group-OK

_____ **Comprehension:** None 1-word Simple OK

Personality traits: _____ **Speech:** None Nonsense Echo Repeats Accurate

___ Introvert (private, alone time, SPACE, quiet)

___ Extrovert (common areas, talking, close, touching)

___ Mixed _____

Overall Activity Preferences: ___ Doer ___ Talker ___ Watcher

Sensory Preferences: (little/lot, same/different, details) **Sensory Dislikes:** (speed, variety, types, specifics)

Sights _____ Sights _____

Sounds _____ Sounds _____

Touch/Physical contact _____ Touch/Physical contact _____

Movement _____ Movement _____

Smells _____ Smells _____

Tastes _____ Tastes _____

Productive – Work/Jobs – Valued Roles

History:

Current Possibilities:

Leisure – Play – Fun (Passive activities & Active activities)

History:

Current Possibilities:

Wellness – Self-care – Physical Fitness & Brain Fitness

History – Body Fitness:

Current Body Possibilities:

History – Brain Fitness:

Current Brain Possibilities:

Rest – Restorative – Re-energize – Spiritual

History:

Current Possibilities:

Major Life Events of Note: (positive or negative) _____

Favorites:

___ animals ___plants/flowers ___music

___ people/children/babies ___belongings/objects

___ places/scenery/landmarks or pictures/art

Major Dislikes:

___ animals ___plants/flowers ___music

___ people/children/babies ___belongings/objects

___ places/scenery/landmarks or pictures/art

Practice Tools: PAC™ Consultants

Recognizing GEMS® States Behavior, Language, Interests, and Responses

Watch someone at ease and during 1-3 activities (mealtime, personal care task, and a leisure or productive activity) and then identify which GEMS® State the person is and explain why. Try this activity with others who are having a hard time seeing it from another's perspective.

Gem State	Activities Observed	Behaviors Noted	Language Noted	Responses Noted	Interests Noted
Sapphire					
Diamond					
Emerald					
Amber					
Ruby					
Pearl					

Rating:

- Identifies GEM® States – accurately and completely
- Understands the general idea, but still needs some guidance or help with specifics
- Doesn't seem to have the GEM® information available to use in daily interactions

Practice Tools: PAC™ Consultants



Behaviors and Medications

Medication List

Medication	Used to Treat	How Long On? Change/New	Dosage	Possible(-) Side Effects

Thoughts about Meds/Impact on Behavior or Issues:

Recommendations:

Follow-up:

Teepa's Thoughts: Dementia Meds

A Layman's Explanation of the Drugs Commonly Used in Dementia Treatment



Teepa Snow, MS, OTR/L, FAOTA

First of all, I am not a medical doctor or a pharmacist, but I have been around many of them and have spent a fair amount of time trying to be clear about what medications and drugs do when someone has a condition. So if you want medical info, I am not the person to talk to, but if you want my ideas...here they are.

As far as the drugs go, let me share what they are for and how they work in layman's terms. First of all, they are not meant to change the disease process at all. They don't actually have any way to slow down the changes to the brain that come with Alzheimer's or other types of dementia. They also don't continue to work for cells that are so impaired that they stop sending messages or die. What they do, do (this is a simplified version): Brain cells don't actually touch one another, so to send messages and communicate they have main bodies and then arms that reach out toward other cells and fingers on the ends that form synapses or close connections with other 'fingers' – without actually touching. When one brain cell gets a message, it gets excited and produces chemicals that it shoots out the fingertip and sends over to the next brain cell's fingertip where the chemical hooks on to the next cell's tip and gets that cell excited.

Now, brain cells produce lots of different chemicals to send messages. The chemical that we are most interested in when it comes to dementia is acetyl-choline (it helps with learning and memory formation & retrieval). But here's the problem...if we only had the chemical attach to the next cell, we would only be able to send one message and then the fingertip would be 'locked up' and would not be able to get any other messages. Fortunately, we are made in an amazing way. As soon as we send the first chemical out to send the message, our brain cells also produce another chemical, an enzyme. The enzyme's job is to go over to the locked connection and get the chemical to release and come with it, so the fingertip of the brain cell is ready for another message. The fancy word for the enzyme involved in this action for acetyl-choline is acetylcholinesterase.

When most dementias hit, brain cells do two things. They get sick internally so that they produce less of the chemicals, especially acetyl-choline. AND they start shriveling up and shrinking. This causes the junctions and connections to be further apart and less well connected. The result is that even though a brain cell is trying to communicate with the others, it is making less chemical and it is having trouble getting the chemical to the next brain cell. Because the enzyme is still produced at the same rate and is still active and effective. So what happens is that it destroys or hooks up with the acetyl-choline BEFORE it sends the message, rather than after.

