Dealing with Distress in Persons with Dementia: Using Empathy & Support

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Dementia Care and Training Specialist
A Positive Physical Approach for Someone with Dementia

1. **Knock** on door or table - to get attention if the person is not looking at you & get permission to enter or approach
2. **Wave and smile** – look friendly and give the person a visual cue – make eye contact
3. Call the person by **name** OR at least say “Hi!” – pause then start approaching or let the person come to you, if s/he likes to be in control
4. Move your hand out from a wave to a greeting **handshake** position
5. Approach the person from the front – come in within 45 degrees of the center
6. **Move slowly** – one step/second, stand tall, don’t crouch down or lean in as you move toward the person
7. 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
8. Stand to the side of the person at arm’s length – respect personal space & be supportive not confrontational
9. **Shake hands** with the person – make eye contact while shaking
10. Slide your hand from a ‘shake’ position to **hand-under-hand** position – for safety, connection, and function
11. Give your name & greet – “I’m (name). It’s good to see you!”
12. **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
13. NOW, deliver your message…

**Approaching When The Person is DISTRESSED!**

**TWO 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. 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…”.

**BASIC CARD CUES – WITH Dementia**

- Knock – Announce self
- Greet & Smile
- Move Slowly – Hand offered in ‘handshake’ position
- Move from the front to the side
- Greet with a handshake & your name
- Slide into hand-under-hand hold
- Get to the person’s level
- Be friendly -make a ‘nice’ comment or smile
- Give your message… simple, short, friendly
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)*
   1 - give a short, direct message about what is happening
   2 - give simple choices about what the person can do
   3 - ask the person to help you do something
   4 - ask if the person will give it a try
   5 - break down the task - give it one step at a time
   **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 the BEST that s/he can
   **AND 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

   • 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**

3 - 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

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!**

Key Points About ‘Who’ the person Is….
- preferred name
- introvert or extrovert
- a planner or a doer
- a follower or a leader
- a ‘detail’ or a ‘big picture’ person
- work history - favorite and most hated jobs or parts of jobs
- family relationships and history - feelings about various family members
- social history - memberships and relationships to friends and groups
- leisure background - favorite activities & beliefs about fun, games, & free time
- previous daily routines and schedules
- personal care habits and preferences
- religious and spiritual needs and beliefs
- values and interests
- favorite topics, foods, places
- favorite music and songs - dislike of music or songs
- hot buttons & stressors
- behavior under stress
- what things help with stress?
- handedness
- level of cognitive impairment
- types of help that are useful
Types of Help - Using Your Senses

**Visual -**

- Written Information - Schedules and Notes
- Key Word Signs - locators & identifiers
  
  Objects in View - familiar items to stimulate task performance

  Gestures - pointing and movements

  Demonstration - provide someone to imitate

**Auditory -**

- Talking and Telling - give information, ask questions, provide choices

  Breaking it Down - Step-by-Step Task Instructions

  Using Simple Words and Phrases - Verbal Cues

  Name Calling - Auditory Attention

  Positive Feedback - praise, "yes", encouragement

**Tactile - Touch -**

- Greeting & Comforting - handshakes, hugs, 'hand-holding'

  Touch for Attention during tasks

  Tactile Guidance - lead through 'once' to get the feel

  Hand-Under-Hand Guidance - palm to palm contact

  Hand-Under-Hand Assistance - physical help

  Dependent Care - doing for & to the person
<table>
<thead>
<tr>
<th>Areas to Explore</th>
<th>What Did You Find Out?</th>
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</thead>
<tbody>
<tr>
<td>Preferred Name</td>
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<tr>
<td>Preferred Hand</td>
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<tr>
<td>Living Situations &amp; history</td>
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<tr>
<td>(where are you from today &amp; originally, who &amp; did you live with, what type places did you live in (house, apt, farm…))</td>
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<td>Marriage history &amp; status</td>
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<td>(who’s involved, has been involved, and how do you feel about them?)</td>
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<tr>
<td>Family history &amp; membership</td>
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<tr>
<td>(who’s who and how do you feel about them? Think about several generations….)</td>
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<tr>
<td>Work history</td>
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<tr>
<td>(what jobs have you had in your life? How did you feel about them? What are some jobs you would have loved to do, but never did? )</td>
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<tr>
<td>Leisure history</td>
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<tr>
<td>(what do and did you do for fun and in your spare time? How do you feel about ‘having fun’? What would you like to do if you had the money? time? Skill? )</td>
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<td>Spiritual history</td>
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<td>(what religion do you and did you follow, how involved are you and were you, and how important is it to you? How do you feel about other religions?)</td>
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<tr>
<td>Personal care practices &amp; history</td>
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<tr>
<td>(eating habits, sleeping habits, grooming habits, bathing habits…)</td>
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<tr>
<td>Time Use History</td>
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<tr>
<td>(schedules &amp; routines…. When do you and would you like to do things?)</td>
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<tr>
<td>Important Life Events</td>
<td></td>
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<tr>
<td>(what are some things that were very important to or happened to you? Do others know about these events?)</td>
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<tr>
<td>Hot Buttons</td>
<td></td>
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<tr>
<td>(what are things/activities /topics/actions that really tend to upset you?)</td>
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</tbody>
</table>
Progression of the Disease – What is Lost & What Remains?

**Diamond - Early Loss – Running on Routine – Repeating Stories**
- Some word problems and loss of reasoning skill – tells/asks the same thing over & over
- Easily frustrated by changes in plans or routines
- Seeks reassurance but resents take over
- Mostly does well with personal care and activities – in familiar setting
- Tends to under or over estimate skills
- Looks for authority figures – may challenge them or respect them…
- Misremembers how or why things happened – may accuse others of stealing & lying

**Emerald - Moderate Loss - Just Get It Done! – Wanting a Purpose and a Mission**
- Gets tasks done, but quality is poor – resents physical help or offers to “help”
- Leaves out steps or makes errors and WON’T go back and fix it
- Needs things to do of value -Can help with lots of things – doing ‘with’ works well
- Likes models and samples – uses others’ actions to figure out what to do
- Asks “what /where/when” LOTS – gets lost in past time
- Can do personal care tasks with supervision & prompts – friendly, not bossy
- Still very social BUT content is limited and confusing at times

**Amber - Middle Loss - See It – Touch It – Take It – Taste It – Hunting & Gathering**
- Handles almost anything that is visible
- Does not recognize other’s ownership
- Likes to explore – get into things, take things apart, collect things, hide things, handle things
- Language is poor and comprehension very limited, except for ‘social’ & automatic speech
- Responds to tone of voice, body language and facial expression
- Loses the ability to use tools and utensils during this level
- Does things because they feel good, look good, taste good – refuses if they don’t
- Stops doing when it isn’t interesting anymore
- Can often imitate you some – But not always aware of you as a person

**Ruby – Severe Loss – Gross Automatic Action – Constant GO or Down & Out**
- Hard to transition from moving to still, or still to moving
- Paces, walks, rocks, swings, hums, claps, pats, rubs….
- May mostly ignore people and small objects
- Doesn’t stay down long in any one place – keep it short
- May not be interested in food – significant weight loss can happen at this level
- Offer smaller and more frequent meals – use finger foods and traveling snacks
- Will have trouble chewing meat, raw vegetables & fruits, may spit things out
- Copies slowly - can grossly imitate big movements and actions – use demonstration
- Generally enjoys rhythm and motion – music and dance

**Pearl - Profound Loss - Stuck in Glue – Immobile & Reflexive**
- Generally bed or chair bound – can’t move much on own
- Often contracted with ‘high tone’ muscles – moving into a fetal position
- Poor swallowing and eating – aspiration common & increased ‘infections’
- Still aware of movement and touch -often sensitive to voice and noise
- Difficulty with temperature regulation & circulation
- Primitive reflexes can dominate – grasp, suck, root, startle, yawn…
- Responds best to slow rhythmic movements, touch, and voice
- Needs contact with you to be connected – moments of clarity can happen
- May be in pain – (try Tylenol every six hours – NOT PRN)
Having a Conversation

To Start Talking.....

First
- Recognize the person and their situation or feelings (don’t lie and don’t be cruel...)
- Use EMPATHY – “it looks like…”, “it sounds like….”, “it seems like…”

Then
- If in early stages of the disease, gently offer orienting information
- If in the middle or later stages of the disease, figure out the meaning of the behavior or words and use...
  - **Redirection** – same type of activity in a more acceptable manner, or with ‘safer’ materials, or in a safer space (Example: cleaning out cabinets rather than the crash cart)
  - **Distraction** – changing to a different but equally valued activity (Example: looking for her cat that no longer exists to helping to put away dishes from the dish drainer and clean up the dining room)

When having a conversation...
- use familiar phrases or words to help the person 'talk'
- use familiar objects or actions to give a focus for the interaction
- be prepared to have the SAME conversation over, and over, and over…..
- use your non-verbal interaction skills to show interest and engagement
- be prepared for unexpected emotional shifts and outbursts
  (remember - it's part of the disease)
- don't try to correct the person... GO WITH THE FLOW! - use empathy not reality!
Communication - When Words Don’t Work Anymore…

Keys to Success:
• Watch movements & actions
• Watch facial expressions and eye movements
• Listen for changes in volume, frequency, and intensity of sounds or words
• Investigate & Check it out
• Meet the need

It’s all about Meeting Needs…
• Physical needs
• Emotional needs

Probable Needs:
  Physical
  • Tired
  • In pain or uncomfortable
  • Thirsty or Hungry
  • Need to pee or have a BM or already did & need help
  • Too hot or too cold

  Emotional
  • Afraid
  • Lonely
  • Bored
  • Angry
  • Excited
  • In Pain

What Can You Do?
• Figure it out…Go thru the list
• Meet the need… Offer help that matches need
• Use visual cues more than verbal cues
• Use touch only after ‘permission’ is given

Connect – Visually, Verbally, Tactilely
Protect Yourself & the Person – use Hand Under Hand & Supportive Stance techniques
Reflect – copy expression/tone, repeat some key words, move with the person
Engage – LISTEN with your head, your heart, and your body
Respond – try to meet the unmet needs, offer comfort and connection

*** IF IT DOESN”T seem to be working – STOP, BACK OFF – and then TRY AGAIN – changing something in your efforts (visually, verbally, or through touch/physical contact)***
Normal & Common Changes with Aging

A. Sensory changes with aging
   1. reduced speed of processing
   2. reduced discrimination
   3. takes more to get a response
   4. responses are slower

B. Motor Changes with Aging
   1. slower reactions
   2. muscles are a little weaker
   3. joints are stiffer
   4. less endurance
   5. less reserve
   6. more fearful of rapid movement

C. Cognitive Changes with Aging
   1. slowed processing
   2. less flexibility
   3. more difficulty with new learning
   4. more rehearsals needed
   5. benign forgetfulness – immediate recall goes first

D. Emotional Changes with Aging
   1. increased incidence of depression
   2. increased incidence of anxiety
   3. with stress – mood swings
   4. with some drugs – emotional side effects
<table>
<thead>
<tr>
<th>Change</th>
<th>Impact</th>
<th>Conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vision – loss of acuity</td>
<td>can’t read small print</td>
<td>presbyopia</td>
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<tr>
<td>Vision – loss of color vision</td>
<td>can’t tell blue from green</td>
<td>‘color blindness’</td>
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<tr>
<td>Vision – less light in eye</td>
<td>can’t see in dim light</td>
<td>night blindness</td>
</tr>
<tr>
<td>Vision – more trash in eyeball or on lens</td>
<td>can’t see in bright sun/glare</td>
<td>cataracts</td>
</tr>
<tr>
<td>Vision – more pressure in eyeball</td>
<td>can’t see on edges</td>
<td>glaucoma -lack peripheral vision</td>
</tr>
<tr>
<td>Vision – loss of middle area</td>
<td>can’t see to read or look at people</td>
<td>senile macular degeneration</td>
</tr>
<tr>
<td>Vision – loss of one side of vision – after a stroke</td>
<td>can’t see to the affected side</td>
<td>hemianopia</td>
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<tr>
<td>Vision – slowed accommodation</td>
<td>can’t adjust light to dark quickly</td>
<td>can’t drive at night</td>
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<tr>
<td>Vision – can’t tell depth</td>
<td>can’t judge distances/steps</td>
<td>no depth perception</td>
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<tr>
<td>Hearing – can’t hear consonants</td>
<td>mishear words and miss info</td>
<td>presbycusis</td>
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<tr>
<td>Hearing – can’t hear high noises</td>
<td>can’t understand women</td>
<td>hard of hearing</td>
</tr>
<tr>
<td>Hearing – can’t tune out background noise</td>
<td>won’t come to groups, talks over others</td>
<td>can’t tell who is talking</td>
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<tr>
<td>Smell – can’t smell things</td>
<td>may eat bad food, can’t smell own body odor, can’t smell smoke, no appetite</td>
<td>weight loss, food poisoning, ‘smelly’, burns, …</td>
</tr>
<tr>
<td>Taste – reduced number of taste buds &amp; reduced sensitivity</td>
<td>foods taste different, add more sugar or salt, reduced appetite</td>
<td>weight loss</td>
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<tr>
<td>Touch – can’t feel touch as well</td>
<td>more bruises and scrapes</td>
<td>injuries – unknown origin</td>
</tr>
<tr>
<td>Touch – don’t sweat as well</td>
<td>can’t take the heat</td>
<td>heat stroke</td>
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<tr>
<td>Touch – don’t produce oil on skin</td>
<td>dry skin</td>
<td>rashes, irritations</td>
</tr>
<tr>
<td>Balance – slowed reactions</td>
<td>more falls</td>
<td>fractures, bruises, skin tears, fear of falling</td>
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<tr>
<td>Strength – muscles not as strong</td>
<td>can’t lift or do as much</td>
<td>de-conditioned</td>
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<tr>
<td>Flexibility – less ROM</td>
<td>can’t stretch as far to do things</td>
<td>limited floor to rise, overhead activities</td>
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<tr>
<td>Coordination – slowed reaction times</td>
<td>can’t do things as fast or as well</td>
<td>‘slow driver’, little accidents, spills, trips…</td>
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<tr>
<td>Endurance – less heart and lung reserve</td>
<td>wear out faster, takes longer to ‘catch breath’, pass out…</td>
<td>reduce activity, become fearful of doing too much, get exhausted</td>
</tr>
<tr>
<td>Cognitive – slower processing</td>
<td>takes longer to think things thru…. may look undecided</td>
<td>let others make decisions, change mind, lose track of conversation</td>
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<tr>
<td>Cognitive – less flexible</td>
<td>not comfortable with changes, takes a long time to make changes, goes back to old routines</td>
<td>refuses changes, resists change, gets angry if pushed</td>
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<tr>
<td>Cognitive – forgetful</td>
<td>needs cues to remember, if stressed gets worse, immediate recall hard to do</td>
<td>benign senile forgetfulness, complains about forgetting</td>
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<tr>
<td>Emotional – depression</td>
<td>loss of interests, joy, activities, weight, sleep, appearance…</td>
<td>clinical depression</td>
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<tr>
<td>Emotional – anxiety</td>
<td>fearful, ‘nervous’, ‘shaky’…</td>
<td>irritated, angry, tearful, pacing…</td>
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<tr>
<td>Change</td>
<td>Symptoms</td>
<td>Impact on Life &amp; Living Situation</td>
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<tr>
<td>--------------------------------------------</td>
<td>-----------------------------------------------</td>
<td>-----------------------------------------------------------------------</td>
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<tr>
<td>Loss of near acuity (presbyopia)</td>
<td>Can’t read small print</td>
<td>Can’t read newspaper articles, ads or magazines</td>
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<td>Hard to pay bills</td>
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<td>Hard to read package directions</td>
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<td></td>
<td></td>
<td>Hard to read nutritional value info</td>
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<tr>
<td>Loss of visual accommodation</td>
<td>Can't adjust light&lt;=dark quickly</td>
<td>Can’t see when headlights flash in eyes</td>
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<td>Can’t see when lights are first flipped on at night</td>
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<td>Can’t adjust near&lt;=far quickly</td>
<td>Can’t see well between sunlight and shade</td>
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<td>Hard to adjust when driving - instrument panel &lt;= oncoming traffic</td>
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<td>Hard to watch TV and do anything else</td>
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<td>Hard to work on tabletop &amp; look up at a board in front</td>
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<tr>
<td>Garbage builds up in the eyeball</td>
<td>Need more light to see well</td>
<td>Can’t see to read or work if lighting is minimal</td>
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<td>Direct light or glare ‘blinds’</td>
<td>Can’t make out details when lighting is down</td>
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<td>Dim seems dark</td>
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<td>Hard to read on colored paper</td>
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<td></td>
<td></td>
<td>Direct sunlight is blinding</td>
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<td></td>
<td>Windows create ‘blind’ spots</td>
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<td></td>
<td>Uncovered bulbs are brighter, but are ‘blinding’ light</td>
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<td></td>
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<td>Shiny paper can’t be read</td>
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<tr>
<td>Depth perception is reduced</td>
<td>Increased falls &amp; risk of falls</td>
<td>Can’t see edges of steps</td>
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<td>Can’t see curbs</td>
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<td>Hard to judge distances</td>
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<tr>
<td>Loss of blue-green discrimination</td>
<td>Can’t tell shades of blue or green</td>
<td>Make mistakes in clothing or color selection</td>
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<td>Make errors in medications</td>
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<tr>
<td>Loss of upper range hearing (presbycusis)</td>
<td>Can’t hear consonants in speech</td>
<td>Make mistakes in information gathering</td>
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<td>Can’t ‘screen out’ background noise</td>
<td>Avoid large groups or busy settings</td>
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<td>Difficult to localize sounds</td>
<td>Become irritable in noisy settings</td>
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<td>More difficult to hear high-pitched noises</td>
<td>Misunderstand who is talking</td>
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<td>Can’t hear women as well</td>
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<td></td>
<td></td>
<td>Miss information that is shared verbally</td>
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<tr>
<td>Change</td>
<td>Symptoms</td>
<td>Impact on Life &amp; Living Situation</td>
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<tr>
<td>Muscle strength &amp; endurance is reduced</td>
<td>Fatigue more quickly</td>
<td>Takes longer to get things done</td>
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<td>Can't do as much at one time</td>
<td>Strains and sprains can occur more often</td>
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<td>Things seem heavier and more awkward</td>
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<td>Mechanical advantage becomes more important</td>
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<tr>
<td>Skin is more fragile - less padding on the extremities</td>
<td>Skin tears and bruises are more common</td>
<td>Sharp edges and points in the environment cause damage with minimal contact</td>
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<td>Reports of pain with injury are often reduced</td>
<td>Hard to know when or how an injury happened</td>
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<td></td>
<td>Use of arms and hands to accommodate for vision loss can result in additional injuries</td>
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<tr>
<td>Cardiovascular system is less efficient</td>
<td>Run out of breath and energy more quickly</td>
<td>Climbing stairs is tiring</td>
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<td></td>
<td>Takes longer to recover when 'worn out'</td>
<td>Carrying large loads is difficult</td>
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<td></td>
<td>Frequent breaks are needed for the heart and lungs to 'catch up'</td>
<td>Less 'work' creates an aerobic workout</td>
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<td></td>
<td></td>
<td>Need recovery times between activities</td>
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<tr>
<td></td>
<td></td>
<td>Warm, moist air makes breathing more difficult</td>
</tr>
<tr>
<td>Reaction times are slowed</td>
<td>Can't 'catch' self to correct movement errors</td>
<td>Increased risk of falls on unstable surfaces</td>
</tr>
<tr>
<td></td>
<td>Takes longer to respond to a stimulus</td>
<td>Increased risk of falls on changing walking surfaces</td>
</tr>
<tr>
<td></td>
<td>Slower to move away from danger (heat, sharps, cold, friction...)</td>
<td>Greater exposure to hot/cold water - burns or hypothermia more common</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Slower to move self, vehicle, objects out of harm’s way</td>
</tr>
<tr>
<td>Bones become more fragile</td>
<td>Fractures occur more easily</td>
<td>Collapse of the front of spinal vertabrae causes pain and stooped posture</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hip fractures occur spontaneously as well as in response to minor falls</td>
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<tr>
<td></td>
<td></td>
<td>Wrist and forearm fractures occur more often with forward falls or trips</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Shoulder fractures don't always heal - the arm doesn't work well</td>
</tr>
<tr>
<td>Joints become more rigid</td>
<td>Flexibility is reduced</td>
<td>Motion becomes more limited - can't stretch as far</td>
</tr>
<tr>
<td></td>
<td>Surfaces wear down and become painful with weight-bearing or stress</td>
<td>Can't turn head to sides as well - field of vision reduced</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Gait changes and becomes slower and steps are less distinct</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Getting up and down can be more difficult and painful</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Symptoms</td>
<td>Impact</td>
</tr>
<tr>
<td>----------------------------</td>
<td>------------------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Diabetes</td>
<td>Impaired vision</td>
<td>Can’t see fine print, small objects, or details</td>
</tr>
<tr>
<td></td>
<td>Impaired sense of touch</td>
<td>Can’t feel blisters, ‘sticks’, cuts, or skin damage to hands or feet</td>
</tr>
<tr>
<td></td>
<td>Limb loss due to infections &amp; poor circulation</td>
<td>Learn to use wheelchair or prosthesis</td>
</tr>
<tr>
<td></td>
<td>Routine of food, exercise &amp; medication is needed</td>
<td>Can’t miss meals, skip medication times or forget to exercise</td>
</tr>
<tr>
<td>Hypertension</td>
<td>Vision damage</td>
<td>(See visual changes with aging)</td>
</tr>
<tr>
<td>(a silent killer)</td>
<td>Organ damage</td>
<td>Less ‘reserve’ available when stressed</td>
</tr>
<tr>
<td></td>
<td>Increased risk of stroke</td>
<td>(see stroke &amp; heart disease)</td>
</tr>
<tr>
<td>Heart Disease</td>
<td>Congestive heart failure - poor pumping</td>
<td>Can walk only short distances</td>
</tr>
<tr>
<td></td>
<td>Heart Attacks - heart damage</td>
<td>Self-care activities wear you out</td>
</tr>
<tr>
<td>Urinary Incontinence</td>
<td>Stress incontinence - leaks</td>
<td>Can’t catch your breath</td>
</tr>
<tr>
<td></td>
<td>Urge incontinence - quick floods</td>
<td>May have to avoid ‘heavy’ work activities</td>
</tr>
<tr>
<td></td>
<td>Overflow incontinence - back up into kidneys</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Functional incontinence - can’t get to the right place in time</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mixed - multiple types and causes</td>
<td></td>
</tr>
<tr>
<td>Arthritis</td>
<td>painful and swollen joints</td>
<td>difficulty holding and manipulating objects and tools</td>
</tr>
<tr>
<td></td>
<td>limits in hand motion and control</td>
<td>hard to get up and down, hard to clean and garden</td>
</tr>
<tr>
<td></td>
<td>limits in knee and hip movements</td>
<td>hard to reach, do laundry, and dress</td>
</tr>
<tr>
<td></td>
<td>limits in shoulder movement</td>
<td></td>
</tr>
<tr>
<td>Senile Macular Degeneration</td>
<td>central field of vision is missing</td>
<td>can’t read or look immediately to front</td>
</tr>
<tr>
<td></td>
<td></td>
<td>can’t see who you are talking to have only peripheral vision</td>
</tr>
<tr>
<td>Cataracts</td>
<td>limited vision due to glare sensitivity</td>
<td>can’t see near windows</td>
</tr>
<tr>
<td></td>
<td></td>
<td>can’t see fine detail</td>
</tr>
<tr>
<td></td>
<td></td>
<td>can’t read magazines</td>
</tr>
<tr>
<td>Glaucoma</td>
<td>tunnel vision</td>
<td>can’t see floor, sides, top</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Symptoms</td>
<td>Impact</td>
</tr>
<tr>
<td>----------------------------</td>
<td>---------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Depression</td>
<td>Reduced appetite&lt;br&gt;Loss of energy&lt;br&gt;Loss of interest in activities and life&lt;br&gt;Changes in sleep patterns&lt;br&gt;Problems thinking &amp; problem solving</td>
<td>Don't care for self, home, or others&lt;br&gt;Make poor decisions&lt;br&gt;Unaware of environmental risks&lt;br&gt;Increased risks of falls at night&lt;br&gt;May eat spoiled food</td>
</tr>
<tr>
<td>Dementia (Alzheimer’s, MI dementia)</td>
<td>Progressive loss of cognitive function&lt;br&gt;Loss of recall, STM, then LTM&lt;br&gt;Loss of judgment and environmental awareness&lt;br&gt;Loss of self</td>
<td>Forgets information&lt;br&gt;Misreads the environment&lt;br&gt;Gets lost&lt;br&gt;Tries to do familiar things - makes significant/dangerous errors</td>
</tr>
<tr>
<td>Alcoholism</td>
<td>cognitive losses&lt;br&gt;Loss of social support&lt;br&gt;Liver damage&lt;br&gt;Impaired safety awareness</td>
<td>Increased risk for falls or injuries&lt;br&gt;Increased problems with maintaining home care and self care skills&lt;br&gt;Nutritional problems</td>
</tr>
<tr>
<td>Parkinson’s Disease</td>
<td>Mask-like face&lt;br&gt;Rigid posture&lt;br&gt;Difficult to start movements&lt;br&gt;Shuffling gait&lt;br&gt;Difficulty chewing and swallowing</td>
<td>Hard to communicate with others&lt;br&gt;Hard to get up or down&lt;br&gt;Difficult to go up or down steps&lt;br&gt;Difficult to step over objects&lt;br&gt;Hard to do any fine motor activity</td>
</tr>
<tr>
<td>Stroke - left side involved</td>
<td>Left arm and leg don’t work well&lt;br&gt;Difficulty with order &amp; organization&lt;br&gt;Lacks awareness of deficits&lt;br&gt;Problems with numbers and visual motor skills</td>
<td>Problems with mobility&lt;br&gt;Problems with planning out movements &amp; activities&lt;br&gt;Poor safety awareness during activities&lt;br&gt;Trouble with visual information &amp; scanning</td>
</tr>
<tr>
<td>Stroke - right side involved</td>
<td>Right arm and leg don’t work well&lt;br&gt;Difficulty with language and speech&lt;br&gt;Slow in attempting things&lt;br&gt;Problems with fine motor actions&lt;br&gt;Vision losses to the right side</td>
<td>Problems with mobility&lt;br&gt;Problems with performing actions and tasks&lt;br&gt;Hesitant to try things&lt;br&gt;Trouble with understanding speech&lt;br&gt;Difficulty finding using words</td>
</tr>
<tr>
<td>COPD</td>
<td>Difficulty breathing&lt;br&gt;Have to puff to breath&lt;br&gt;Can’t raise arms over head and breathe at the same time</td>
<td>Need to use oxygen&lt;br&gt;Have to rest arms on tabletop to breathe well&lt;br&gt;Hard to shower or bathe&lt;br&gt;Wear out quickly - need to sit &amp; rest</td>
</tr>
</tbody>
</table>
Ten Recommendations for Working with Older Adults

I. Thou shalt **ASK** not **tell** older people how to make changes!

II. Thou shalt give older people **choices** not absolutes!

III. Thou shalt think carefully about **compensating for loss** and its meaning before acting.

IV. Thou shalt consider helping to **restore abilities** and function before giving up.

V. Thou shalt recognize that **aging is a process**, not a product or end point

VI. Thou shalt acknowledge **the person first**, their strengths next, then their deficits.

VII. Thou shalt listen to the **meaning of the message**, not just the words.

VIII. Thou shalt recognize that **habits of a lifetime** are hard to break & take energy, will, and time to do so.

IX. Thou shalt always remember that older people are **more different** than they are alike!

X. Thou shalt treat older people as you would wish to be treated --- with **respect**.
Personal Information Sheet

Name: ___________________________

Age : _________  Diagnoses: _____________________________________

Marital Status: _____________________

Work History: ______________________________________________________________
   ______________________________________________________________________

Income (after retirement): _____________________________________________________

Location of Home: __________________________________________________________

Type of Home: _____________________________________________________________
   ______________________________________________________________________

Leisure Interests: ___________________________________________________________
   ______________________________________________________________________

Family History of Illness and Disease: ___________________________________________
   ______________________________________________________________________

Home Care Activities: ________________________________________________________
   ______________________________________________________________________

Primary Transportation Option: ________________________________________________

Check your preferences from those listed below:

___ Spend most time with others - be with people
___ Spend most time with close friends or family
___ Spend most time doing things - on your own
___ Spend most time sitting quietly - on your own
___ Read newspapers, books or magazines
___ Listen to radio or music
___ Watch TV or movies
___ Talk with other people
___ Go for walks or runs
___ Work in the yard or garden
___ Clean or decorate the house
___ Build or make things
___ Cook or bake
___ Play on the Internet
___ Eat fresh fruits & vegetables
___ Eat sweets & desserts
___ Eat salty treats
___ Eat fried foods, eggs or meats
___ Drink coffee, caffeinated sodas, or tea
___ Eat whenever its convenient - no set time
___ Follow all the guidelines & rules to stay safe
___ Willing to take only small risks - safety is best
___ Make own decisions - safety is equally important
___ Personal choice is more important than safety
___ Sit on the couch and hang out
___ Take quiet, slow walks
___ Work out at the weight room or aerobics center
___ Get exercise through home care or leisure tasks
___ Plan things out in advance and follow ‘the plan’
___ Plan out some, then ‘play it by ear’
___ Live spontaneously, just let it happen

___ Stay at home
___ Go out with friends and family
___ Socialize and visit others
## Planning Worksheet

<table>
<thead>
<tr>
<th>Area - Activity</th>
<th>Potential Problems</th>
<th>Potential Solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cook a meal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Take a bath or shower</td>
<td></td>
<td></td>
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<tr>
<td>Select and watch a TV program, video, or listen to the radio or preferred music</td>
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<td></td>
</tr>
<tr>
<td>Do a load of laundry</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Go buy groceries &amp; put them away</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pay your bills and manage your money</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work in the yard</td>
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</tr>
</tbody>
</table>
Demystifying Resistance

Caring for Someone with Dementia: How You Help Makes a Difference

Teepa Snow, MS, OTR/L, FAOTA
Dementia Care & Training Specialist, Positive Approach, LLC
Counseling Associate – Duke University School of Nursing
How Can We Help With Resistive Behaviors?

FIRST – Describe the Behavior
Use OBJECTIVE words
What happens? Where does it happen? Who is involved? When does it happen?
What else has been going on during the day?

THEN... *Figure out what you know and what you don’t know!*
Take the time to fill in ALL the pieces of the puzzle!

**Who is the Person?**
History & Life Patterns & Preferences

**Health Issues?**
Problems with senses, movement, pain, emotions, temperature, fatigue…

**Level of Dementia?**
Memory, language, understanding, impulsiveness, sensory awareness

**Other people?**
Approach, words, actions & reactions

**Environment?**
What’s going on all around? How does it look, sound, feel?

**Patterns & Routines?**
How does this fit in with the rest of the day? Is this related to old personal habits or rituals?

NOW --- BRAINSTORM —
Given all the pieces of the puzzle… What do you think is going on? How would you explain the behavior of this person?

THEN --- COME UP WITH AN ACTION PLAN!
What will you try? How do you think it might help? How will you know if it works? Who will be doing what?
**First** – Describe the Behavior – Be Objective

What happens?

Where does it happen?

When does it happen?

Who is involved?

What is said? Done?

How does it start? Stop?

don’t know. Fill in all the parts of the puzzle.
NOW --- BRAINSTORM –
Given all the pieces of the puzzle… What do you think is going on?
How would you explain the behavior of this person?

THEN --- COME UP WITH AN ACTION PLAN!

What will you try?
How do you think it might help?
How will you know if it works?
Who will be doing what?
Concerns about Nutrition and Dementia

Three Categories
♦ Adequacy
♦ Safety
♦ Independence

Diamond - Level 5 – Early Loss –
At this level the person is able to do the everyday things related to fixing and eating familiar meals fairly well, with few errors. They are starting however to have trouble getting things organized or in doing things differently or learning new diets, meal preparation techniques, shopping patterns, and time awareness is sometimes impaired.

Issues:
♦ Routines are generally OK, BUT any changes in routines due to changes in health or well-being are hard to implement
♦ Problems are sometimes in meal preparation & shopping, not eating
♦ ALSO impulsive purchases and decisions around food and cooking start

How Can You Help:
♦ Meal preparation – keep things simple, consider re-structuring family gatherings for less demand and coordination
♦ Shopping - use lists or a partner in familiar places
♦ Cooking – do the familiar or keep it simple
♦ Following diets – be realistic and reasonable in expectations
♦ Food storage – help with clean up, give leftovers to a family member, do frequent frig checks
♦ ROLE in the family – respect the desire to stay in charge – provide support NOT ‘take over’
♦ Eating behaviors – watch for changes or eating more than usual or eating less, watch for changes in frequency of meal intake, watch for increases in ‘eating out’
♦ Medication coordination – help in matching medication regimens with meals, vitamins
♦ Hydration – look at type of fluids (consider reducing ‘caffeine’ and sugar) and the amount of fluids (8-10 cups a day)
♦ Drinking – watch amounts of alcohol consumed
♦ Consider – introducing a microwave and prepared meals IF the person is amenable
Emerald - Level 4 – Moderate Loss
At the level the person still frequently believes they can do whatever needs to be done. They like to complete familiar tasks and activities related to fixing and eating food, BUT they are having trouble with sequencing and getting things done in the right order, losing attention during tasks, doing what they ‘notice’ visually, and are not aware of their errors becoming frustrated, sad, or angry when others point out mistakes for need for ‘help’.