The drugs, Aricept, Exelon, and Reminyl (different formulas) have a main action, they TRICK the enzyme into hooking onto them rather than hooking on to the real chemical, so they allow more acetyl-choline to stay active, get messages through, and brain cells to keep communicating, AS LONG AS THEY ARE ABLE. So the drug is a decoy. They are called acetylcholinesterase inhibitors. They are only helpful when cells are still active and only if the person is having LOW levels of acetyl-choline. So as the disease progresses and different parts of the brain become more involved, these drugs may be helping those cells share their messages by keeping the enzyme from interfering. It looks like about 1/3 of everyone taking the drug benefit significantly from it and it helps them function at a higher level than they would be able to otherwise. For another 1/3, it probably helps a little, but not as much. Probably not enough to make it worth the amount of money it costs. And the last 1/3 it isn't helping at all, and the side-effects or negative impact on other organ systems that also use acetyl-choline in their activities (cardio-vascular system, urinary system, digestive system) make it not a good option. Namenda is a different drug. It first came out as Memantine in Europe and had about 10 years of research over there before it made it to the US. Namenda has a different function.

Another problem for brain cells as the disease progresses is that some brain cells start picking up too much of a chemical called glutamate. Glutamate is active as a 'fuel' for cells to get messages sent and heard. The problem is that with many dementias cells start getting too much glutamate in the mix and then they get HYPER-EXCITED and when cells stay hyper-excited for too long, they get sick and die. The other problem is that hyper-excited cells don't work well and don't listen or send messages as well. So Namenda has the ability to keep cells from picking up too much glutamate. It is called a glutamate moderator. It is supposed to help cells get the 'just right' amount of glutamate. Research has shown, however that it doesn't change the course of the disease. It can't really stop cells from dying, but it may help them perform better while they are alive.

The studies that have been done, seem to show the better results if it is used with one of the other medications (acetyl-cholinesterase inhibitors). The benefit is generally limited, but in this condition we are often looking for any positive glimmer we can find. For all the medications, it is really a trial and error process to figure out what works better for that person, at that point in the disease. I do think everyone should be given a try on the medications, because they may help and they may make life a little easier for them. The main thing is that we want to make sure we start LOW and go SLOW to try to reduce the impact of side effects and so that the person has time to adapt to the changes. These drugs are not just 'brain cell' drugs. They can and do affect other systems.

PAC Consultant: Changing Ability

Changes in Ability OR Challenging Behaviors: What Does Your Person Do?

Decision Making Problems:

- Won't pick a health care POA (Power of Attorney) or discuss advance directives
- Won't allow financial guidance and doesn't have a financial POA
- Won't go to the doctor
- Won't let anyone go with them to the doctor
- Won't see another doctor
- Hiding dirty or wet clothing or pads
- Stopping up toilets or sinks with soiled items

Understanding, Way-Finding and Memory Problems:

- Has *lost* important things – checkbook, money, jewelry, purse, bills, receipts....
- Has accused others of taking or hiding 'lost' items
- Gets lost in the car
- Gets lost while out in the community
- Can't find the bathroom or other room in the house
- Gets lost in a familiar store or other place

Time Awareness, Attention, and Safety Problems:

- Burns pots or pans – can't make familiar foods correctly
- Puts spoiled food back in the fridge – lets things set out or stores them in the wrong places then uses them
- Accidents while driving – fender benders, bumps in lots, *dings*
- Problems with driving – citations for errors or speeding
- Breaks or *messes up* equipment or appliances
- Does tasks with poor safety awareness
- Mistakes medicines

Loss of Short term/Immediate Recall Skills:

- Calls you over and over
- Tells you the same thing over and over
- Calls others with the same message, over and over
- Does not do tasks that normally they did... shower, bathe, groom, change clothes, eat meals.... unless prompted
- Making up stories – theft, abuse, neglect, visits, conversations...(confabulation)

Loss of Routines, Circadian Rhythm, and Self-Awareness Skills:

- Refuses to do things... shower, change clothes, shave, groom, take off coat, go to store, go to bed
- Refuses meds – “don’t need them”, “aren’t mine”, “I feel too bad”
- Wanting to do something again, although it was just done (not remembering they just did it)

Loss of Ability to See from Another’s Point of View and Understanding:

- ***Bad mouthing*** you to others
- Resisting care – fights when you try to help (verbally or physically)
- Swearing and cursing
- Making 911 calls – without good reason
- Making 911 calls – with false reports
- Mixing day and night – up all night, napping during the day
- Mixing day and night – up for long stretches sleeping only a little
- Night time wakefulness after only a couple hours of sleep
- Shadowing – following you around constantly – doesn’t want you out of their sight
- Threatening caregivers – physically or verbally
- Striking out at others – with some provocation
- Striking out at others – without provocation
- Being rude – saying things loudly or to others about their looks or actions, racial slurs, comments about others

Object Confusion- What is seen doesn't match what they do/know:

- Not recognizing who you are to them
- Misidentifying other people who they *should* know
- Misusing objects, tools, utensils
- Playing with food rather than eating it
- Making messes when trying to do something without guidance or help
- Making errors in dressing or bathing – leaving things out or skipping steps - (leaving night things on and putting clothes on top of them, inside out, layering)

Need to *DO Something* – Inability to Do What They Used To – Stuck:

- Eloping – going off on a mission – to another place, time, & situation
- Wandering – roaming off thru an unlocked or open door
- Getting *into* things – handling and *messing* with things
- Shredding or tearing things apart
- Packing – *going home*
- Moving things from place to place
- Collecting and gathering things – hiding them in strange places
- Taking things from restaurants or stores... from sugar packets or silverware, to shoplifting

Unaware of Others and Private vs. Public Settings – OK vs. NOT OK:

- Approaching others too *intensely* – children or people in public places
- Undressing in public settings
- Touching *private self* in public setting
- Seeking intimacy or talking about sex
- Touching caregiver in intimate ways
- Making comments about others bodies or sexual content in conversations
- Urinating or having BMs in the wrong places

Not Engaging in Life:

- Apathetic – doesn't want to do anything
- Just sitting around or going back to bed unless ***forced*** to do something
- Ignoring others or closing eyes when in groups
- Feeling ***sick*** – complaining about physical health – no illness that the MD can find

Hallucinating:

- Seeing things and people that aren't there, but not scary
- Seeing things or people that scare or frighten them
- Hear voices or sounds
- Feel things that you can't see or find

Not Processing Internal Cues (or at least not *in time*):

- Drinks a lot – too much
- Eats a lot – too much – gaining too much weight
- Won't eat or drink
- Not hungry or thirsty
- Not safe swallowing – aspirating – choking, not coughing
- Putting too much in their mouth at a time
- Not chewing things up
- Pocketing food in cheeks

Communication Problems:

- Talking like they are younger than they are
- Saying that you or others are out to hurt, kill, or harm them
- Not talking at all or very little
- Not making sense when they talk
- ***Jabbering*** all the time
- Calling out for ***help*** - not able to say what they need
- Yelling during care or movement
- Not doing a task they agreed to – says “Yes”, but then doesn't DO anything
- Not matching task ability – says “No”, but then turns around and does it

Movement Problems:

- Having trouble going up or down stairs safely
- Having trouble getting in or out of the car
- Having trouble with getting out of or into bed
- Having trouble moving safely – falls – getting hurt
- Having trouble sitting down or getting up
- Having trouble walking
- Having trouble keeping their head up
- Having trouble sitting up safely
- Having trouble moving at all – contractures forming

PAC Consultant: Time to Change?

How Do You Know When It's Time? What Should You DO?

Three major factors to consider:

1. Safety
2. Ability
3. Engagement

Safety: Primary issue – Does the person's ability to judge risk and ability match previous skills and are you comfortable with it?

- How safe is the person where they are? Physically? Cognitively? Emotionally? Socially? Spiritually?
- Do they still have good judgment? Have they shown changes over time in this area? Inconsistencies?
- Do the challenges of being where and how they are match abilities and interests? What's new?
- Is the set-up and environment secure enough and stable enough for them at this point in time?
- What appliances, equipment, or tasks are risky? Are there supports in place and plans to monitor?
- Have you checked in with other sources and people to verify and validate your beliefs & feelings?

Ability: Primary issue – Does the person still have the physical, cognitive, social, and emotional capacity to stay where and how they are?

- Are their balance, coordination, strength, endurance, and motor control skills adequate for demands?
- Are their vision, hearing, sense of touch, pain awareness/responses OK for what is needed in the setting?
- Are there still people available who the person connects to and spends time with? Is the time productive?

Engagement: Primary issue: Does the person DO things, not just talk about doing it? Is their support system in place to keep it going?

- Is the person still able to go where they want and need to have fun, feel valued and productive, meet spiritual needs, have social contact, and fill their time?
- Is the person able to use systems that exist to DO what they need to do and want to do? Has this changed over recent times?
- Is the support system becoming stressed with supporting this person?

PAC™ Consultant: Signs of Stress

10 Signs of Caregiver Stress

If you experience any of these signs of stress on a regular basis, make time to talk to your doctor.

1. Denial about the disease and its effect on the person who has been diagnosed.

"I know Mom is going to get better."

2. Anger at the person with Alzheimer's, anger that no cure exists, or anger that people don't understand what's happening.

"If he asks me that one more time I'll scream!"

3. Social withdrawal from friends and activities that once brought pleasure.

"I don't care about getting together with the neighbors anymore."

4. Anxiety about the future.

"What happens when he needs more care than I can provide?"

5. Depression that begins to break your spirit and affects your ability to cope.

"I don't care anymore."

6. Exhaustion that makes it nearly impossible to complete necessary daily tasks.

"I'm too tired for this."

7. Sleeplessness caused by a never-ending list of concerns.

"What if she wanders out of the house or falls and hurts herself?"

8. Irritability that leads to moodiness and triggers negative responses and actions.

"Leave me alone!"

9. Lack of concentration that makes it difficult to perform familiar tasks.

"I was so busy, I forgot we had an appointment."

10. Health problems that begin to take a mental and physical toll.

"I can't remember the last time I felt good."

Source: Alzheimer's Association

PAC Consultant Tool: Care Partner

Alzheimer's caregiver burnout

When prolonged and excessive stress from caring for a loved one with Alzheimer's or dementia leaves you feeling emotionally, mentally, and physically exhausted, you may be facing burnout. Burnout reduces your productivity and saps your energy, leaving you feeling helpless, hopeless, angry, and resentful. Eventually, you may feel like you have nothing more to give. The warning signs of caregiver burnout include:

- Excessive stress and tension
- Debilitating depression
- Persistent anxiety, anger, or guilt
- Extreme irritability or anger with the person living with dementia
- Decreased overall life satisfaction
- Relationship conflicts and social isolation
- Lower immunity and greater need for healthcare services
- Excessive use of medications, drugs, or alcohol. Burnout can damage your health and the health of the person you're caring for, so if you recognize the signs, it's important to take action right away to Cope with the stress and burnout during Dementia care. No matter the day-to-day demands of care partnering with a person living with Dementia, it's imperative that you carve out time for your own self-care.