Issues:
♦ difficulty keeping track of tasks and time
♦ getting stuck in repeatedly thinking they need to cook something or buy something or eat something
♦ storing things in unsafe places then using
♦ problems following recipes and plans
♦ easily distracted especially with visual information
♦ difficulty ‘scanning’ to find things
♦ mis-using some tools or mistaking some supplies (salt versus sugar)
♦ not eating enough or eating too much
♦ can’t remember whether they have eaten or cooked already
♦ staying on any restricted diets or medical programs
♦ being ‘rude’ in public eating places
♦ eating only one ‘meal’ over and over
♦ eating dessert before the meal is finished and then being ‘done’
♦ seeing empty plates and thinking the meal was missed
♦ being rigid about meal times or foods
♦ dentures get misplaced or lost (as do glasses and hearing aids)

How Can You Help:
♦ Shopping - with a list and a partner, after a review of what is already there to avoid over-purchase OR have someone else take over the list and have the person gather items in the cart
♦ Cooking – only with a partner to monitor for ‘timing’ and ‘stove use’, assist with coordinating food items to get a meal, offer options to be prepared (“Do you want to fix beans or peas tonight?”), offer tasks to do NOT the whole meal, put items out of sight when meals are not needed, consider changing the control on the stove so it can be locked out when guidance is not available
♦ Look for evidence or ‘burned pots’ ‘bad food’, ‘mis-storage’ and then create a response plan
♦ Diet – try to be realistic and limit availability to items that are ‘truly’ problems
♦ Eating – Consider food items that may not need cutting or preparation on the plate (bite-sized pieces are already provided), serve only one course at a time (for the whole table), consider weekly repeated menus with the familiar,
♦ If eating too much or too often – make meals much smaller and offer more between meal ‘snacks’ and put away plates and food as soon as the meal is done AND get the person out of the eating or cooking area as much as possible
♦ Eat with the person… show by doing with NOT doing for
♦ Check dentures for fit & structure mouth care 2-3 times a day
Amber - Level 3 – Moderately Severe Loss
The person will gradually have more and more difficulty with fine motor activities at this level (chewing, using utensils, swallowing safely). Spillage is more common and adequate nutrition can become a problem.

Typical Issues
♦ Gradual decrease in ability to chew well- may choke, spit foods out, refuse food, hold food in mouth, or swallow things whole
♦ Poor control over bite size and speed of eating – generally too fast
♦ Uses fingers to feed self – sloppy and poor awareness of spillage
♦ Will reach across and eat other’s food
♦ Will frequently only eat or drink when helped to do so
♦ Seems to ‘play in food’ rather than eating it
♦ Will put things other than food in mouth
♦ May try to drink too quickly – lots of spillage, may choke self, or aspirate
♦ Gradual loss of ability to use utensils (knife, fork, spoon)
♦ May eat only a few items – tend toward desserts/sweets – stops eating meat, fresh vegetables and fruits, and foods with lots of texture or pieces (like rice)
♦ May be very slow to eat, drifting off during meals, touching things but not eating or leaving the table
♦ Hands and fingers are used to explore the world around them
♦ dentures get misplaced or lost (as do glasses and hearing aids)
♦ dentures don’t fit anymore
♦ teeth are in bad condition and there may be mouth pain

How You Can Help:
♦ Watch during meals and snacks
♦ Sit with the person and ‘nibble’ while being prepared to help
♦ Use a bright colored placemat and contrast colored plate
♦ Consider getting an ‘inner lip’ plate to control spillage
♦ Monitor weight each 2-3 weeks for changes
♦ Consider a multi-vitamin – can do liquid or powder if necessary
♦ Increase the amount of finger foods and easy to eat foods
♦ Use alternate sources of protein – eggs, yogurt, cheese, beans
♦ Reduce the number of items served at a time
♦ Only use 1-2 utensils
♦ Give hand-under hand guidance for a few bites, if having trouble getting started
♦ Limit the amount on the plate at a time, if food is eaten too quickly
♦ Consider a cup with a cover and possibly a straw to reduce spillage and control speed of drinking
♦ Check with an OT or SLP to see if texture changes may be needed due to difficulty chewing or swallowing
♦ Check dentures for fit and hygiene – may need to not use them, if they are uncomfortable or the person takes them out
♦ Help with mouth care 3 times a day – after meals to make sure all food is out of the mouth
♦ Wash hands and faces with warm wet cloths before and after meals
♦ Change your help as abilities fluctuate during the day – mornings may be easier than other meals
Ruby - Level 2 - Severe Loss

The person will typically have difficulty eating, interest in food will vary and may drop a lot, the person is not able use their fingers effectively to self-feed and will need help with both attention to the food and eating and drinking. The person make keep mouth closed when offered food or make hold it in their mouth, or spit it back out. Weight loss is common at this level with more time spent walking or rolling around and poor interest in eating. Hand under hand assistance is very helpful at this level.

Issues:
♦ Limited appetite and thirst
♦ Poor chewing
♦ Hand skill is poor
♦ Hand hygiene is poor
♦ May not like to sit down at a table
♦ May refuse food or drink with greater frequency
♦ May spit out food or drink
♦ May hold items in mouth
♦ Aspiration risks may be high
♦ Weight loss is very, very common and can be severe
♦ Skin problems arise due to poor nutrition and hydration (dry skin, frail skin, pressure areas, sores)
♦ Can’t make needs or preferences known with words
♦ May grab and try to eat non-food items, packets or food or condiments, or paper products
♦ Fluids may need to be thickened to reduce risk of aspiration or choking
♦ May go to sleep during attempts to help eat
♦ Speed slows a lot

How Can You Help:
♦ Provide hand-under-hand help
♦ Monitor carefully during meals for safety and adequacy
♦ Offer supplements BETWEEN meals
♦ Offer fluids through many options – popsicles, jello, sherbet, smoothies, pureed fruit (applesauce, etc.)
♦ Offer food frequently during the day – walking snacks
♦ Start with several sips of liquid before giving food to make sure mouth is moist and food won’t stick
♦ Use 5 bites and a drink to keep food from building up in the mouth
♦ If the person is sleepy or drowsy – consider helping them wake-up before eating – a cool cloth
♦ Go slow with eating – help eat at the 'best' times of the day
♦ Mornings may become the 'heavy meal' since many folks eat best then
Pearl - Level 1 – Extreme Loss
The person will become bed or chair bound with little movement in arms or legs, limited ability to take deep breaths or coordinate breathing and eating. Risk of swallowing and breathing problems will increase. The person may stop eating and drinking at any time – this is related to loss of control from the brain and changes in the digestive tract – less being absorbed.

Issues:
♦ Lack of hunger and thirst sensation - refusals of food or drink
♦ Poor swallowing and breathing coordination – swallowing & aspiration problems
♦ Poor ability to fight infections – URI & UTI are common
♦ Dehydration – not interested or able to take in enough fluids
♦ Malnutrition – not interested and alert enough to eat enough
♦ More mouth breathing so dry mouth is common
♦ Pressure sores may form due to lack of movement
♦ Frequent periods of drowsiness or sleepiness – hard to get food and drink in safely

How Can You Help:
Use a rhythmic, deep voice when communicating and helping
Use hand under hand when possible or modified hand-under-hand
Get the person upright and have them stay upright for at least an hour or so after meals
Check mouth before and after meals – use a moist washcloth to wipe
Give some fluids first and after about every 5 bites (even if it is thickened liquid)
Go slow
Use an invigorating back rub to help stimulate alertness at times
Talk as you go to help stay connected to the person
Offer comfort mouth care as desire for food and drink leaves
Consider pleasant aromas to help stimulate interest or comfort

*** talk about AND decide what you want to do about end-of-life issues ***
♦ ? When are antibiotics causing more discomfort than helping ?
♦ ? When should you quit ‘pushing’ food and drink and only OFFER ?
♦ ? Would this person want a feeding tube for themselves ?
♦ ? Can you give the person permission to leave you ?
♦ ? Do you understand the difference between starving and being thirsty and what the end of this condition looks like?
# Best Ways of Helping By Gem Levels

## Diamond – Early Stage
**ACL - Level 5**

**Visual cues:**
- Written info – highlighted
- Schedules posted near door
- Key word signs
- Way finding signs
- Location markers
- Name tags
- Place markers
- Objects in view

**Verbal cues:**
- Talking and sharing information
- Use of preferred name/title
- Ask to try
- Ask for help
- Provide options and alternatives
- Providing positive feedback
- Say “please”. “May I”, and “Thank you”
- Say “I’m sorry” if the person is getting angry or upset

**Tactile cues:**
- Offer friendly greeting using PPA
- Touch to direct visual attention during task only if touch seems OK for that person
- Consider introducing lotion application to hands/arms/feet/legs to help the person begin to get more comfortable with having someone touch during care tasks

## Emerald - Mid Stage
**ACL - Level 4**

**Visual cues:**
- Simple written words or direction markers
- Key word signs and location markers
- Daily schedules only
- Place objects/tasks in view to do REMOVE when not wanting the person to do it
- Offer tool or item to be used with the correct orientation
- Open doors to show what is there
- Use simple pointing and gestures to clarify requests
- Show objects in choice options rather than just words
- Offer only two options rather than full range of possibilities
- Do the action, task, portion of task yourself (in supportive position)

**Verbal cues:**
- Talking and sharing info – simplify & reduce amount
- Task focused conversation
- Ask for help
- Ask to try something
- Break the task down into steps, rather than a whole process (rather than – “go & get ready” use first – “Let’s go get your hair looking good”, then mouth care…. Etc.)
- Use of friendly supportive greeting and comments
- Use preferred name to get attention and re-connect
- Give positive feedback as task is attempted – keep it mature – deep voice, simplified
- At completion, indicate THANKS and positive affirmation

**Tactile cues:**
- Hand-under-hand to greet and connect and guide some movements
- Touch for comfort and in greeting
- Touch body parts to draw attention during a task
- Provide minimal tactile guidance
- Do NOT touch or take over without permission
Amber – Moderate Stage  
ACL - Level 3

Visual cues:
- Limit what is seen – one item at a time
- Place objects and tools in view
- Show the movement or action
- Offer the tool or item correctly oriented
- Demonstrate the action or next step on yourself
- Use SUBSTITUTION – not subtraction - Point to or offer next object, item, or tool, as you offer to take the one the person has in hand
- Offer positive head motions, smiles, and gestures indicating success or acknowledgement or sensory reactions and responses – change intensity of the sensation if possible

Verbal cues:
- Call preferred name to get attention or re-direct
- Repeat some of the words the person is using to indicate connection and listening – tone may be questioning or affirming depending on situation
- Use limited words – 2-3 at a time to give information
- Offer directive words rather than conversation
- Combine verbal with strong visual cues
- Break tasks down into single steps, cue through each
- Use a firm, deep, friendly voice tone
- Use affirming statements and say THANK YOU at the end of task attempts
- Indicate you are “sorry” if the person is emotionally distressed by the sensory experience

Tactile cues:
- Greet and sustain HuH to ensure connection and protection for both people
- Give a slight squeeze in HuH to redirect attention to you during interaction – if distracted
- Use touch to a body part to redirect attention to task
- Use hand-under-hand to guide through movement action, or portion of a task 1-2 times – then release for person take over
- Use HuH during most complex portion of the task, then encourage person to re-control the action/tool once done with that portion
- When doing a task near a ‘high-intensity’ sensory area (lips/tongue/mouth/face, palms of hands or fingers, soles of feet or toes, or genitalia or perineal area) – provide a SECOND point of contact that is stable and offers firm steady pressure – open flat palm on shoulder, back, hip, at knee

Ruby – Severe Stage  
ACL – Level 2

Visual cues:
- Once eye contact is established, direct visual regard to object, task, motion with a strong, slow simple gesture
- Use of big movements with gestures that are simple and directive for direction or action
- Demonstrate with your own body what action or movement you are seeking
- Slowly repeat the motion or action several times
- Use head motions and smiling to give positive feedback

Verbal cues:
- Call name to get attention
- Keep voice calm, deep, relaxed
- Use simple, directive phrases to seek information
- Repeat some of the words the person uses to seek connection (add a questioning tone or an affirming tone to indicate listening and attention
- Limit talking based on response by the person - be quiet OR offer friendly responses to attempts to converse depending on what the person is doing – using some of their words
- Offer positive affirmation of cooperation or participation – not based on success or accuracy – keep words simple and use visual affirmation

Tactile cues:
- Provide a firm, gentle pressure at a joint or in combination with a strong and simple directive visual and verbal prompt to get movement (not pushing or pulling – just cueing)
Use HuH to offer guidance – use arm/hand to begin the movement
If guidance is not enough, use HuH assistance throughout tasks that require tool or object use that requires fine-motor coordination or manipulation
When doing a task near a ‘high-intensity’ sensory area (lips/tongue/mouth/face, palms of hands or fingers, soles of feet or toes, or genitalia or perineal area) – provide a SECOND point of contact that is stable and offers firm steady pressure – open flat palm on shoulder, back, hip, at knee

Pearl – End Stage
ACL- Level 1

Visual cues:
• Making eye contact
• Using head movements and facial expressions to communicate
• Use demonstration for action requests
• Use gestures with non-HuH arm or hand to guide or direct attention or focus

Verbal cues:
• Use name to gain attention – GO SLOWLY
• Give simple information about what you are going to be doing

• Give simple 1-3 word directive words or phrases to help with movement as you assist with the movement
• Use a calm, firm, deep voice that is soothing if trying to relax the person or that has some energy and excitement in it if trying to wake the person or keep them engaged
• Use positive comments and affirmation as attempting to anything with the person

Tactile cues:
• When doing a task, if at all possible keep one hand open and still on shoulder, hip, back, elbow, knee – so that there is only movement at one point and there is a second point of contact that is stable
• Use HuH if the person has a grasp reflex to prevent ‘grabbing’ during interaction and task completion
• When doing a task near a ‘high-intensity’ sensory area (lips/tongue/mouth/face, palms of hands or fingers, soles of feet or toes, or genitalia or perineal area) – provide a SECOND point of contact that is stable and offers firm steady pressure – open flat palm on shoulder, back, hip, at knee
• When cleaning or drying underarms or groin start movement from back of body, reach to front from the rear and stroke from front to back, BUT without digging into flesh from the front or trying pry thighs apart to get into perineal area.
Dealing with Distress

Caring for Someone with Dementia: How You Help Makes a Difference

Teepa Snow, MS, OTR/L, FAOTA
Dementia Care & Training Specialist, Positive Approach, LLC
Counseling Associate – Duke University School of Nursing
How Can We Help With Distress?

**FIRST** – Describe the Behavior
*Use OBJECTIVE words*
What happens? Where does it happen? Who is involved? When does it happen? What else has been going on during the day?

THEN… *Figure out what you know and what you don’t know!*
Take the time to fill in ALL the pieces of the puzzle!

**NOW --- BRAINSTORM ---**
Given all the pieces of the puzzle… What do you think is going on? How would you explain the behavior of this person?

**THEN --- COME UP WITH AN ACTION PLAN!**
What will you try? How do you think it might help? How will you know if it works? Who will be doing what?

**Who is the Person?**
History & Life Patterns & Preferences

**Level of Dementia?**
Memory, language, understanding, impulsiveness, sensory awareness

**Environment?**
What’s going on all around? How does it look, sound, feel?

**Health Issues?**
Problems with senses, movement, pain, emotions, temperature, fatigue…

**Patterns & Routines?**
How does this fit in with the rest of the day? Is this related to old personal habits or rituals?

**Other people?**
Approach, words, actions & reactions

**Environment?**
What’s going on all around? How does it look, sound, feel?

**Health Issues?**
Problems with senses, movement, pain, emotions, temperature, fatigue…

**Who is the Person?**
History & Life Patterns & Preferences

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Problems with senses, movement, pain, emotions, temperature, fatigue…

**Patterns & Routines?**
How does this fit in with the rest of the day? Is this related to old personal habits or rituals?

**Other people?**
Approach, words, actions & reactions
First – Describe the Behavior – Be Objective

What happens?
Where does it happen?
When does it happen?
Who is involved?
What is said? Done?
How does it start? Stop?

Then - Review what you know and don’t know. Fill in all the parts of the puzzle.
NOW --- BRAINSTORM –
Given all the pieces of the puzzle… What do you think is going on?
How would you explain the behavior of this person?

THEN --- COME UP WITH AN ACTION PLAN!
What will you try?
How do you think it might help?
How will you know if it works?
When will it begin?
The ability to remember information...

The ability to use words and language...

The ability to understand what is being said...

The ability to control your impulses, temper, & moods...

REALIZE …

It Takes TWO to Tango … or tangle…

- By managing your own behavior, actions, words & reactions you can change the outcome of an interaction.
- Being ‘right’ doesn’t necessarily translate into a good outcome for both of you
- Deciding to change your approach and behavior WILL REQUIRE you to stay alert and make choices… it is WORK
- It’s the relationship that is MOST critical NOT the outcome of one encounter

As part of the disease people with dementia ‘tend to’ develop typical patterns of speech, behavior, and routines. These people will also have skills and abilities that are lost while others are retained or preserved.

**Typically Lost – can’t use**

**Memory skills**
- immediate recall
- short term memory
- clarity of time and place
- depth of categorical information
- relationships & specifics

**Understanding skills**
- interpretation of abstract meaning
- early - misses ¼ words
- later – misses ½ words
- subtle emotions, ‘unsspoken’ agreements
- at the end – most words

**Language use skills**
- specific word finding
- descriptive abilities
- reading for content
- content of speech
- spoken communication
- words
- meaningful ‘yes’ and ‘no’
- socially acceptable expressions of emotion
- verbal communication of needs and desires

**Emotional & Impulse control skills**
- ability to ‘demand’ respect
- ability to limit or control emotions
- ability to control impulsive speech
- ability to control impulsive actions
- don’t act out when ‘pushed’
- ability to keep private thoughts and actions in private places

**Motor Skills & Sensory Processing**
- at first very little as far as skills go
- later – initiation or getting started
- later – parts of tasks get left out/skipped
- mis-interprets sensory information
- organized scanning is lost
- visual field is restricted
- may become hypersensitive OR hyposensitive to touch, sound, light…

**Preserved – can or may use**

**Memory skills**
- long ago memories
- emotional memories
- confabulation
- procedural memories
- awareness of familiar versus unfamiliar

**Understanding skills**
- ‘gets’ the concrete meaning
- picks out familiar or meaningful words
- covers well
- facial expressions that are consistent with the message being sent

**Language use skills**
- desire to communicate
- ability to use hands or actions to describe
- reading aloud
- rhythm of speech
- para-verbal communication (how you say it)
- music and song
- automatic speech
- swearing, sex words, ‘socially unacceptable’ words
- non-verbal communication of needs and desires

**Emotional & Impulse control skills**
- desire to be respected
- ability to feel emotions and have needs
- say what is on your mind – with errors
- do what you want to do
- sometimes, feel badly after its done
- sometimes, behaving differently in ‘public’ if cues are strong

**Motor Skills & Sensory Processing**
- the movement patterns for pieces of tasks
- gross motor movements last longer than fine motor
- can often do the mechanics – BUT not safely or well
- looks for stuff – seeks out things
- mouth (lips, tongue), fingers and palms, soles of feet, & genitalia or ‘private body parts’
- recognize faces, voices – familiar from not familiar
Progression of the Disease – Levels of Cognitive Loss

**Diamond - Level 5 – Early Loss – Running on Routine – Repeating Stories**
Some word problems and loss of reasoning skill
Easily frustrated by changes in plans or routines
Seeks reassurance but resents take over
Still does fairly well with personal care and activities
Tends to under or over estimate skills

**Emerald - Level 4 – Moderate Loss - Just Get It Done! – Wanting a Purpose and a Mission**
Gets tasks done, but quality is poor
Leaves out steps or makes errors and WON’T go back and fix it
Can help with lots of things – needs some guidance as they go
Likes models and samples – uses others’ actions to figure out what to do
Asks “what /where/when” LOTS
Can do personal care tasks with supervision & prompts
Still very social BUT content is limited and confusing at times

**Amber - Level 3 – Middle Loss - See It – Touch It – Take It – Taste It – Hunting & Gathering**
Handles almost anything that is visible
Does not recognize other’s ownership
Can still walk around and go places
Language is poor and comprehension very limited
Responds to tone of voice, body language and facial expression
Loses the ability to use tools and utensils during this level
Does things because they feel good, look good, taste good – refuses if they don’t
Stops doing when it isn’t interesting anymore
Can often imitate you some – But not always aware of you as a person

**Ruby - Level 2 – Severe Loss – Gross Automatic Action – Constant GO or Down & Out**
Paces, walks, rocks, swings, hums, claps, pats, rubs…..
Ignores people and small objects
Doesn’t stay down long in any one place
Not interested in food – significant weight loss expected at this level
Can grossly imitate big movements and actions
Generally enjoys rhythm and motion – music and dance

**Pearl - Level 1 – Profound Loss - Stuck in Glue – Immobile & Reflexive**
Generally bed or chair bound – can’t move much on own
Often contracted with ‘high tone’ muscles
Poor swallowing and eating
Still aware of movement and touch
Often sensitive to voice and noise
Difficulty with temperature regulation
Limited responsiveness at times, very aware at others
How care is delivered matters, how the person is touched, matters
A Positive Approach

- **Come from the FRONT** – let them know you are coming
- **Go SLOW** – reaction times slow as we age – it takes longer for info to get in
- **Get to the SIDE** – be supportive NOT confrontational
- **Get LOW** – don’t use your height to intimidate
- **Offer HAND** – let them start the interaction
- **Call NAME** – the name that person PREFERENCES!
- THEN wait…….

- **Start Message**
  - Give basic information
    “It’s time to…”
  - Give simple choices
    this or that (orange juice or milk) (eat or go to the bathroom first)
  - Give single step directions
    break down the task (to go to eat…. lean forward…, pull your feet in…)
  - Ask the person to HELP you
    it feels better to give than to receive!
  - Ask the person if they will at least TRY???????
    sometimes you’ll try even if you don’t think you can!
  - DON’T Ask “Are you ready…??? “or “Do you WANT to…?”
  - DON’T have verbal diarrhea

- **WAIT for a response (silently count to 10)**
  IF No response … ask again

  IF Responding ....
  - **Give positive STROKES - Feedback**
    - “Good job!”
    - “Yes!”
    - “That’s it”
    - smile, nod
    - hug
    - stroke or rub

**REMEMBER – You HAVE THE POWER!**
Keep it Calm!
Keep it Adult!
Keep it Positive!
Keep it Simple!
AVOID Flight, Fright, or Fight… they waste your time!
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)
     1 - give a short, direct message about what is happening
     2 - give simple choices about what the person can do
     3 - ask the person to help you do something
     4 - ask if the person will give it a try
     5 - break down the task - give it one step at a time
     ** 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 the BEST that s/he can
     AND 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
     ♦ 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

3 - 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

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!

Key Points About 'Who' the person is....
- preferred name
- introvert or extrovert
- a planner or a doer
- a follower or a leader
- a 'detail' or a 'big picture' person
- work history - favorite and most hated jobs or parts of jobs
- family relationships and history - feelings about various family members
- social history - memberships and relationships to friends and groups
- leisure background - favorite activities & beliefs about fun, games, & free time
- previous daily routines and schedules
- personal care habits and preferences
- religious and spiritual needs and beliefs
- values and interests
- favorite topics, foods, places
- favorite music and songs - dislike of music or songs
- hot buttons & stressors
- behavior under stress
- what things help with stress?
- handedness
- level of cognitive impairment
- types of help that are useful
### Personal History

<table>
<thead>
<tr>
<th>Areas to Explore</th>
<th>What Did You Find Out?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preferred Name</td>
<td></td>
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<tr>
<td>Preferred Hand</td>
<td></td>
</tr>
<tr>
<td>Living Situations &amp; history</td>
<td></td>
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<tr>
<td>(where are you from today &amp; originally, who do &amp; did you live with, what type places did you live in (house, apt, farm…))</td>
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<tr>
<td>Marriage history &amp; status</td>
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<tr>
<td>(who’s involved, has been involved, and how do you feel about them?)</td>
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<tr>
<td>Family history &amp; membership</td>
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<tr>
<td>(who’s who and how do you feel about them? Think about several generations…)</td>
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<tr>
<td>Work history</td>
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<tr>
<td>(what jobs have you had in your life? How did you feel about them? What are some jobs you would have loved to do, but never did?)</td>
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<tr>
<td>Leisure history</td>
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<tr>
<td>(what do and did you do for fun and in your spare time? How do you feel about ‘having fun’? What would you like to do if you had the money? time? Skill?)</td>
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<tr>
<td>Spiritual history</td>
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<tr>
<td>(what religion do you and did you follow, how involved are you and were you, and how important is it to you? How do you feel about other religions?)</td>
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<tr>
<td>Personal care practices &amp; history</td>
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<tr>
<td>(eating habits, sleeping habits, grooming habits, bathing habits…)</td>
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<tr>
<td>Time Use History</td>
<td></td>
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<tr>
<td>(schedules &amp; routines…. When do you and would you like to do things?)</td>
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</tr>
<tr>
<td>Important Life Events</td>
<td></td>
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<tr>
<td>(what are some things that were very important to or happened to you? Do others know about these events?)</td>
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<tr>
<td>Hot Buttons</td>
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<td>(what are things/activities/topics/actions that tend to upset you?)</td>
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<tr>
<td>Chill Pills</td>
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<tr>
<td>(what are things/activities/topics/actions/people that help calm you?)</td>
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</tr>
</tbody>
</table>
Is this a Problem Behavior that NEEDS to be fixed?

1st

Describe the behavior in detail---
• Where does it happen?
• When does it happen?
• Who is involved?
• How does it start? Stop?
• What is said? done?

Then

Answer these questions---
• Could the level of dementia explain some of this behavior?
• Could how the person was approached or helped have some impact?
• Does the person have other medical or psychiatric conditions that might be active?
• Could personal history (work, leisure, family, religion, personality, routines...) play a role?
• Could the environment or cues in it be causing some of the trouble?
• Could the time of day or personal habits be a factor?

BRAINSTORM with the Puzzle Pieces

Come up with a PLAN of ACTION!
- decide on what to do
- decide who will do what
- decide how to do it
- decide when to start it & when to look again

This is not really a PROBLEM behavior for the person with dementia. It may be irritating or embarrassing for the caregiver, but it is really a... ‘SO WHAT’ behavior

Learn to let it go!
Leave it alone!
Don’t sweat the small stuff!

NO
RETHINK & Problem solve again!

Are things better?

NO

YES
CELEBRATE!

It’s time to PROBLEM-SOLVE!

Does the behavior put someone at RISK?

YES

NO
Drugs that can affect cognition

- Anti-arrhythmic agents
- Antibiotics
- Antihistamines - decongestants
- Tricyclic antidepressants
- Anti-hypertensives
- Anti-cholinergic agents
- Anti-convulsants

Drugs Which Most Commonly Affect Your Memory

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<tr>
<th>Type of Drug</th>
<th>Generic Name</th>
<th>Brand Name</th>
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<tbody>
<tr>
<td>Analgesics</td>
<td>meperdine</td>
<td>Codeine, Demerol, Fiorinal</td>
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<tr>
<td>Antianxiety drugs</td>
<td>alprazolam</td>
<td>Xanax</td>
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<td>Steroid</td>
<td>prednisone</td>
<td>Prednisone</td>
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For more Memory articles, please visit the Memory Topic Page
**Person Behaviors:**

**Approach - Social Behaviors**
- Can initiate social greetings and interactions
- Responds to social greetings
- Will look to see who is at door and respond to a 'knock'
- Carries on conversations - takes turns, asks questions, answers questions (*may be wrong*)
- Seeks out familiar when stressed, unfamiliar when bored
- Uses verbal cues and visual information (*may misinterpret*)
- Can choose and select from among options
- _Speed may be slowed_

**Task Behaviors**
- Often lacks initiation for task start-up
- Uses routines and habits to get through the day
- Can physically perform routine self-care and 'work-related' tasks
- _Speed may be slowed_
- Prefers to have options and to be in-charge of activities
- Follows daily routines and schedules with minimal prompts or reminders
- Blames self or others for errors
- Stops doing tasks that are too challenging or asks someone else to do them

**Caregiver Behaviors:**

**Approach Behaviors**
- Use preferred name
- Ask permission to enter space - acknowledge response
- Engage in conversation
- Offer information about the day, activities, self
- Provide options for time use

**Task Behaviors**
- Prompt and support start of tasks
- Offer options for tasks
- Follow routines
- Hi-light changes in routines
- Use social interaction to engage the person in tasks
- Engage in social exchange during tasks

**Environmental Considerations:**

**Approach Environments**
- Treat the 'room' as personal space
- Make sure personal space is respected
- Ask permission - Turn on the lights
- Ask permission - Turn off the TV/Radio if interacting
- Get to resident's eye level - sit down to interact or walk along side

**Task Environments**
- label locations and storage spaces clearly
- keep things in familiar spaces
- honor location preferences
- use hi-lighted colors or contrasts to emphasize areas
- provide task lighting to focus attention to next task
- limit distractions BUT honor visual and auditory preferences (TVs, radios....)
- make sure all necessary items are present for tasks
Person Behaviors:
Approach - Social Behaviors
- Can initiate social greetings and interactions - often with a request for information or help
- Responds to social greetings - hand shakes & eye contact
- Has very short conversational interchanges - can't come up with much content
- Picks up on selected words or ideas and goes off-target in conversations
- Can make simple choices with two options - may need items presented physically or gestured to
- May carry on conversation with another resident with some assist from staff or the environment

Task Behaviors
- Often starts or repeats tasks if given a visual cue (objects, pictures, people, furniture) to do so
- Uses visual information - objects & pictures, gestures, environmental aids
- Uses verbal cues that are short, concrete, or step-by-step
- Has difficulty interpreting written information - looks at it, but loses its meaning
- Forgets and leaves out steps in familiar tasks
- Repeats familiar activities several times a day - not remembering they have been done already - especially if the visual cues or environmental cues are still there
- Will not do tasks, even if they are very familiar if the cues are missing (eating, shaving, washing)
- Has a poor quality of performance, since it is more important to do it
- Asks repeatedly what they are supposed to do, where to be

Caregiver Behaviors:
Approach Behaviors
- Use preferred name
- Offer your hand - may maintain hand contact to help stay connected
- Keep information short and concrete
- Answer questions with a concrete suggestion and gesture or object presentation
- Offer concrete choices with objects or gestures for 'what to do'
- Use aids during conversation - pictures, objects, environmental information

Task Behaviors
- Pre-set up objects and space for tasks
- Set out items in sequence for task completion, put them away as the step is finished
- Monitor and guide verbally and visually through each step
- Assist with touch or guidance only for the step causing difficulty, then verbal or visual cues
- Stay down and to the side for activities
- Expect slowing and difficulty with step to step transitions
- Provide stability and support, don't push or pull to get action… GUIDE only
- Eliminate extraneous chatter or social conversation during task completion

Environmental Considerations:
Approach Environments
- Treat the 'seating surface' as personal space
- Make sure personal space is respected
- Tell & then turn on the lights
- Tell & then turn off the TV/Radio if interacting
- Get to resident's eye level - sit down to interact or walk along side

Task Environments
- Keep surfaces clear and present only what is to be used - pre-set areas with task cues and objects
- Use 'locked' areas to store items that should be used with staff help
- Have objects and areas visible throughout the day to encourage activities
- provide task lighting to focus attention to the task
- eliminate or limit non-task distractions, visual and verbal
Person Behaviors:
Approach - Social Behaviors
- Misses some approach information
- May look at your hand or what you are holding, rather than you as a person
- Initiates contact with touching, single word, or eye contact
- Often responds with facial expression imitation
- Leaves interactions without closure
- Has minimal ability to take turns or converse
- Seeks out pleasurable stimulation from objects, people, and the environment
- Avoids, escapes, or resists unpleasant stimulation

Task Behaviors
- Focuses on objects, visible cues, textures, & colors
- Touches and holds onto items and props
- Skill at tool use will vary greatly, but there is an interest in them
- Attention may be very intense on one item/action OR may be very scattered moving from one item to another randomly
- May put non-food objects in the mouth to eat or explore them
- May engage in familiar actions/activities repeatedly regardless of need or results
- May continue an activity once assisted to initiate and stimulation old habits
- May actively resist movement to the next step of a task, helped with clear and strong cues
- May exhibit negative affect and attempts to leave tasks if they are ‘unpleasant’
- Can attend only to one thing at a time, is distracted by activity, movement, talking, visual info

Caregiver Behaviors:
Approach Behaviors
- Use preferred name
- Offer your hand – use preferred client hand and use thumb control position from outset
- Use hand-under-hand palm to palm contact to provide clear connection & encourage attention
- Use familiar greeting and smile to start interactions
- Maintain hand contact for next interaction

Task Behaviors
- Place visual cues in work space as they are to be used in the activity
- Guide using hand-under-hand technique or demonstration to help initiate the tasks
- Break all tasks down into short, simple action steps
- Use hand under hand technique for table top and personal care tasks to get started & change steps
- Give simple 2-3 word directions, using inflection and gestures while helping with the movement
- Limit talking during a task, as it may halt action
- Expect to help to start and transition between steps
- Don’t try to go back and ‘fix’ missed steps – wait to the next rendition

Environmental Considerations:
Approach Environments
- Treat the immediate area and surfaces around the person as personal space
- Put chairs at right angles to each other for communicating and working
- Provide light for area that highlights the work space
- Limit visual information not related to tasks, offer visual cues to help initiate actions

Task Environments
- Keep work surfaces clear and have tools or props available only as they are to be used
- Use firm, supportive sitting surfaces (upright chairs with foot resting support and armrests)
- Use task lighting to help focus attention on the task area
- Eliminate extra noise, movement, and activities during a task
RUBY - Level 2 – Gross Movement – ‘Stop and Go Slow”

**Person Behaviors:**

**Approach - Social Behaviors**
- May disregard you as a person
- Will look and investigate parts of you (hand, arm, hair, shirt)
- May not extend hand or respond to approach
- Typically will respond with look, glance, word, or attention to preferred name and touch
- Grasp is reflexive and release is inconsistent
- Tends to ignore others
- **Speed will be slowed**

**Task Behaviors**
- If moving, tends to keep moving
- If still, tends to stay still
- Minimal ability to use hands and tools
- Able to mimic only grossly for movement and action
- **Speed will be slowed**
- May halt and not be able to move to the next step of a task without physical assist
- May refuse or become distressed about tasks that don't feel good
- May have rocking, humming, or clapping during a task

**Caregiver Behaviors:**

**Approach Behaviors**
- Use preferred name
- Offer your hand on the person's lap - slide it into the person's palm if there is no response
- Use hand-under-hand palm to palm contact to reduce risk of grasping that can be painful
- Determine hand choice to offer or use prior to acting
- Use single word greeting and smile
- Maintain hand contact for next interaction

**Task Behaviors**
- Eliminate all but basic, required materials, props for the activity
- Allow gross movement while doing tasks or offering hand-under-hand technique
- Use hand under hand technique for table top and personal care tasks
- Demonstrate the motor task you want the person to do
- Give single word directions, using inflection and gestures while helping with the movement
- Limit talking during a task, as it may halt action
- Use imitation of gross action to help get action started
- Expect to do a majority of all tasks

**Environmental Considerations:**

**Approach Environments**
- Treat the 'person' as personal space
- Put chairs at right angles to each other for communicating
- Provide light for area
- Provide auditory and tactile information simultaneously

**Task Environments**
- Keep work surfaces clear and have tools or props available only for your use
- Use firm, supportive sitting surfaces (upright chairs with foot resting support and armrests)
- Use task lighting
- Eliminate extra noise, movement, and activities during a task
- Keep space warm
- Have all items at hand for your use
PEARL - Level 1 – Reflexive – ‘Minimal Contact with the Outside World’