These tips can help:

- Seek regular respite care. You cannot do it all alone. Ask other family members, friends, or members of your place of worship for help with respite care so you can get a much needed break. You can also seek help from volunteer organizations, support groups, day care programs, and residential respite care facilities. Schedule frequent breaks throughout the day, take time out to pursue hobbies and interests, and stay on top of your own health needs. Seek professional help if you recognize you're exhibiting any warning signs of caregiver burnout.
- Get moving. Regular exercise not only keeps you fit, it releases endorphins that can really boost your mood. Aim for at least 30 minutes of exercise on most days. If it's difficult to get away for that long at once, break the time up into 10 minute sessions sprinkled throughout the day. Take a walk or jog outside, dance to your favorite music, work out to an exercise DVD, or cycle to the store. Taking a group exercise class or working out with friends can give you a much needed social outlet as well.
- Talk it over. Talk to a trusted friend, family member, clergy member, or therapist, about how you feel and what you're going through. The person you talk to doesn't have to be able to solve your problems, he or she just has to be a good listener. The simple act of talking face-to-face with someone who cares can be extremely cathartic. Opening up won't make you a burden to others. In fact, most friends will be flattered that you trust them enough to confide in them, and it will only strengthen your bond.

- Take time to play. In the early stages of Dementia, include your loved one in short walks, board games, or jigsaw puzzles. Join an online scrabble tournament, practice your golf swing, or play with a pet. A daily dose of fun is good medicine, and doesn't require money, a car, or huge blocks of time.
- Try something new. Challenge yourself to learn a new skill while you are "on the job." Order a self-paced foreign language program or try an exercise video game. From tennis to golf to pitching a strike, so-called "exergames" offer living room-friendly activities for every age and skill level. With just a few minutes of practice each day, you can flex mental muscle and relieve harmful stress.
- See the funny side. Humor is a well-known antidote to stress, sadness, illness, and boredom. Give yourself permission to chuckle at the absurdities you and your loved one experience, and surround yourself with laughter. Instead of heavy dramas on TV or video, go for a hearty belly laugh by watching episodes of your favorite sitcom. Your infectious good mood can help replenish your inner resources and sooth your loved one. Making time for reflection during Dementia care. One of the biggest challenges as a care partner for someone living with Dementia is to accept what is happening to your loved one. At each new change in your loved one's abilities, you will need to shift your expectations about what your loved one is capable of. By accepting each new reality and taking time to reflect on these changes, you can better cope with the emotional loss, and deepen the feelings of satisfaction and love in your role as care partner.
- Keep a daily journal to record and reflect on your experiences. By journaling your thoughts, you can mourn losses, celebrate successes, and look for those thought patterns that keep you from acting in the present.
- Count your blessings. A daily gratitude list can chase away the blues and let you focus on what your loved one is still capable of, rather than the abilities he or she has lost.
- Celebrate what is possible. Your loved one still has many abilities. Structure activities to invite participation on whatever level is possible, and you will both find real enjoyment.
- Try to envision your loved one's world. Imagine not being able to remember and do life's simple tasks. By valuing what your loved one is able to give, you can find satisfaction on even the toughest days.
- Practice relaxation techniques. Meditation, deep breathing, visualization, mindfulness, yoga, or rhythmic exercise can calm, restore, and promote happiness. Experiment with different techniques to find the ones that work best for you.
- Improve emotional awareness. Remaining engaged, focused, and calm in the midst of such tremendous responsibility can challenge even the most capable care partner. By developing your emotional awareness skills, however, you can relieve stress, experience positive emotions, and bring new peace and clarity to your care partnering role.

More help for supporting caregivers Source: www.helpguide.org

– Visit for more information

– Teepa videos featured on home page

PAC Consultant Tool: Care Stress

Coping with the Stress of Caring When Someone is Living with Dementia

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Dementia Care and Training Specialist

Caring about someone living with dementia can be one of the most stressful situations possible for an adult child, friend, or spouse. The process frequently starts off with one of you being more aware than the other that something is going wrong and not knowing what it is or how to deal with it in an effective or helpful manner. This is made worse in over 70% of cases because medical professionals do not screen for or recognize the early signs that a change in cognitive abilities is, in fact, taking place. Because the initial signs are subtle, inconsistent, and episodic many individuals and their support systems are in conflict and struggling LONG before an official diagnosis is finally made. These negative emotional interactions can color the relationship as the condition progresses, making care provision challenging and frustrating for all involved. The stress is frequently made worse by disagreement among the family, caregivers, or even between the family support and professional providers.

Since many forms of dementia can typically last over 10-15 years, cannot be cured or stopped, affect every aspect of life and function, and ultimately result in the person's death, we all have a right to be stressed! But we also have the option to DO something about it, to cope with and manage our stress in a productive and helpful way. We actually need to for our own mental, physical, and spiritual well-being.