**Person Behaviors:**

**Approach - Social Behaviors**
- May attend to, respond to, OR **startle** to voice, touch, temperature, sounds
- Eye contact is poor and may be absent
- Ability to reach out is minimal
- Grasp and flexion patterns are strong and reflexive to movement and touch
- Release is not voluntary
- Moaning or sound production is common with contact

**Task Behaviors**
- Moves into flexion patterns with activities and stretching
- Has a strong grasp reflex if palm is touched or stimulated
- Can’t actively 'let go' of objects without help most of the time
- Has poor protective reactions to oral intake, oral care, movement, positioning
- No awareness of 'risky' responses to care
- Reflexive speech and swearing may be elicited with startle, movement, or action
- Quick movements or actions will produce fearful, angry, or anxious motor behaviors

**Caregiver Behaviors:**

**Approach Behaviors**
- Move slowly and keep voice calm and soothing and slow
- Make sure hands are all 'warm' prior to contact
- Use flats of fingers and palms of hands when giving care
- Use hand-under-hand palm to palm contact to manage grasping that will occur
- Maintain a point of contact for the entire interaction
- Say ‘Hi, (name), this is (your name), I am going to help you…”

**Task Behaviors**
- Move slowly and talk slowly focusing on comfort and soothing content and tone
- Keep one hand on the person at all times
- Tell the person in simple terms what you are doing, step-by-step as you are doing it
- Give person time to relax between tasks
- Make sure materials and supplies are warm and pleasant to touch
- Hold the person’s hand in thumb control position at all times when trying to move arms or place a hand roll or object in the hands to control grasp reflex
- Use ‘safest’ positioning and techniques for task performance when reflexes are impaired
- Expect to do a majority of all tasks
- Consider humming or singing, if this is soothing to the person

**Environmental Considerations:**

**Approach Environments**
- Treat the 'person' as personal space
- Turn off other stimulation when giving care
- Provide light for area – ensure light is NOT in the person’s eyes
- Provide auditory and tactile information simultaneously
- Close off interaction prior to leaving

**Task Environments**
- Be aware of and control all sensory components in activities – smell, touch, taste, sound, and sight
- Use comfortable but supportive sitting (special upright seating for oral care and intake)
- Use task lighting that is focused on the task not the person
- Eliminate loud noise, fast movements, or bright lights during a task
- Keep space warm and control air flow into the space (close doors)
- Arrange props and supplies within arms reach prior to starting task
## Gem Levels
Understanding What Each Level Means

### Imagine Driving a Car... At Each Gem Level

<table>
<thead>
<tr>
<th>Gem Level</th>
<th>Basic Meaning</th>
<th>So If They Were Driving a Car.... They would</th>
</tr>
</thead>
</table>
| **Sapphire**    |                                                                             | • Goes slower & stops sooner  
• Reacts slower  
• Takes longer to learn how to operate a ‘new’ car  
• May want to ‘rehearse’ a trip  
• Likes to allow PLENTY of time to make a trip  
• May worry about trips/travel  
• Doesn’t like to be pushed or followed too closely  
• May give up some driving responsibilities due to ‘fear’ of failure or vision or mobility changes  
• May blame others for causing risky situations |
| • Slower to learn  
• Slower to change  
• Slowed reactions and processing | **Normal Aging** Changes – NO Dementia  
Slowing Down                                                                 |                                                                                                               |
| **Diamond**     |                                                                             | • Can drive their OLD, FAMILIAR CAR on their routine trips, along well-known routes, during the usual times, with the regular people in the car, as long as there are NO problems with the weather, equipment, light levels, detours, heavy traffic, distracting conversations of sights, their health, and their family!  
• If there are any changes they may:  
  • Get lost  
  • Get upset or angry  
  • Get scared or panic  
  • Make mistakes that are dangerous  
  • Accuse others of mis-behaving, breaking the law  
  • Make things up to explain what happened  
  • Demand to do it ‘their way’  
  • Refuse to let someone step in and tell them what to do  
  • Get so involved with talking to a passenger, they forget to watch the road |
| • Still sharp  
• Still clear  
• RIGID  
• Expects respect  
• Seeks authority figures  
• Faking it | **Early Dementia** Or Mild Depression  
Mild Cognitive Impairment  
Using old habits & routines to Get By  
Covers up mistakes  
Gets angry at others  
Fears getting caught  
Likes being valued as smart, pretty, thrifty, clever, experienced….  
Wants to tell their old stories  
Wants to let you know who they have been  
Wants to give something to others |                                                                                                               |
| **Emerald**     |                                                                             | • Can do many of the mechanics of driving BUT can’t hook it all together to drive safely  
• Can get in and turn on the car, can put it in gear, but may be looking out the front while it is going in reverse  
• Can ‘know’ how to ‘change the oil’ BUT will make mistakes doing it – empty out the oil, put in a new filter, then fill up the crank case with anti-freeze  
• May turn on the windshield wipers when trying to change the radio station  
• Try to get in a car at the mall that looks like one they owned several years ago – may even try to break in  
• Become upset when they can’t find a car that they had when they were a teenager – accuse a family member of stealing it  
• Try to manually shift an automatic transmission  
• Stop to fill up with gas at every station  
• Forget to pay one time, then overpay the next  
• Sit at the entrance ramp and wave at the passing cars, then get out to flag help down on a busy highway |
| • Change is clear to others  
• Flaws are not so noticeable to the person  
• Still can pull it together at times  
• Has some social graces, but makes mistakes  
• Uses what is seen to try to figure out what to do  
• Going into the past | **Moderate Dementia** Or Significant Depression  
Repeats some steps Skips some steps  
Thinks it’s OK  
Fears being disrespected  
Gets lost in time & place  
Go back in time  
Mis-remembers & makes stuff up to fill in  
Wants to be ‘normal’  
Wants to be in the ‘action’  
Wants to be helpful and involved OR left alone to do what they want to do  
Do things or supervise others doing things |                                                                                                               |
<table>
<thead>
<tr>
<th>Amber</th>
<th>Mid Dementia</th>
<th>Profound Dementia</th>
<th>Ruby</th>
</tr>
</thead>
<tbody>
<tr>
<td>• In the moment</td>
<td>• Wants to mess with the radio – pushing all the buttons and switches on the</td>
<td>• Unlimited to sit up in the car, leans into the door or onto a partner</td>
<td>• No fine motor</td>
</tr>
<tr>
<td>• All about</td>
<td>dashboard and console</td>
<td>• Generally not aware they are even in a car, but once in a great</td>
<td>only big movements</td>
</tr>
<tr>
<td>sensation</td>
<td>• Gets in the glove compartment and takes everything apart</td>
<td>while will look out and say something like “It’s that beautiful”, or “Pretty,</td>
<td>– over and over</td>
</tr>
<tr>
<td>• All about</td>
<td>• Rolls the windows up and down and throws things out, then tries to open</td>
<td>pretty, pretty”</td>
<td>&amp; over &amp; over</td>
</tr>
<tr>
<td>exploration</td>
<td>the door to go get them</td>
<td>• May like the feel of riding in the car, especially on a long</td>
<td></td>
</tr>
<tr>
<td>• No safety</td>
<td>• May suddenly shift gears or even put the car in reverse, with little or</td>
<td>highway trip – the hum of the engine, the rhythm of the tires, drumming of rain</td>
<td></td>
</tr>
<tr>
<td>awareness</td>
<td>no warning</td>
<td>on the roof</td>
<td></td>
</tr>
<tr>
<td>• No ability to</td>
<td>• May start off wanting to drive the car, but then may just let go of the</td>
<td>• May like to feel the wind and sun on their face as you slowly</td>
<td></td>
</tr>
<tr>
<td>understand</td>
<td>wheel and start to fasten and unfasten their seatbelt over and over</td>
<td>cruise</td>
<td></td>
</tr>
<tr>
<td>another</td>
<td>• Pulls all the knobs off the controls and puts them in their pocket</td>
<td>• May like to sit and cuddle in the backseat, with a blanket over</td>
<td></td>
</tr>
<tr>
<td>person’s point</td>
<td>• Says they want to “Let’s go!” but won’t get in the car</td>
<td>them, like you used to do when you went to a drive in movie</td>
<td></td>
</tr>
<tr>
<td>of view</td>
<td>• Will not get in the car for over 2 hours, but then suddenly gets into the</td>
<td>• May hum to old tunes on the radio</td>
<td></td>
</tr>
<tr>
<td>• Do what is</td>
<td>• Do what is LIKED – avoid what is disliked</td>
<td>• May yell out with bumps or direction changes</td>
<td></td>
</tr>
<tr>
<td>liked</td>
<td>• Sensations and awareness of the world around them</td>
<td>• May suck down some of a milkshake you get at a drive thru</td>
<td></td>
</tr>
<tr>
<td>– avoid what is</td>
<td>• Moments of alertness</td>
<td>• May sniff and get alert when passing by some fresh cut grass,</td>
<td></td>
</tr>
<tr>
<td>disliked</td>
<td>• Aware of sensations at times</td>
<td>newly mown hay, cinnamon scented bakery, or wood smoke</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Slow to respond</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Ruled by reflexes</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Can over-react</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Additional Details

- **Amber**
  - In the moment
  - All about sensation
  - All about exploration
  - No safety awareness
  - No ability to understand another person’s point of view
  - Do what is liked – avoid what is disliked

- **Mid Dementia**
  - Into touching, fiddling, getting into stuff
  - Not aware of the bigger picture
  - Not aware of how their actions affect other things
  - Not aware of danger or risk
  - Likes what they like – doesn’t know when to stop
  - Wears you out, if you don’t take breaks

- **Severe Dementia**
  - More interested in big movement than little – getting in/out of the car
  - May still like the radio, but volume and station are important
  - You will need to think about what they might be trying to tell you/need since they will not know or be able to show you

- **Profound Dementia**
  - Limited movements and responses
  - Reactions can seem extreme
  - Less alert most of the time
  - BUT there are moments of clarity and connection
  - Still needs some stimulation, but careful monitoring is needed

- **Ruby**
  - No fine motor movements – over and over
  - Limited words, repetitive actions or motions
  - Moves forward, not backing up
  - Loses all depth perception
  - Startles easily
Personal History & Individual Information Sheet

1. What is the person’s preferred name? ____________________________________________

2. Tell me about the person’s original home and recent living locations ______________________________________
   a. Where is the person from originally? __________________________________________
   b. Most recently? ______________________________________________________________
   c. Any important travel or home history? ________________________________________
   d. How did the person feel about the move here? __________________________________

3. Tell me about the person’s childhood family and life __________________________________________
   a. Family members, key names & relationships, feelings about childhood, any stories they have told a lot? __________________________________________
   b. Any major life events or traumas that might cause emotional distress or be talked about a lot? __________________________________________

4. Current family and life __________________________________________
   a. Any recent deaths or losses? __________________________________________________
   b. Any favorite people or ones who are ‘the bad guy’ at this time? _________________________
   c. Any recent role changes or relationship changes? ________________________________
   d. Any recent positive or happy events? __________________________________________

5. Tell me about past jobs or work the person has done __________________________________________
   a. Any ‘company’ names we should know? __________________________________________
   b. At work, was the person more of a supervisor or a worker? (used to doing things or monitoring others, going to meetings, or staying physically active, inside or outside work) ____________________________
   c. Any military service history? Branch? War? _______________________________________
   d. Feelings about jobs – what did they like/hate? _______________________________________
   e. Has there been a variety of work places and jobs or just one? _________________________
   f. If a ‘mother/housewife’ did she care for the house or have servants? ________________
   g. How did she feel about housework, cooking, cleaning, kids? ________________________

6. Tell me about how the person spent time when they were not at work? Hobbies, leisure time use, social time use __________________________________________
   a. Past hobbies and ‘free time’ activities? Identify what they liked and how they liked to enjoy it (doing it, watching it being done, going with others or doing it alone, how much and any specifics (like team names, TV show titles, organizations names, level of skill, length of time since last done)________________________
      i. Physical activities and sports _________________________________________________
      ii. Social organizations and groups ____________________________________________
      iii. Outdoor activities _______________________________________________________
      iv. Cultural activities (musical, art, educational, craft events or displays) _____________
      v. Craft activities (hand work, wood work, mechanical work) ______________________
      vi. Reading or books (types, authors, listening/reading, newspaper) ______________
      vii. TV viewing (amount, times, programs, setting) ________________
      viii. Games – tabletop activities (puzzles, board games, cards, party games) __________
      ix. Volunteerism __________________________________________________________________
      x. Outings or travel __________________________________________________________________
      xi. Favorite vacations __________________________________________________________________
xi. Personal pampering (facials, hand treatments/manicures, barber shop, foot baths, lotions)
Any allergies or smell dislikes? ________________________________
b. Describe recent changes in these patterns ________________________________
c. Describe the person’s reaction to these changes ________________________________
d. If the person had ‘nothing to do’ what would they do at this time? How would they probably behave? ________________________________

7. Tell me about the person’s favorite types of music ________________________________
a. Any information on music that the person grew up with versus new tastes? ________________________________
b. Does the person like to sing or just listen? ________________________________
c. Any favorite songs or artists? ________________________________
d. Are there any spiritual or religious music that the person likes? ________________________________
e. Is there any type of music the person has typically DISLIKED? ________________________________
f. Has the person ever played an instrument – professionally or for fun? ________________________________
g. Does the person still have any skill at playing an instrument? Reading music? ________________________________
h. Does the person seem to have strong emotional reactions to any particular pieces of music or songs? ________________________________
i. Has the person gone to live performances? What types? Reactions? ________________________________

8. Tell about the person’s spiritual or religious involvement ________________________________
b. Recent involvement? ________________________________
c. Specific place of worship that is important to know about? ________________________________
d. What faith/religion is the person? ________________________________
e. Are they actively practicing in their faith? ________________________________
f. Are there local resources for sustaining their practices that we should know about? ________________________________
g. Is their faith/religion a major comfort to them? What practices/rituals are part of their daily/weekly habits? How can we help sustain these? ________________________________

9. Tell me about the person’s cultural and ethnic heritage and background ________________________________
a. Where were their parents/grandparents from? (country, region, setting) ________________________________
b. What cultures or ethnic groups were part of their history? ________________________________
c. Are there any cultures/groups the person may prefer? ________________________________
d. Are there any cultures/groups the person may dislike/fear? ________________________________
e. Does the person speak other languages? Is English primary? ________________________________

10. Tell about the person’s favorite places to eat and types of foods ________________________________
a. Has the person liked going out to eat? Where? ________________________________
b. Has the person gone out recently? How was the experience? ________________________________
c. Are there any foods that the person should not eat due to allergies, reactions, negative history, or diet restrictions? Is the person aware and agreeable to these restrictions? ________________________________
d. What are some of the person’s favorite drink items (hot/cold)? What would encourage them to drink something? Are there times or situations that are helpful to encourage drinking fluids? ________________________________
e. Any DISLIKED drinks? ________________________________
f. Does the person enjoy alcohol beverages? What are they? Has the MD approved their continued intake? Are there restrictions on this? Should we provide a non-alcoholic alternative? What suggestions do you have? ______________________________________________________________

11. What are some of the person’s favorite food items? ______________________________________________________________
   a. What are some favorite COMFORT foods? ________________________________________________________________
      Any reason to restrict these foods? ________________________________________________________________
   b. Any modifications needed to ensure safe intake or limit availability? ________________________________________
   c. Are there old family recipes that are important to them? Can they be shared? ____________________________
   d. Has weight or eating become an issue recently? Is the person aware of it? ____________________________
   e. What is the person’s favorite meal of the day? ______________________________________________________________
   f. Does the person like to snack or ‘nibble’ between meals? Specifics? ________________________________
   g. Any DISLIKED foods? ________________________________________________________________
   h. Since we have parties and social events - How does the person behave around ‘freely’ available food and drink? Will they self-limit, serve themselves, take ‘too much’, take it back to their room and ‘forget it’, enjoy serving others? ________________________________________________________________

12. Are there any things that typically annoy/anger the person if they see/hear/experience them? ______
   a. What are they? _____________________________
   b. What has been the person’s reaction? _____________________________

13. Are there things the person typically finds comforting or relaxing? _____________________________
   a. What are they? _____________________________
   b. What has been the person’s reaction? _____________________________
   c. How long does it typically take to calm the person? _____________________________

14. Tell me about the person’s personality and preferences on the following:
   a. Likes it WARM or COOL
   b. Likes it STILL or BUSY
   c. Likes it NOISY or QUIET
   d. Likes it CROWDED or EMPTY
   e. Likes to WATCH OTHERS or TO DO THINGS
   f. Likes to be OUTSIDE or INSIDE
   g. Likes to stay ALONE or BE AROUND OTHERS
   h. Likes to LEAD or FOLLOW
   i. Likes to JOIN RIGHT IN or OBSERVE FROM THE SIDE
   j. Likes to DO WORK or SUPERVISE OTHERS WORKING
   k. Likes THINGS to BE FAIR or PEOPLE TO FEEL OK
   l. Likes to MOVE MORE or TALK MORE
   m. Likes WORK or LEISURE or RELAXATION
   n. Cares more about APPEARANCE or INTELLIGENCE
   o. Cares more about DETAILS or JUST GETTING STARTED
   p. Seems FOCUSED on TIME AND SCHEDULES or DOESN’T KEEP UP WITH TIME OR SCHEDULES
   q. Likes to START CONVERSATIONS & INTERACTIONS or WAITS FOR OTHERS TO START INTERACTING

15. In the past, how much did the person use their hands for leisure/work/relaxation? Always doing something or not much of a ‘busy’ hands person throughout the day? _____________________________
   a. What were some of the person’s favorite ‘hand’ activities? _____________________________
   b. Have there been recent changes in this? What have you noticed? _____________________________
   c. Is there a difference in hand use, dependent on the setting or time of day? _____________________________

16. How well is the person able to use their hands at this time?
   a. Tremors, arthritis, pain, fractures, stroke, contractures, ‘fiddling’, ‘tasks’, ‘holding’
   b. Hand dominance? L R
   c. Any history in hand use we should know about? ______________________________________
Personal History and Individual Information Collection Guidelines

When asking for this information, make sure you let the person you are talking to understand WHY we want this information.