The person requiring and receiving care generally cannot appreciate the details or the complexity involved in the problems they are experiencing and does not understand why they are no longer able to live their lives as they have been doing without “interference” and “help” that they believe is not needed. Care partnering for someone living with dementia is also an ever changing process. The conditions of Alzheimer's, Lewy Body Dementia, Vascular Dementia, Frontal-Temporal Lobe Dementia among others are all progressive and are ultimately terminal with the gradual destruction of nerve cells in the brain. The ultimate result is that the brain can no longer guide and direct the person with the disease in how to think, talk, understand, behave, respond to sensation, move, and even fight infection, swallow, and breathe. Partnering in care with someone you have known as a vital and independent individual is incredibly stressful. You are losing the ‘person’ as you are caring for them AND they may very well resent and resist your efforts to help and protect them as the dementia progresses.

Care partners of people living with dementia are 80% more likely than other care partners to perceive that they are very stressed in their care partnering role. They are 50% more likely than their peers to have depression. They have a 63% higher mortality risk than their peers and are more likely to have less effective immune systems resulting in more illnesses, fatigue, and a lowered stress threshold. Care partners in combination with the person living with dementia should be considered as both needing care, support, and intervention, BUT it rarely happens without a direct request for help on the Care partner's part. Several studies have indicated that care partners of people living with dementia typically spend over 70 hours a week in care related activities while others spend only 62. Dementia care is the third most expensive disease category in the US, and yet little of it is paid for by governmental programs, adding a financial burden to the care partner. Approximately 70-80% of care is provided by care partners in the community or in the home, representing one of the highest percentages for any illness or condition. In over 40% of all cases of dementia care partnering, there will be at least one care partner unable to continue giving care before the person living with dementia passes away, due to their own death or worsening physical or emotional illness.

The amount of burden or stress a care partner of someone living with dementia experiences is not so much related to the length of time they have given care, the amount of physical care provided, or the dramatic shift in abilities of the person. The severity of the stress is closely related to the behaviors that the person living with dementia is having, the amount of support the care partner feels that they have, the amount of depression or apathy the person living with dementia has, and the knowledge and skill the care partner has about the disease and the disease process. Care partners of people living with dementia also routinely experience a significant worsening of feelings or distress and guilt, depression, burden, and illness AFTER placing the person in an institution. This is a unique and very troubling finding, indicating that the burden and stress of care partnering is much more than the physical demands of the job, and needs to be addressed even after placement has occurred. The purpose of my training is to provide care partners with some basic information about dementia and common symptoms, the progression of the condition and how to provide support and help.

My goal is to help EVERYONE involved become more skilled and less stressed so life is better. Take a look at the list of Stress Tamers and see if you can 'make a little change' –'take a baby step' for you and the person you care about!

Practical Tips: Care Partner

Practical Tips for Caring for Someone with Dementia

Teepa Snow, MS, OTR/L, FAOTA

Dementia Care and Training Specialist

A Positive Physical Approach™

1. Knock on door or table - to get attention - signal your approach
2. Stop moving at the boundary between public & personal space – 6 ft out - get permission to enter or approach
3. Open hand motion near face and smile – look friendly and give the person a visual cue – make eye contact – open hand near face – cues eyes to look there
4. Call the person by preferred name OR at least say “Hi!” – avoid endearments
5. Move your hand out from near your face to a greeting handshake position – make sure they notice you hand out to shake – then stand tall and move forward SLOWLY
6. Approach the person from the front – come in within 45 degrees of center - visual
7. Move slowly – one step/second, stand tall, don’t crouch down or lean in as you move toward the person
8. Move toward the right side of the person and offer your hand - give the person time to look at your hand and reach for it, if s/he is doing something else – offer, don’t force
9. Stand to the side of the person at arm’s length – respect intimate space & be supportive not confrontational – but don’t go too far back’ – stay to the front - visual
10. Shake hands with the person – make eye contact while shaking
11. Slide your hand from a ‘shake’ position to Hand-under-Hand™ position – for safety, connection, and function
12. Give your name & greet – “I’m (name). It’s good to see you!”
13. Get to the person’s level to talk – sit, squat, or kneel if the person is seated and stand beside the person if s/he is standing
14. NOW, deliver your message...

Approaching When the Person is DISTRESSED!

Some CHANGES

1. Look concerned not too happy, if the person is upset
2. Let the person move toward you, keeping your body turned to the side (supportive – not confrontational)
3. If the person is seated and you DON'T get permission to enter personal space – turn sideways and kneel at 6' out – offer greeting & handshake again – look for an OK to come into their personal space – it will usually come at this time (submissive posture)
4. After greeting... try one of two options...
 - a. “Sounds like you are (give an emotion or feeling that seems to be true)???”
 - b. Repeat the person's words to you...

If s/he said, “Where's my mom?” you would say “You're looking for your mom (pause)... tell me about your mom...” If the person said “I want to go home!”, you would say “You want to go home (pause)... Tell me about your home...”.

PAC Communication Tips

Communicating – Talking

First - ALWAYS use the positive physical approach!

Then - Pay attention to the THREE ways you communicate:

1. How you speak

- ◆ Tone of voice (friendly not bossy or critical)
- ◆ Pitch of voice (deep is better)
- ◆ Speed of speech (slow and easy not pressured or fast)

2. What you say

THREE basic reasons to talk to someone...

1. To get the person to DO something (5 approaches to try)
 - a. give a short, direct message about what is happening
 - b. give simple choices about what the person can do
 - c. ask the person to help you do something
 - d. ask if the person will give it a try
 - e. break down the task - give it one step at a time

Note: Only ask “Are you ready to...” If you are willing to come back later.
2. Just to have a friendly interaction - to talk to the person
 - ◆ go slow - Go with Flow
 - ◆ acknowledge emotions - "sounds like... seems like... I can see you are..."
 - ◆ use familiar words or phrases (what the person uses)
 - ◆ know who the person has been as a person what s/he values
 - ◆ use familiar objects, pictures, actions to help & direct
 - ◆ be prepared to have the same conversation over & over
 - ◆ look interested & friendly
 - ◆ be prepared for some emotional outbursts
 - ◆ DON'T argue... BUT don't let the person get into dangerous situations

REMEMBER - the person is doing they can – GO with the FLOW!

3. Deal with the person's distress or frustration/anger

- ◆ Try to figure out what the person really NEEDS or WANTS ("It sounds like..." "It looks like..." "It seems like..." "You're feeling...")
- ◆ Use empathy not forced reality or lying

3. Once the person is listening and responding to you THEN –

- ◆ Redirect his attention and actions to something that is OK OR
- ◆ Distract him with other things or activities you know he likes & values

Always BE CAREFUL about personal space and touch with the person especially when s/he is distressed or being forceful.

4. How you respond to the person

- ◆ use positive, friendly approval or praise (short, specific and sincere)
- ◆ offer your thanks and appreciation for his/her efforts
- ◆ laugh with him/her & appreciate attempts at humor & friendliness
- ◆ shake hands to start and end an interaction
- ◆ use touch - hugging, hand holding, comforting only IF the person wants it

5. If what you are doing is NOT working –

- STOP!
- BACK OFF - give the person some space and time
- Decide on what to do differently...
- Try Again!

Always strive to be curious and KNOW as much as you can about who the person WAS and who the person is NOW...

- Personality Traits
- Six Pieces of the Puzzle
- Multiple Intelligences
- Side Dominance
- Preferences
- History

Positive Approach to Feedback

Giving Feedback in PAC Training

Key Points in Giving Feedback When Coaching Someone through Learning New Skills:

- Make sure the person knows they will be getting feedback
- Make sure the place and time are *good* for both of you – nothing else distracting you, comfortable and *private*
- Give feedback as soon as you can after the observation – we learn better when we can remember what happened and waiting makes it harder to be accurate and focused
- Start by asking the person what they thought about the session and their use of the skills being learned
- Use ACTIVE LISTENING SKILLS – friendly and open body language, encouraging words, asking not telling
- Consider using CONCRETE tools to help keep it from being *personal* – Use the forms and information from the training sessions to reinforce and validate their words that will point out skills USED and MISSING
- When sharing your observations – start with the positive, then add the skills to WORK ON – offer concrete and specific ideas or thoughts
- ASK the person to share back with you what their NEXT STEPS should be. Confirm that they heard what you said.
- Agree on a time and place for follow up sessions
- THANK the person for working with you and being willing to try to put this new skill in their daily routine
- IF YOU are nervous or feeling uncomfortable, you can either let the person know you are feeling that way, but want to work with them OR ask a team partner to practice with you ahead of time to improve your comfort level

PAC™ Tools: Kubler-Ross

The Kübler-Ross Grief Cycle

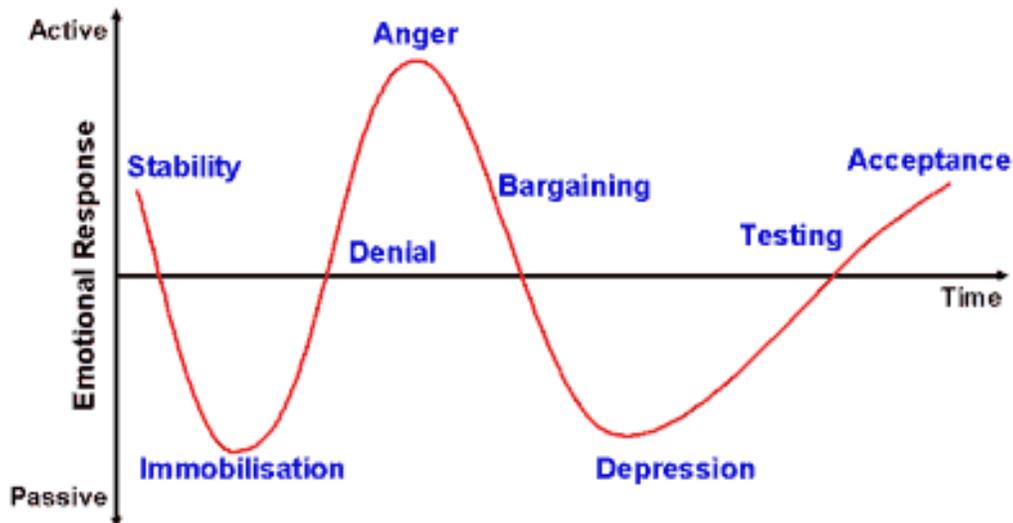
Five Stages of Grief - Elisabeth Kübler Ross