• Let the person know we want to try and make sure that we are matching the person’s needs and preferences rather than just providing general activities and our care.
• We want to make sure that everyone caring for this person knows something about him/her so that we can make them feel more comfortable and at home
• We want to be able to fill in ‘blanks’ if the person cannot recall specifics
• We want to be able to respond to questions with empathy and validate what is beneficial
• We want to be able to better understand behaviors or concerns that the person may express, in actions or emotions, if they don’t have clear words and understanding of what the current situation is.

Make sure your questions sound friendly and curious, not pushy or intrusive

For some questions, I have added some prompts you might include, if you don’t get much from the person or you want to find out a little more.
If the person seems to not know what you want, offer choices – for example:
  • For the Where are they from question – Ask about ‘country’ or ‘city’? Ask about moving ‘a lot’ or ‘never’?
  • For the work history question – Ask ‘stayed at home’ or ‘worked outside the home’? OR Ask ‘one job’ or ‘lots of jobs’?
If the person is just giving ‘facts’ – Ask about any stories or events their person has told them about the topic/area.
If the person you are talking to, knows that there are others who might be able to provide more or different information, ask if it is OK to talk with that person and how to reach them

ONCE you have completed this form, you will transfer the MOST important information onto the INDIVIDUAL INFO SHEETS that are kept at the WELLNESS CENTER
Dementia Hospital Bag
What to Bring with You When Going to the Hospital

Information Sheet – Typed or Printed Neatly:

- Preferred name
- List of Illnesses or other medical conditions
- Medications (drugs, OTC, vitamins, herbs...)
  - Bring the bottles if you can...
  - Allergies or histories of bad reactions
  - Discourage stopping ACIs if possible (Aricept, Exelon, Reminyl)
- Need for glasses, dentures, hearing aid
- Amount of help needed for activities
- Degree of impairment
  - Memory
  - Language
  - Understanding
  - Hand skills
  - Movement
  - Judgment
  - Impulse control
- Family information
  - (names and relationships, favorites, names to avoid, may include pets)
- Work history
  - (jobs, preferences, old and recent)
- Leisure history
  - (what they liked and did, what they disliked)
- Living situation
  - (where from, lived where, with whom, history, current)
- Spiritual history
  - (participation & comfort in faith)
- Daily schedule and patterns
  - (typical times of high activity and rest, what is the person used to)
- Self-care preferences and patterns
  - (grooming, bathing, exercise, dressing, amounts of help used)
- Major Life Events
  - (are there things that affected them from the past)
  - (bad hospital stays from before...)

- Hot buttons
  - (what gets them upset, words, actions, responses...)
- Favorite Foods
- Food Dislikes & Allergies
- Favorite music
  - Bring it in and plan to use it
- Touch and visual preferences
  - Stuff to look at, do, touch
  - Ask about massage, recreation, volunteers
- Highlight any Behaviors of Concern:
  - Wandering or elopement
  - Anxiety/agitation
  - Need for or desire for movement
  - Calling out or yelling
  - Swallowing or eating problems
  - Falls risk
  - Dis-inhibition – say or do things
  - Immobility
  - Tendency to pull on things and tubes
  - Emotional lability
- What does the person do when...?
  - Hungry
  - Thirsty
  - Tired
  - Hurting
  - Constipated or needing to have a BM
  - Needing to urinate/pee
  - Wet/incontinent
  - Have had a BM
- How do they express these emotions...?
  - Lonely
  - Scared
  - Angry
  - Sad
  - Happy
  - Confused

Papers to Pack:
- Health Care Power of Attorney - notarized
- Advance Directives - notarized
- List of Names and Phone Numbers for YOUR Care Team and Phone Leader
- Copy of your calendar for the next few days (if you keep one)
- Contact numbers for your work (if you work)
- Blank notepad or notebook – to record notes or info you want to keep track of or questions you want to ask
Stuff to Pack:
- Extra set of clothing for the ‘patient’ – pick favorites and comfortable clothes
- Extra set of PJs or a gown to wear if the hospital gown is bothersome
- A set of clothes for yourself – especially if you may have to go to work from the hospital
- Morning supplies for care (for the patient and for you) – mouth care and grooming
- Cell phone charger (if you use one)
- Favorite things to SMELL – lotions, perfumes, colognes, after shaves, herbs, room fresheners, oils (lavender is calming and citrus is energizing
- Favorite Things to LOOK AT – photo album (copies of older pictures) have a ‘cheat sheet’ of information for staff, picture books (coffee table books), favorite pictures to put up or poster, objects that have meaning and comfort
- Favorite Things to LISTEN TO – make CDs of favorite music from their past (childhood, adolescence, and young adulthood), bring CDs of favorite sounds, bring a CD player, bring head phones (just in case there is a roommate with problems), hymn book with ‘favorites’ marked, song books with ‘favorites’ marked, books on tape of favorite readings or stories, POSSIBLY – a tape from favorite person, expressing their love and concern or telling stories
- Favorite things to FEEL – bean bag sock (heated), favorite blanket or cover or clothing item, stuffed animal, cloth samples
- Favorite things to EAT – Check with nursing to make sure it is OK to have the person eat and any dietary restrictions while in the hospital – packaged snacks and extra sealable bags for leftovers or small portions for between meals or missed meals
- Favorite things to DRINK - Check with nursing to make sure it is OK to have the person drink and any drink restrictions while in the hospital – packaged drinks, drink mixes to add to water (if that helps to keep the person hydrated), any special cups or containers the person uses to improve ability to drink (Styrofoam or paper cups frequently don’t work well for folks)

- Favorite things to DO – this set of items will need to change over time as the disease progresses. Here are some simple alternatives for different levels”
  - Diamonds - Early stage – still clear and sharp BUT rigid (uses old habits and routines to function)
    - Familiar ‘lap’ or table top activities or supplies – crossword puzzles, word searches, books, crochet or knitting, letter writing or card writing supplies (bring the address book),
    - Reading materials - magazines with pictures and positive stories (can be older ones) Reader’s Digest, National Geographic, Smithsonian, LIFE, Woman’s Day, Sports Illustrated, hunting, fishing, or car magazines..., newspapers, favorite books or books on tape, spiritual readings
    - Games - board games such as scrabble, checkers, chess, Chinese checkers, yahtzee, category games, cards for card games, or jigsaw puzzles (100-300 pieces)
  - Emeralds – Moderate stage – Tends to do what is visually cued, needs familiar cues to get started or to ‘try’ – often on the go – green light is on – doesn’t tend to fix errors - no longer always clear, prefers to stay active or busy, does things but makes mistakes BUT can’t see them or fix them, gets lost in time, place, and situation at times – asks “What do I do now?” “What happens now?” “Where should I go?”, may need help BUT doesn’t know it and doesn’t like anyone telling them what to do or when to do it – likes to have choices (use either/or, or two options) - higher risk of ‘elopement’ (trying to leave with a purpose or after a disagreement).
    - ‘lap’ or tabletop activities – things to look at, talk about, and do
      - cards to look at and have read (they can be older), familiar or favorite magazines or books, may include book of faith, photo albums, newspaper sections
      - books of pictures, sayings, short stories, word games, recipe books, sports magazines
      - sorting supplies – colored index cards, foam shapes, poker chips, coins, hardware items (nails bolts, washers), beads or buttons, swatches of material...
      - games or activities – checkers, card games, matching games, use scrabble tiles for making words (not a formal game), cutting out coupons with blunt tip scissors, tearing out or cutting out pictures for a future project, simple word games (books are available), jigsaw puzzles (24-64 pieces)
      - CDs of old radio programs or favorite speakers or stories, sing-a-long books or hymnals
- May need some ‘old life’ props, pictures, and activities that match up to the ‘time’ the person is in… early adulthood, early career, early family life...
  - Ambers – Middle stage – constant ‘eyes’ on needed for safety, busy with fingers, hands, touching, tasting, doing, fiddling, exploring, checking out… Dislikes ‘restraint’ or limits AND may react very strongly to negative stimulation or sensory experiences, not able to make specific needs and preferences known most of the time – can become hyper-focused or very distractible (hard to keep on task) – can ‘copy’ or imitate you if doing side-by-side, may help for ‘a while’
    - Tabletop or lap activities – sensory activities – things to manipulate, handle, fiddle with, put together or take apart, put stickers around a border, sort by color, put coins in a piggy back or container, hinged clothespins and a sheet of cardboard, sewing cards...
    - Sensory activities – lotion for hand massages, back rubs, foot massages, scented cloths in sealed bags, ‘feeling’ bag, etc.
    - Music – song lists, song books, hymnals, CDs
  - Rubies – Late stage – fine motor stops – all about gross motor action, can grossly copy you, watches movement and action and YOU, may want to move a lot, may be drowsy for some of the time – hard time going from being active to being still, may be more restless if needing to stay in bed or seated – may need more support from you than from anything you bring, can get overwhelmed very quickly, may not be interested in food or drink most of the time
    - Plan to use seating options, touch and contact to help the person stay where they need to be
    - Plan to use music to help calm and rest or to increase attention and focus
    - May prefer watching to doing – bring favorite blanket or stuffed animal or something to hold
    - Plan to rearrange room so you can sit where the person can see you and reach you
  - Pearl – Final stage – unable to sit up or move without major assistance, contractures forming, weight loss extreme, less alert and responsive, more responsive to familiar voices, sounds, touch, or faces – sensitive to movement and touch, also to noise and temperature
    - Bring extra warm socks and shoulder/arm covers, mittens or gloves, light weight, warm covers/blankets, warm head covers
    - Bring CD or tape player and favorite music – mostly quiet and relaxing music, but also some that is more energizing and arousing for meal times
    - Offer more physical contact – not a lot of movement, but reassurance with flats of fingers and palms of hands, stroking and circular movements
Individual Info

Name(s): ___________________  Gender:  M  F  Level of Dementia: ____________________________  

Dominant hand:  L  R  ?  Age: _______

Where from? (originally)________________________________________________________________________________
(recently) ___________________________________________________________________________________________

Childhood family: _______________________________________________________________________________________

Important People: _______________________________________________________________________________________

Past Jobs: _______________________________________________________________________________________________

Past Hobbies: ___________________________________________________________________________________________

Favorite Music: _________________________________________________________________________________________

Disliked Music: _________________________________________________________________________________________

Favorite Topics of Conversation: __________________________________________________________________________

Topics to Avoid: _______________________________________________________________________________________

Favorite TV programs or Movies: __________________________________________________________________________

Favorite Meals or Foods: _______________________________________________________________________________

Disliked Foods: _________________________________________________________________________________________

Spiritual/Religious Habits: ______________________________________________________________________________

Cultural/Ethnic Background & Concerns: ____________________________________________________________________

Things that irritate/bother: ______________________________________________________________________________

Things that help or soothe: ______________________________________________________________________________

Any other critical info: __________________________________________________________________________________

Personal Care habits:

- has dentures  - has partial plates  - brush teeth - how often?  - when preferred?  
- shaving - how often?  - when preferred?  - Method preferred -  - standard razor  - electric razor  
- make-up  - nail painting (clear or color)  
- self-toilet – cues that help  
- bathing – typical method used?  - tub bath,  - shower,  - sponge bath  - when preferred?: ______________

Start the day INFO: wake up routine, typical time, what comes first? _________________________________________________

End the day INFO: go to sleep routine, typical time, place, lighting, noise, others? _______________________________________

Start the day INFO: wake up routine, typical time, what comes first? _________________________________________________

End the day INFO: go to sleep routine, typical time, place, lighting, noise, others? _______________________________________

Personality & Preferences:

(circle or highlight preferences or tendencies)

Likes it Hot  -  Likes it Cold  -  Loner  -  Joiner  -  Doer  -  Watcher

Inside - Outside  -  Leader  -  Follower  -  Emotional  -  Logical

Quiet - Busy  -  Work  -  Leisure  -  Do More  -  Talk More

Date Completed: __________________________

PICTURE of the PERSON
<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Group of Drugs Used</th>
<th>Examples of Drugs in Group</th>
<th>Possible Problems -(side effects)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss of memory, language, orientation, functional abilities, behavior</td>
<td>Acetylcholinesterase inhibitors</td>
<td>Aricept, Exelon, Reminyl - Razadyne</td>
<td>Stomach upset, diarrhea, loss of appetite, headache, sleeplessness</td>
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<tr>
<td></td>
<td>Glutamate uptake moderation</td>
<td>Namenda</td>
<td>Constipation, increased appetite, agitation/sleepiness</td>
</tr>
<tr>
<td>Depression &amp; apathy</td>
<td>Anti-depressants –SSRIs and other new classes</td>
<td>Zoloft, Wellbutrin, Celexa/Lexapro, Remeron, Effexor (avoid Paxil or Prozac)</td>
<td>Orthostatic hypotension, nausea, insomnia, drowsiness, cardiac arrhythmia</td>
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<tr>
<td></td>
<td>Mood stabilizers</td>
<td>Depakote, Neurontin, Tegretol</td>
<td>Liver problems</td>
</tr>
<tr>
<td></td>
<td>Stimulants to increase arousal</td>
<td>Ritalin</td>
<td>Fast acting, can cause hyper-arousal, increased BP, pulse</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Anti-anxiety drugs (benzos, antidepressants)</td>
<td>Buspar, Ativan, Serax, Desyrel, or SSRIs</td>
<td>Worsening of agitation, postural instability, falls, worsening confusion</td>
</tr>
<tr>
<td>Agitation – verbal &amp; physical distress &amp; aggression</td>
<td>Anti-psychotics – if it is unprovoked</td>
<td>Should be very low doses (avoid ones with anticholinergic effects)</td>
<td>More wandering, more agitation, orthostasis,</td>
</tr>
<tr>
<td></td>
<td>Anti-depressant – if it is an agitated depression</td>
<td>Desyrel (also can help with sleep)</td>
<td>Orthostatic hypotension, nausea, insomnia, drowsiness, cardiac arrhythmia</td>
</tr>
<tr>
<td></td>
<td>Anti-convulsants/mood stabilizers – can reduce agitation</td>
<td>Depakote, Neurontin, Tegretol</td>
<td>Orthostatic hypotension, nausea, insomnia, drowsiness, cardiac arrhythmia</td>
</tr>
<tr>
<td>Insomnia</td>
<td>“Sleeping pills”, benzodiazepines</td>
<td>Sonata, Ambien, Lunesta</td>
<td>Daytime sleepiness, increased confusion, falls</td>
</tr>
<tr>
<td></td>
<td>Sedating anti-depressants</td>
<td>Desyrel, Pamelor, Remeron</td>
<td>Orthostatic hypotension, nausea, insomnia, drowsiness, cardiac arrhythmia</td>
</tr>
<tr>
<td></td>
<td>Anti-psychotics</td>
<td>Not recommended for sleep</td>
<td>Agitation, long half-life, hang-overs</td>
</tr>
<tr>
<td>Hallucinations, delusions, paranoia or spontaneous violence</td>
<td>Atypical anti-psychotics</td>
<td>Zyprexa, Risperdal, Geodon, Abilify</td>
<td>Sedation, orthostatic hypotension, incoordination</td>
</tr>
<tr>
<td></td>
<td>Typical anti-psychotics: current recommendations discourage use</td>
<td>Haldol, Mellaril, Thorazine</td>
<td>Tardive dyskinesia, somnolence, lack of appetite, tremor, agitation, balance and coordination problems, orthostatic hypotension</td>
</tr>
<tr>
<td>Sexual acting out (Not effective)</td>
<td>Anti-depressants, anti-androgens, estrogen patches</td>
<td>(SSRIs – listed above)</td>
<td>See above</td>
</tr>
<tr>
<td>Infections</td>
<td>Respiratory, urinary etc</td>
<td>Antibiotics - if bacterial Symptom management - if viral</td>
<td>Make confusion worse, cause stomach distress-diarrhea/nausea lead to dehydration</td>
</tr>
<tr>
<td>Pain</td>
<td>Arthritis, post-surgical pain,</td>
<td>Tylenol – acetaminophen</td>
<td>Possible liver damage - rare</td>
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<td></td>
<td></td>
<td>Advil, Celebrex, Aspirin</td>
<td>Gastric distress, ulcers, possible sudden death or vascular events (stroke)</td>
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<td></td>
<td>Narcotics</td>
<td>Can make confusion, somnolence, agitation worse, constipation, vomiting</td>
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<tr>
<td></td>
<td>High Cholesterol</td>
<td>Cholesterol busting/ lowering</td>
<td>Lipitor, other statins</td>
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# The Impact of the Environment on People with Dementia