EKR stage	Interpretation
1 - Denial	Denial is a conscious or unconscious refusal to accept facts, information, reality, etc., relating to the situation concerned. It's a defense mechanism and perfectly natural. Some people can become locked in this stage when dealing with a traumatic change that can be ignored. Death of course is not particularly easy to avoid or evade indefinitely.
2 - Anger	Anger can manifest in different ways. People dealing with emotional upset can be angry with themselves, and/or with others, especially those close to them. Knowing this helps keep detached and nonjudgmental when experiencing the anger of someone who is very upset.
3 - Bargaining	Traditionally the bargaining stage for people facing death can involve attempting to bargain with whatever God the person believes in. People facing less serious trauma can bargain or seek to negotiate a compromise. For example "Can we still be friends?" when facing a break-up. Bargaining rarely provides a sustainable solution, especially if it's a matter of life or death.
4 - Depression	Also referred to as preparatory grieving. In a way it's the dress rehearsal or the practice run for the 'aftermath' although this stage means different things depending on whom it involves. It's a sort of acceptance with emotional attachment. It's natural to feel sadness and regret, fear, uncertainty, etc. It shows that the person has at least begun to accept the reality.
5 - Acceptance	Again this stage definitely varies according to the person's situation, although broadly it is an indication that there is some emotional detachment and objectivity. People dying can enter this stage a long time before the people they leave behind, who must necessarily pass through their own individual stages of dealing with the grief.

(Based on the Grief Cycle model first published in *On Death & Dying*, Elisabeth Kübler-Ross, 1969.
Interpretation by Alan Chapman 2006-2013.)

The Extended Grief Cycle

The Extended Grief Cycle can be shown as in the chart below, indicating the roller-coaster ride of activity and passivity as the person wriggles and turns in their desperate efforts to avoid the change.



The initial state before the cycle is received is stable, at least in terms of the subsequent reaction on hearing the bad news. Compared with the ups and downs to come, even if there is some variation, this is indeed a stable state.

And then, into the calm of this relative paradise, a bombshell bursts...

- Shock stage*: Initial paralysis at hearing the bad news.
- Denial stage: Trying to avoid the inevitable.
- Anger stage: Frustrated outpouring of bottled-up emotion.
- Bargaining stage: Seeking in vain for a way out.
- Depression stage: Final realization of the inevitable.
- Testing stage*: Seeking realistic solutions.
- Acceptance stage: Finally finding the way forward.

* This model is extended slightly from the original Kubler-Ross model, which does not explicitly include the Shock and Testing stages. These stages however are often useful to understand and facilitating change.

Teepa's Thoughts on Denial

Denial is a Stage of Grief and Loss, Not a Dirty Word!

How many times have you heard it said, “She’s in DENIAL!” or “That family member is in DENIAL!” or that “She has to KNOW the person has dementia.... Needs more help...., can’t do that safely anymore.” The words are used like weapons. The phrase is said with a tone of disbelief or disgust. There are several common scenarios when the statement “He/She is simply in DENIAL!” is neither helpful nor accurate. The first occurs when someone is experiencing the early changes that come with dementia. It is very common for some members of the family to state in an accusatory tone of voice that the person, their spouse, or another member of the family is “in denial”. It is stated in such a way as to clearly indicate the person being spoken of is ‘ignoring’ what is obvious and is unwilling to ‘face the facts’ or deal with the ‘reality’ of the situation. A second situation occurs when a health care professional makes the statement about a person living with dementia or a family member regarding the diagnosis or the degree to which the condition is impacting the person’s ability to safely function in the existing environment and with the existing support structure in place. The implication is that the person is unwilling or unable to see the need for changing or the risk that is posed when it is very clear and real. It is typically accompanied with a ‘throw our hands in the air’ and just wait until something happens to prove we were right, since there is ‘no use reasoning’ with the person ‘in denial’. The third scenario typically occurs near the end of the journey, when some members of the support system believe it is time for the journey to end while the ‘other person is ‘simply denying’ that there is nothing more to be done.

It is easy for the person NOT experiencing the intensity of loss to ‘dismiss or discount’ the feelings of the other. The ‘accuser’ typically tries to use details, and logic to ‘help’ the person better understand their position and ‘why’ they are ‘right’ and the individual in denial is therefore ‘wrong’. The resistance they meet reinforces their belief that the person is making a ‘choice’ to refuse or ignore their information and information is being missed is that the person is in incredible DISTRESS. The person CANNOT be logical or reasonable.

In all cases, I believe it is time to change our attitudes and behaviors toward the individual who is ‘in denial’. It is much more helpful and healthy to recognize that denial is not a ‘willful disregard for the facts’, but rather a stage of grieving the loss of the person, the past, the life that was, the relationship that is changing, or the end of the journey. It is a state of being that must be understood, appreciated, and experienced in order to move on thru other stages of grief before reaching acceptance. The really frustrating and difficult part of dementia is that this process of grief will be repeated over and over before the end of the journey. Each person involved in the life of the person with dementia, will experience ‘loss’ and grief in his or her own time and at different points and moments. It can happen in the most unexpected moments. throughout the journey from beginning to end. It can ‘surprise’ you with its intensity and arrival, just when you thought you had figured it out and were on the right track, had the situation under control, ‘got it’... It’s an ever changing landscape and condition (both chemical and structural) that will present you with countless opportunities to be confronted with a ‘new loss’ or ‘change’... it comes and it goes....