<table>
<thead>
<tr>
<th>Auditory Environments</th>
<th>Negative Impact</th>
<th>Neutral Impact</th>
<th>Positive Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>♦ Non-specific noise (clatter, rustling) ♦ Competing sounds (TV, radio, other conversations) ♦ Distressed residents positioned within hearing range ♦ High pitched repetitive alarms (wandering control systems)</td>
<td>♦ Silence</td>
<td>♦ Preferred rhythmic music during some unoccupied time ♦ Preferred rhythmic music to stimulate movement ♦ Quiet when sharing information ♦ Acoustically supportive space ♦ Positive &amp; purposeful sounds from other spaces (music in the dayroom, laughter in the lunchroom, singing in a resident’s room)</td>
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</table>

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<th>Visual Environments</th>
<th>Negative Impact</th>
<th>Neutral Impact</th>
<th>Positive Impact</th>
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</thead>
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<tr>
<td>♦ Dim or poorly illuminated work areas (dim rooms, dim bathrooms, dim, bedside areas) ♦ Glare &amp; direct sunlight (unshuttered or uncurtained windows) ♦ Bright light directed into eyes (overhead lights if lying in bed) ♦ Cluttered work surfaces ♦ Distant work surfaces (tables more than 10-12” from chest) ♦ Disorganized materials or supplies ♦ Invisible objects or materials that cue tasks (smell and sight of food prep, hidden grooming and hygiene supplies, hidden clothing) ♦ No contrast between work surface and task materials ♦ Light-dark patterns on walking surfaces ♦ Highlighted locked exits ♦ Closed – invisible spaces (closed doors to other areas, closed bathroom doors, closed room doors) ♦ Non-labeled spaces (lack of names and pictures at room entrances, lack of labels on drawers)</td>
<td>♦ Pictures on the wall higher than chair height</td>
<td>♦ high, non-glare illumination of all work surfaces and tables ♦ Deflected or defused light from windows ♦ Visible sunlight in day, dark at night ♦ Indirect but strong light ♦ Positioning of person so light is on work surface not in eyes ♦ Clear work surfaces – only presenting relevant props and materials ♦ Work surface immediately in front of person for task performance ♦ Organized presentation of materials (oriented for person use) ♦ Visible cues for task performance (coffee pots, grooming items out, clothing displayed &amp; ordered) ♦ High contrast between work surface and task materials ♦ Non-contrast, non-glare walking surfaces ♦ Invisible exits ♦ Visible task locations – open bathroom doors, open hallway doors, open bedroom doors ♦ Labeled spaces – personal room markers (name and pictures) and drawer markers (pictures of contents)</td>
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<tr>
<td>Tactile Environment</td>
<td>Routines of Care</td>
<td>Habits</td>
<td>Locations</td>
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<td>♦ Lack of objects to use, manipulate, handle, or mouth (sensory deprivation leads to self-stimulation and self-injurious behaviors)</td>
<td>♦ Touch ‘appealing’ objects to use, manipulate, handle, mouth</td>
<td>♦ use of habits from working with ‘cognitively intact’ persons to ‘cognitively impaired persons</td>
<td>♦ busy, noisy, or cluttered (distracting)</td>
</tr>
<tr>
<td>♦ Hard and heavy mobile objects (can be misused)</td>
<td>♦ Secured heavy and hard objects</td>
<td>♦ use SOP for all personal care tasks</td>
<td>♦ calm and quiet places</td>
</tr>
<tr>
<td>♦ Sharp or pointed objects</td>
<td>♦ Sharp or pointed objects only introduced and used with close staff supervision and support</td>
<td>♦ lack of knowledge by caregivers about historic personal care habits of each person</td>
<td>♦ organized and calm</td>
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<td>♦ Unstable support surfaces (loss of balance)</td>
<td>♦ Stable support surfaces (locking brakes, non-wheeled chairs in rooms, out-of-bed sitting)</td>
<td>♦ inconsistent use of person-based habits by staff</td>
<td>♦ use specific spaces - give visual cues</td>
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<td>♦ Difficult to access sitting surfaces (too low, hard to get to)</td>
<td>♦ ‘Right’ height seating</td>
<td>♦ historically consistent personal care routines</td>
<td>respectful of personal space needs</td>
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<td>♦ Unavailable work surfaces</td>
<td>♦ Work surfaces immediately in front of the person</td>
<td>♦ purposeful use of ‘new’ habits to promote preserved abilities with cognitively impaired persons</td>
<td>full of meaningful visual cues - personal or task oriented information</td>
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<td>♦ Cold temperatures of surfaces and spaces (increased tone and withdrawal)</td>
<td>♦ Warm spaces</td>
<td>♦ use of individualized care plans for personal care task achievement</td>
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<td>♦ Too hot surfaces or objects (can burn before reacting)</td>
<td>♦ Warm objects and surfaces</td>
<td>♦ use of knowledge regarding the historic personal care habits of each person</td>
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<td>♦ Touch ‘appealing’ objects to use, manipulate, handle, mouth</td>
<td>♦ Safety-set water temperatures</td>
<td>♦ consistent use of person-based habits by ALL staff</td>
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<td>♦ Secured heavy and hard objects</td>
<td>♦ Pre-checked food and drink temperatures</td>
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Use of the Environment to Promote Function

The Physical Environment

People – what they say, what they show, what they do  
auditory cues & help  
visual cues & help  
tactile cues & help

Places – what you see, what you hear, what you touch, where you it  
sound  
lighting & displays  
seating surfaces  
work surfaces & objects  
location

The Social Environment

Routines – What happens when? What is the order of the day? Who does what?  
schedules  
patterns  
sequences of activities during each day, each week, each month

Habits – What do you ‘always’ do? What prompts your behavior?  
automatic action  
situational cues  
resident historic behaviors  
caregiver historic behaviors  
pREFERRED ways of doing tasks, acting, & interacting
Suggested Use of Environmental Modifications

Lighting
1. For wake-up Routine
   a. Announce entrance to personal space
   b. Turn on low level lighting near person
   c. Complete awakening person with voice and appropriate touch
   After making sure person is awake -
   d. Turn on all available light to light task area
   e. Do not use lighting that shines into person’s eyes rather than on the work surface
2. For task routines
   a. Turn on all available light to task area – prior to starting task
   b. Do not use lighting that shines into person’s eyes rather than on the work surface
   c. Turn off task lighting when task is completed
3. For non-task time
   a. Turn on lighting in sitting area for adequate illumination
   b. Make sure lighting is not in person’s eyes

Sound – Music
1. For task time
   a. eliminate or minimize random noise – close door, oil wheels
   b. eliminate competing or distracting sounds – turn off TV or radio (with permission)
   c. may use preferred music to comfort during difficult tasks
   d. caregivers will talk with person during task performance – content based on person comprehension abilities
2. For non-task time
   a. use CD player to play preferred CDs in selected locations at a moderate volume
   b. sing along with preferred music in selected locations
   c. allow for periods of quiet and periods of music

Sitting Surfaces
1. For task time
   a. People will be approached using the Positive Approach technique
   b. People will be assisted into in supported sitting.
      1) If possible to transfer or move each person to a chair use the bedside chair or personal wheelchair that provides back, seat, arm, leg/foot support so the person is upright
      2) If not possible to have a person up in a chair, position the person up in bed so hips are a bend in bed, place pillow behind knees, raise head of bed to >60 degrees, place a pillow behind the head and shoulders, place a second pillow on unstable side of chest (under the elbow)
   c. Once the person is stable, the caregiver will get seated
   d. CAREGIVERS will use rolling stools to get to person eye-level
      1) caregiver will bring stool to task area prior to task initiation
      2) caregiver will remove stool to safe location when task is completed
2. **For non-task time**
   a. People will be approached using the Positive Approach technique
   b. People will be assisted into a comfortable and safe supportive seating position

   *People with dementia should not generally be asked to perform tasks on the edge of the bed or while lying flat in the bed. These positions create risks for poor balance, startle reactions, swallowing problems, and impulsive unsafe movements.*

**Work Surfaces**

1. **For task time**
   a. **for tasks completed in the person's room -** use one of the following three surfaces
      - fold-down table top
      - overbed table
      - sink work surface
      
      1) assist the person into supported sitting
      2) provide a *stable work surface* immediately in front of the person
         a) place the chair so the fold-down table top/ overbed table/ or sink work surface is in front of the person, within 12" of the chest
         b) gather supplies needed, place them on alternate work surface (bedside table or overbed table)
         c) position yourself as the helper to the person's dominant side, use the *rolling stool*
         d) provide support and assistance as needed, presenting tools and materials as needed
         e) once the task is completed, the caregiver will remove the supplies and the work surface
      
      3) assist the person to another location or is provided with a meaningful activity in this location prior to caregiver leaving the area

   b. **for tasks completed in group or dining areas**
      1) use the Positive Approach to introduce the task to the person
      2) place the chair the person is seated in into full upright position
      3) assist the person to locate his seating location in the room
      4) assist the person to position the seat within 12" of the *tabletop*
         a) gather supplies, food tray, or props needed for the task on an alternate work surface
         b) prepare items for use by the person on alternate surface, if preparation is needed
         c) position yourself as the helper on the person's dominant side, use the *rolling stool* to get to person's eye level
         d) provide support and assistance as needed, presenting tools and materials as needed
         e) once the task is completed, the caregiver will remove the supplies and offer to assist the person to move away from the work surface OR provide props for alternate activity
      
      IF this is a group activity - prior to starting the task....
      5) place other persons at a right angle and at greater than or equal to arm's length to that person
      6) the caregiver will use the *rolling stool* to move among members of the group to provide assistance and support as needed for successful task performance
2. **For non-task time - when a work surface is needed** -
   a. use the Positive Approach to initiate interaction with the person
   b. provide a stable work surface within 12" of the person's chest
   c. place props or objects of interest in front of the person
   d. caregiver sit on *rolling stool* to provide help
   e. use appropriate guidance or prompting to help person begin interacting with the object or prop
   f. monitor person for need or desire to stop the activity - remove the props and work surface

**Props & Materials**

1. **For task time**
   a. *For meals (examples)*
      1) Placemats
         a) use non-skid, colored *placemats* to provide stable surface for plate and high-contrast to work surface and plate
         b) present the plate and a single utensil immediately in front of the person
   b. *For grooming - early AM & pre- and post- mealtime (examples)*
      1) Washcloths
         a) Place small *lidded plastic bin* and a *small cooler* on a rolling cart
         b) place large supply of washcloths in the small cooler
         c) Add hot water to cloths
         d) Keep lid closed unless using the cloths
         e) Wring out and present cloths to person - use the Positive Approach to offer the cloth
         f) Provide appropriate assistance for person ability to wash face & hands
         g) Remove the cloth and place it in the plastic bin
      2) Oral Care supplies - Hygiene supplies - Hair care supplies (examples)
         a) store items needed in a *drawer organizer*
         b) keep the organizer in the *picture coded* drawer, if used
         c) place organizer on caregiver work surface
         d) use the Positive Approach to introduce the task
         e) position yourself on the *rolling stool* to the person's dominant side
         f) place the needed props on the person's work surface as needed
         g) provide assistance and support as needed based on person abilities
         h) remove the supplies, clean them as needed and replace the organizer in the correct drawer
   c. *For dressing (example)*
      1) Knobbed coat hanger
         a) set out a set of clothes for the person on the closet door using the *knobbed coat hanger*
         b) provide person with support and assistance as needed to reach and obtain clothing items in the correct order and orientation
         c) caregiver will use rolling stool to stay at person's eye level while providing guidance and help
         d) caregiver will remove used clothing from visual work space and store/place in dirty linen as appropriate
      2) Picture-Coded Drawer Markers
         a) caregiver will look into drawers for item location prior to prompting person to initiate dressing task
         b) caregiver will prompt person as appropriate to direct vision to *pictures* on drawers in correct order
d. For wayfinding (example)
   1) Signage and directional markers
      a) caregiver will direct person's gaze to signs for regard
      b) caregiver will use appropriate guidance or cueing to help person attend to sign and follow the directional indicator
   2) Doors
      a) caregivers will open doors to provide visual access to spaces and supplies/set-up when task is to be initiated
      b) caregiver will turn on lights in the space when the door is opened to draw attention to the space at the start of the task
   3) Personal Room Identification
      a) caregivers will direct person's gaze to picture and name at room for recognition and regard
      b) caregivers will use pictures and personal information to initiate appropriate conversations with persons
   4) Alarm System Activation
      a) caregivers will use control panel to deactivate alarm system to/from the dining area
      b) caregivers will monitor persons for status in dining area and need to return to the unit

2. For non-task time
   a. Pre-meal Routine (example)
      1) Caregivers will prep the coffee and juice bar for function - make sure coffee is brewing, juice is available, unbreakable glasses and mugs are available, condiments are present, and storage area is locked
      2) caregivers will turn on CD player, set volume, and select music
      3) caregivers will approach each person using the Positive Approach
      4) caregivers will offer persons drinks from coffee and juice bar (*care to be taken with persons who are on swallowing precautions*)
      5) caregivers will remove empty or used mugs or unbreakable glasses prior to mealtime
   b. Hallway and Dayroom Displays
      1) caregivers will direct person's gaze and attention to pictures, posters and props located in common spaces
      2) caregivers will use pictures, posters, and supplies to encourage person interaction
   c. Personal Notebooks
      1) caregivers will direct person's gaze and attention to items, pictures, and memorabilia located in personal information notebooks
      2) caregivers will use content of the notebooks to encourage person interaction
Understanding YOUR personality & the PERSON you Care For!

Four Traits –
- How you get your energy & how you like to think things through
- How you like to get information & how you like to do things
- How you decide what should be done & how you react to situations
- How you like to organize and plan & how much control you want over what is happening

<table>
<thead>
<tr>
<th>Extroverts</th>
<th>Introverts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Like to work on problems in a group</td>
<td>Like to work on problems by themselves</td>
</tr>
<tr>
<td>Get energy from being around others</td>
<td>Get energy from being alone</td>
</tr>
<tr>
<td>Speak before they think</td>
<td>Think before they speak</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Doers</th>
<th>Thinkers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Like to do things with their hands</td>
<td>Like to think about things</td>
</tr>
<tr>
<td>Like specifics</td>
<td>Like big picture</td>
</tr>
<tr>
<td>Enjoy routine</td>
<td>Enjoy change</td>
</tr>
<tr>
<td>Like to have all the details laid out</td>
<td>Like to know why they are doing something</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Thinking first</th>
<th>Feeling first</th>
</tr>
</thead>
<tbody>
<tr>
<td>Value workers being treated fairly</td>
<td>Value workers being treated kindly</td>
</tr>
<tr>
<td>Want to be treated equally</td>
<td>Want to be treated as an individual</td>
</tr>
<tr>
<td>Enjoy arguments/exchange of ideas</td>
<td>Value harmony</td>
</tr>
<tr>
<td>Need to be just/honest</td>
<td>Need to be nice</td>
</tr>
<tr>
<td>Want to understand</td>
<td>Want to feel valued as a good person</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Planners</th>
<th>Go with the flow-ers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Like schedules, ‘to do’ lists</td>
<td>Like to go with the flow</td>
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<tr>
<td>Get frustrated when routine interrupted</td>
<td>Get bored with routine</td>
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<td>Do things the way they make sense to do them</td>
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<tr>
<td>Like to have plans in place AHEAD of time</td>
<td>Like to take care of things as they come up</td>
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Remember:

- One type is not better than the other-they’re just different.

- You may function differently than the person you are caring for OR others in your family!

- Recognizing personality traits, respecting and honoring preferences & needs, and building in ways to get needs met can make a difference for everyone!
Use of Touch and Simple Massage in Dementia Care

Key Considerations:
• Touching is different than being touched
• There are different kinds of touch
• Light, moving touch is stimulating
• Deep, slow touch is calming
• Responses must be carefully monitored at all times
• Get permission before using touch - verbal or non-verbal acceptance

Touching by the Person -
• Typical parts of the body of interest - lips & mouth, palms and fingers, soles of feet, genitalia
• Monitor safety awareness with handling, mouthing, and walking or climbing
• Provide varied tactile surfaces of interest in the environment
• Provide objects that have different weights, textures, materials, shapes, surfaces...
• In the early stages, consider the use of cats, dogs, babies, children, or offered hands or shoulders
• In later stages, consider stuffed animals, warmed bean/rice socks, quilts or blankets, aprons with items attached, dolls, or hands
• Consider activity boxes or boards that have ‘hand-based’ experiences - sanding blocks, wiping down tables, assembling PVC pipe, assembling nuts/bolts/washers, washing dishes, kneading bread dough...

Touching the Person -
• Offer a hand shake
• Use hand under hand support
• Touch with flats of fingers and palm
• Use an open palm on the shoulder to comfort and stabilize
• To wake someone who does not wake-up after several name calls - consider a firm still open palm on the forearm or knee
• Offer a squeeze to get attention or offer comfort
• Keep strokes smooth and slow
• Hug responsively or after permission (give visual cues about what you want)
• Dance with the person
• Walk with hand under hand support, hand holding, waist wrap, shoulder wrap...
• Touch body part during a task to get the person to attend to it
Simple Massage -
Two options -
• with clothing over the body part
• with skin exposed - lotion can be used (**check for smell preferences and any allergies**)

Hand massage - (keep the pads of your fingers flat AND your touch firm)
• start with the palm
• wrap your hands around either side from back to palm
• rock the hand from side to side using your hands
• stroke up the back and up the palm
• gently rotate and rub along the sides of each finger
• slowly rotate the wrist
• rub at the base of the thumb

Foot massage -
• consider a foot soak first
• then dry the foot
• wrap your hands around the foot on either side from the top of the foot to the sole
• rock the foot from side to side
• stroke the sole with a flat thumb or fingers
• gently rotate and rub along the sides of each toe
• slowly rotate around the ankle
• stroke along the arch firmly

Face massage -
• stand behind the person
• have the person lean back resting their head on a supporting surface
• use both hands to stroke from midline to the sides on the forehead
• from the nose to the ears, from the chin to the ears, from under the chin to behind the ears
• repeat all four with tiny, flat, finger circles
• repeat strokes over all four
• do slow circles over the jaw joint, mid forehead, and temples

Head massage -
• use palm to stroke over hair 2-3 times
• use the tip pads of fingers to ‘scratch’ with all ten fingers from front to back
• use tip pads to make tiny circles from front to back at least 3-5 fingers per hand
• lay palms flat on the head and make slow circles
• then straight strokes all over the head
Back rub - three different rubs

- **Tips of fingers** - quick, firm circles moving over the back
- **Flats of palms** - slow, deep, soothing circles - consider singing or humming softly, talking rhythmically and deeply, or using music to help calm as well
- **Spine Strokes** - use middle finger and thumb to stroke firmly down either side of the spine at the same time (while you place your other hand on the shoulder or in hand under hand position)

Leg rub -

- support the foot
- then stroke up the front of the shin
- then place the foot flat and place both hands from the front of shin to the calf
- gently massage the calf muscle from ankle to knee
- rock the knee from inward to outward
- gradually bend and straighten the knee
- then flex then straighten the hip
- finish with open palm strokes from foot upward or from knee downward

Arm rub -

- support the hand and arm (have the person lay down or place a pillow under the arm)
- begin with shoulder shrugs (help the person shrug and relax down)
- then roll the shoulders in a slow circle from front to back
- then hold the hand in hand-under-hand and rock the arm from in to out and back slowly
- then start rubbing with your open palm from the hand upwards to the forearm then the upper arm and shoulder
- then give open palm, full hand gentle, slow squeezes all the way up the arm
- end with slow smooth strokes.
Pain Indicators

How Can You Tell If Someone Is In Pain?

- Facial expression
- Voice volume - raised or lowered
- Making sounds during actions
- Changes in vocalizations - intensity or frequency or volume
- Guarding of body parts
- Grabbing or holding objects
- Grabbing or holding you
- Repeating a movement or action over & over
- More confusion and disorientation
- Refusals
- Anger toward others
- Crying
- Whimpering
- Whining
- Grunting
- Gritting teeth
- Stillness - no movement
- Holding breath
- Rapid breathing
- Complaining
- Begging for help
- Not eating or drinking
- Asking for God's help
- Wanting to 'end it all'
- Begging you to 'please not hurt me'

Who Makes It Hard?

- People who can't talk or can't tell you what is 'wrong'
- People who are significantly demented - can't communicate needs
- People who are 'whiners' - have a very low tolerance for pain
- People who have a history of 'drug use' - use drugs to deal with life
- People are 'just plain mean' all the time...

Bottom Line - Perception is ALL

My PAIN is MY PAIN
It is REAL to me...
Don't judge me by YOUR standards
Believe in me ...
and we will work together MUCH BETTER!
How to Help When Pain Exists...
What to Try Before You Get Started...

- Check and see if pain meds have been given (if ordered) - allow about 15-20 minutes for them to ‘kick in’
- If not, get meds on board FIRST... and give them time to work - do something else
- Plan to 'Take Your Time’
- Get everything set up BEFORE you start moving/helping/doing something with the person
- Check room temperature - consider turning it UP...
- Warm up blankets/sheets/towels you are going to use
- Take a look at the person... Do a basic 'assessment'...
- Do you think s/he will be OK?
- Does s/he look different than usual?
- Are you seeing pain signs or symptoms?
- What does your 'gut' tell you? - WHY do you get that feeling???
- Take some deep breaths - make sure you are relaxed & 'in control'
- Prepare & bring along bean/rice socks
- Find out music preferences & have them ready

What to Try When You Are Working...

- Use the Positive Approach (watching for responses... or lack of them)
  - Knock & call preferred name (1 time) - look friendly!
  - Come from the front - where the person can see you - look at their face
  - Go slow - one second = one step
  - Get to the side - be supportive & friendly not threatening
  - Get low - get to the person's level - sit, squat, kneel...
  - Offer the person your hand - slide into hand-under-hand, if possible
  - WAIT for a response - did they notice you
    - If NOT... call the name again & WAIT....
    - If they did notice you

Then...
- Introduce yourself - "It's (your name)..."  pause
- Share BASIC information - "Its about time to (say what is going to happen)..."  pause
- Then... some options to try... depending on the person and what you are seeing...
  - Make empathetic statements - "It looks like you are hurting..."  pause & listen
  - Have the person to help you get started... "Help me pull off the covers..."  pause
  - Have the person try to do something... "Could you give it a try?.... pause
  - Give the person a SIMPLE, OK choice... "Roll to your left or your right?"...  pause
  - Only ask "Are you ready to...."  IF you are willing to come back later!
- ACKNOWLEDGE their responses or attempts....
- If they indicate they are hurting... you hurt them...
  SAY WITH FEELING - “I am so SORRY... I will (do this instead)... Better?”
Other THINGS to TRY...

- A Warm-Up
  - Time with a warm bean-rice bag or a rub with it
  - A little back rub, massage or stoking
  - Gentle and easy rocking movements
  - Some circular movements of body parts
  - Deep breathing
  - Slow stretches

- Give them something to focus on
- Distracting talk – know the person and their background
- Use slow, deep, easy sounds or words... over and over
- Set specific limits on time, distance, activities, repetitions
- Take BREAKS during the activity, if things are hard to do...
- Use hand-under-hand guidance a few times to make sure the person knows what you want them to do
- Use demonstration NOT force
- Resist the desired movement a little and see if it helps the person - rather than pulling on them
- Give the person some 'distance' when possible
- Give POSITIVE FEEDBACK... ENCOURAGE the person
- Let them know 'how much more' at frequent points
- STOP! When they have 'reached their limit' - control yourself

What to Try When You Are Done...

- Give THANKS!
- Acknowledge their hard work --- through their pain
- Tell the person how well they did... if not, how well they tried...
- Make sure the person is as comfortable as possible
- Put on a warm blanket or cover, or use the bean/rice sock
- Offer to do something they like - music, a drink, a snack, time alone, a visit...
- Back off...BUT try to visit or interact AGAIN when you won't have to hurt them
- Repeat the 'warm-ups' as cool-downs
- Check in with your supervisor, if you think the pain is NOT being managed well enough...
  Be willing to share your thinking and reasons...
- Make sure someone else doesn't have something scheduled 'right after' your session - advocate for the person - ask for a break for them
ACTIVITY: Personality traits: Which one is more like you?  
(Adapted from the Keirsey Temperament Sorter)

Choose between each set of words which characteristic is more like you?

- Circle or highlight the chosen words.
- Work quickly—don’t think too hard!

<table>
<thead>
<tr>
<th>Trait 1</th>
<th>Trait 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Like to spend time with others</td>
<td>Like to spend time alone</td>
</tr>
<tr>
<td>Enjoy meeting new people</td>
<td>Feel uncomfortable around new people</td>
</tr>
<tr>
<td>Have lots of casual friends</td>
<td>Have a few special friends</td>
</tr>
<tr>
<td>Like to “talk out” and solve problems</td>
<td>Like to think about problems to yourself</td>
</tr>
<tr>
<td>Like to share space, belongings, troubles</td>
<td>Like personal space &amp; boundaries</td>
</tr>
<tr>
<td>Talk about home life at work</td>
<td>Keep home at home and work at work</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Trait 2</th>
<th>Trait 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need to know WHAT I am supposed to be doing before I do it</td>
<td>Need to know WHY I need to do something before I feel good about doing it</td>
</tr>
<tr>
<td>Like to do things established way</td>
<td>Like to find new ways to do things</td>
</tr>
<tr>
<td>Enjoy doing things with my hands</td>
<td>Enjoy thinking about things &amp; figuring them out</td>
</tr>
<tr>
<td>Prefer clear, specific directions on how to do the job</td>
<td>Prefer to be given the expected goal &amp; figure out how to do it on my own</td>
</tr>
<tr>
<td>Trust my real life experiences</td>
<td>Trust my instincts &amp; gut feelings</td>
</tr>
</tbody>
</table>

Created by M Bunn – 2005, modified by T Snow - 2007
### TRAIT 3

<table>
<thead>
<tr>
<th>Want my boss to be fair</th>
<th>Want my boss to be understanding</th>
</tr>
</thead>
<tbody>
<tr>
<td>I’m logical and honest</td>
<td>I’m sensitive and caring</td>
</tr>
<tr>
<td>Want to be just or even-handed</td>
<td>Want to be kind</td>
</tr>
<tr>
<td>Enjoy a discussion of different opinions</td>
<td>Avoid bringing up topics that cause strong feelings</td>
</tr>
<tr>
<td>Try to understand why someone is upset &amp; decide if it’s a ‘good’ reason</td>
<td>Try to comfort someone who is upset to make them feel OK</td>
</tr>
</tbody>
</table>

### TRAIT 4

<table>
<thead>
<tr>
<th>Like to have and stay on schedule</th>
<th>Like to go with the flow</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very organized</td>
<td>Disorganized</td>
</tr>
<tr>
<td>Follow the plan</td>
<td>Change the plan to fit the situation</td>
</tr>
<tr>
<td>Very conscious of time</td>
<td>Very flexible about time</td>
</tr>
<tr>
<td>More interested in what else has to get done</td>
<td>More interested in what’s happening NOW</td>
</tr>
</tbody>
</table>

Look at responses under each trait then write down how many answers are on the left and how many are on the right side.

<table>
<thead>
<tr>
<th>Left</th>
<th>Right</th>
<th>Most of my answers were:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trait 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trait 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trait 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trait 4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Understanding your personality:

We’ll take each trait and talk about three issues.

1. Myths or misunderstandings about this trait
2. Description of each trait
3. How this trait affects work on a team

TRAIT 1: If your answers are more on the left side, you are an **EXTROVERT**.

If your answers are more on the right side, you are an **INTROVERT**.

**Myths:**
- *Extroverts* are the class clown, dance on table tops.  **NOT TRUE!!!**
- *Introverts* are stuck up, shy, or loners.  **NOT TRUE!!!**

**Extroverts** | **Introverts**
--- | ---
Like to work on problems in a group | Like to work on problems by themselves
Get energy from being around others | Get energy from being alone
Speak before they think | Think before they speak

**Challenges in the workplace**
- When introverts have a bad day they need to…
- When extroverts have a bad day they need to…

TRAIT 2: If your answers are more on the left side, you are a **DOER**.

If your answers are more on the right side, you are a **THINKER**.

**Myths:**
- *Doers* never think, don’t have original ideas, don’t care about values.  **NOT TRUE!!!**
- *Thinkers* never do, can’t really get anything done, are airheads.  **NOT TRUE!!!**

**Doers** | **Thinkers**
--- | ---
Like to do things with their hands | Like to think about things
Like specifics | Like big picture
Enjoy routine | Enjoy change
Like to have all the details laid out | Like to know why they are doing something

**Challenges in the workplace**
- Workers are often
- Supervisors are often
TRAIT 3: If your answers are more on the left side, you put **REASON** first.  
If your answers are more on the right side, you put **FEELINGS** first.

Myths: *Feelings* first people don’t make good decisions.  
*Reason* first people don’t care about people.  

<table>
<thead>
<tr>
<th>Feelings first</th>
<th>REASON first</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reason first people don’t care about people.</td>
<td>NOT TRUE!!!</td>
</tr>
<tr>
<td>Head first</td>
<td>Heart first</td>
</tr>
<tr>
<td>Value workers being treated fairly</td>
<td>Value workers being treated kindly</td>
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<td>Want to be treated as an individual</td>
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</tr>
<tr>
<td>Want to understand</td>
<td>Want to feel valued as a good person</td>
</tr>
</tbody>
</table>

Challenges in the workplace:  
Struggle between what is ‘fair/equal’ and harmony or good feelings among all involved  
Head first people ____________  
Head first people ____________  

TRAIT 4: If your answers are more on the left side, you like **PLANNING**.  
If your answers are more on the right side, you going with the **FLOW**.

Myths:  
*Planners* care more about lists & schedules than the people.  
*Go with the flow types* are unreliable and waste time.  

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<tr>
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<th>Go with the flow-ers</th>
</tr>
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<td>Like to have plans in place AHEAD of time</td>
<td>Like to take care of things as they come up</td>
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</tbody>
</table>

Challenges in the workplace  
Struggle between “getting it done” and “doing it right”  
Planners want to ________________  
Go with the Flow-ers want to ________________  

**Remember:**

One type is not better than the other-they’re just different.

You may function differently at work than at home.
ACTIVITY: Personality and Residents

Work in groups of three or four to complete the worksheet.

Trait: Personality trait
Behavior: How a person with that personality will act when stressed
I can help: What I can do to help that person cope?

<table>
<thead>
<tr>
<th>Trait</th>
<th>Behavior</th>
<th>I can help</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introvert</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extrovert</td>
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<td>Go with the flow</td>
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Work teams and personality

Personality diversity improves the work of the team if…

Team members value others strengths

Team members respect others values

Making it work in the team

• Know yourself

• Know your teammates

• Use this knowledge to improve communication and coping

• Respect diversity-value the difference
Take Care of YOU!!
Stress Tamers...

10 Minute Stress Tamers

- **Sit quietly** in calm surroundings with soft lights and pleasant scents.
- **Aromatherapy** – lavender, citrus, vanilla, cinnamon, peppermint, fresh cut grass.
- **Breathe deeply** – rest your mind & oxygenate
- **Soak** - in a warm bath, or just your hands or feet
- **Read** - Spiritual readings, poetry, inspirational readings, or one chapter of what you like…
- **Laugh and smile** - Watch classic comedians, Candid Camera, America’s Funniest Home Videos, look at kid or animal photos…
- **Stretch** – front to back, side to side, & across
- **Garden** – work with plants
- **Beanbag heat therapy**. Fill a sock with dry beans and sew or tie closed. Heat bag and beans in a microwave for 30 seconds at a time. Place on tight muscles and massage gently; relax for ten minutes.
- **Remember the good times** - Record oral memories - scrapbooks, photo journals, keepsake memory picture frames. Just jot!
- **Do a little** on a favorite **hobby**.
- **Have a cup of decaffeinated tea or coffee**
- **Play a brain game** – crosswords, jigsaws, jeopardy, jumbles…
- **Look through the hymnal** and find a favorite – hum it all the way through…
- **Books on Tape** - Rest your eyes and read
- **Soothing sounds** –
  – Music you love
  – Music especially for stress relief
  – Recorded sounds of nature
- **Listen to coached relaxation recordings**
- **Pamper Yourself** – think of what you LOVE and give yourself permission to do it for 10 minutes
- **Neck rubs or back rubs** – use the ‘just right’ pressure
- **Hand Massages** – with lotion or without – its up to you…
- **Take a walk**.
- **Sit** in the sun.
- **Rock** on the porch.
- **Pray** or read a passage from scripture
- **Journal** - Take the opportunity to “tell it like it is.”
- Cuddle and stroke a **pet**.
- **Have that cup of coffee or tea with a special friend** who listens well.
- **Pay attention to your personality.**
  – If you rejuvenate being alone, then **seek solitude**.
  – If you rejuvenate by being with others, **seek company**.
Tips for Visits

Tips for the Person with Dementia

Take some time out to relax
Do what you enjoy
Consider letting people know when you need a break or are having trouble
Make a list with your partner of what you would like to do this season
Use the list to help keep on track
Consider saying – “I know I know you, but I just can’t place you…” when someone greets you and you aren’t sure who they are to you
Watch or listen to old, familiar music, movies, TV programs that make you feel good
Get some exercise every day
Get plenty of water each day
Be careful about too many sweets or treats
Work with a partner to do familiar and fun ‘doing’ activities – (for example: making, signing or mailing cards OR making up mixes with recipes to share or baking something and wrapping it)

Tips for the Care Partner

Keep gatherings smaller & visits shorter
Offer time out
Make a list of pleasures to do
Encourage visitors to understand before they begin interacting
Encourage going out and doing something fun together rather than just talking
Ask visitors to bring old pictures, old familiar items or props, and be prepared to reminisce about old times
Take breaks from each other
Consider cutting back on traditions if they seem distressing
Help visitors out by introducing them with some orienting information, if they forget to do so
Get some exercise & take care of your stress levels
Get a ‘friend’ to help the person with dementia select gifts, shop, or do something special for loved ones, including you!

Tips for the Visitor

Start off by looking friendly and offering your hand in a handshake
Introduce yourself by name, then PAUSE, if the person still doesn’t seem to ‘know’ you, give them a little more background
Use shorter phrases and PAUSE between thoughts or ideas, giving the person a chance to respond
Talk about the old times more than recent information
Keep memories positive if possible
Accept ‘general comments’, don’t push for specifics
Don’t correct errors, go with the flow of the conversation
Be prepared to hear old stories over and over, use old pictures or props to bring up other old memories… and laugh
Do something with the person rather than just talking to them

If the person says something distressing or seems worried about something, realize it may not be true, but they are not lying to you, their brain is lying to them. Check it out with the care partner before acting on it.