There is much we can do, once we admit to ourselves that we are NOT going to get it right all the time...that our best efforts will sometimes not work. Perhaps if we saw ourselves as standing on a surfboard during a ‘hurricane warning’... that might prepare us better... There are SO MANY factors that contribute to the situation, that we can only do our best and get ready for times we lose our footing, the wave breaks, early or hard, or we over-balance. It is not about getting it right all the time, it is about being willing to learn from each time and get a better ‘feel’ before trying to ride the wave...

So what am I really saying, three major points:

1. When it seems someone is ‘not getting’ what you are trying to give them, PAUSE, stop what you are doing, take a step back and re-examine what is happening... If it is not working then continuing to try more of the same, is unlikely to result in the outcome you are seeking for you or the person you are trying to help – STEP BACK and take a DEEP BREATH – then let it go!!!! – repeat the breath 2 more times and see if your thinking, sensory processing, and emotional control is better – you got ‘stressed out’ – you may have been too focused on ‘your agenda’ and the person you were trying to help keyed in on that and did not like it or get it or their agenda did not match yours. So, take a break and see if you can figure out what is happening.

2. If you enter a situation with someone who is living with dementia or their care partner and you are ‘SURPRISED, HORRIFIED, TERRIFIED, ANGERED, FRUSTRATED, SCARED...’ – or otherwise emotionally WIDE OPEN... STOP and PULL BACK from the situation immediately. Get yourself under control before you do anything... This is true even if the person is in some danger of ‘harming themselves, but not at IMMEDIATE LIFE THREATENING DANGER. UNLESS it is IMMEDIATE AND HORRIBLE – PAUSE... get yourself ready – one or two breaths...TAKE those moments to try and see/hear/feel/smell/taste the situation from that person’s point of view – PUT ON YOUR EMPATHY and VALIDATION HAT!!! Then use your PPA skills to the hilt... If you don’t you will find yourself acting the stages of grief and loss right before you own eyes (denial, anger, bargaining, sadness... but you may or may not reach acceptance depending on the other person’s REACTIONS to you and your ‘meltdown’. My phrase – Who has dementia???? Stress and distress are amazing things – they do awful things to the skills and abilities of the human mind when they hit hard and fast. Afterward – process what happened, allow yourself to recognize and deal with YOUR grief... and then plan for the future, the next time or next thing.

3. Sometimes, it takes a third person. An observer, an interested but not ‘invested’ person to help us see what we are missing, what is driving the system, why we are struggling or the other person is struggling, to help us reconsider, problem solve through it. BUILDING a TEAM, forming new partnerships, REACHING OUT to others who have a variety of skills and abilities is VITAL for everyone. This thing called DEMENTIA ultimately affects everything... but we can choose, with help, to not let it destroy everything. We can choose another way, to use what remains, to value who the person is in a moment, to acknowledge the loss, but celebrate what is still possible. It is not the same, it will never be the same, but it can be more than many people think it can. AND IF BY CHANCE, you can’t go to this concept YET, OK. I can’t make you get there, but perhaps with awareness, knowledge, skill, and competence it can happen for you as well, when the moment is right.

Teepa's Songs

A Positive Approach

To the Tune of "Amazing Grace"

Come from the front

Go slow

Get to the side

Get low

Offer your hand

Call out the name then WAIT...

If you will try, then you will see

How different life can be.

For those you're caring for!

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I Will Change

To the tune of "This Little Light of Mine"

I am gonna meet and greet
Before I start to treat
I am gonna meet and greet
Before I check your feet
I am gonna meet and greet
Before I help you eat
How I start sets us up to succeed!

No more just "Getting' it Done"
I'm gonna DO with you
No more just "Getting' it Done"
I'm gonna help you thru
No more just "Getting' it Done"
We're gonna work, we two
Cause if I do it ALL, we BOTH LOSE!

I'm gonna laugh and dance with you
Not just watch and frown
I'm gonna laugh and dance with you
Not just stand around
I'm gonna laugh and dance with you
We'll really go to town
For the POWER of JOY I have found!

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Progression of the Condition

To the Tune of "This Old Man"



SAPPHIRE true, you and me ~ The choice is ours, and we are free
To change our habits, to read, and think and do
We're flexible, we think it through!

DIAMOND bright, share with ME ~ RIGHT before, where I can be
I need routine *and* different things to do
Don't forget, I get to CHOOSE!

EMERALD – GO, I like to DO ~ I make mistakes, but I am through!
Show me only one step at a time
Break it down and I'll be fine!

AMBER – HEY!, I touch and feel ~ I work my fingers - rarely still
I can do things, if I copy you
What I ***need*** is what I do!

RUBY – skill – it just won't go ~ Changing something must go SLOW
Use your body to show me what you need
Guide, don't force me. Don't use speed!

Now a PEARL, I'm near the end ~ But I still feel things through my skin
Keep your handling always firm and slow
Use your voice to calm my soul.

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