

WHY OT?

Occupational therapy at its core provides client driven care and works to engage individuals in meaningful occupational activities. With the scientific knowledge and creativity behind occupational therapy we understand meeting a client where they are and adapting their environment for them to thrive. With dementia it is important to understand the disease itself, where they are in the disease, and how to help them be successful within their daily occupations. Learning to truly understand the individual, and empower and connect with them is the best way to promote the best quality of life experiences.

Early Warning Signs of Dementia

- Worsening judgment
- Not remembering where you placed an item, forgetting familiar tasks → Example- leaving the stove on, forgetting to pay the bills, wearing the same clothes day after day when there are plenty of others in the drawers and closet
- Repetition of phrases within a short time span
- Struggle finding words
- Confused about time, season, people, and location → Examples- getting lost on the interstate and not knowing what exit to take or not able to follow road signs and are going the wrong way; grabbing a winter coat to put on and its 80 degrees outside; forgetting the most recent place they are living, asking “How did I get here?”
- Executive functioning skills have declined greatly
- No longer able to problem solve
- Mood and personality changes

Three Forms of Dementia

- *Alzheimer's*- most common type, shrinkage of the brain due to plaques and the hippocampus is main area affected controlling new learning resulting in short term memory loss
- *Vascular*- second most common type, caused by multiple TIA's (transient ischemic attacks), strokes, and high blood pressure- not enough oxygen in the brain
- *Lewy-body (LBD)*- brain disorder in which Lewy-bodies build up in areas of the brain, the basal ganglia, which affects procedural learning, motor control centers, and the planning process. It occurs in 20-50% of dementia cases and is often misdiagnosed or overlooked as Parkinson's or Parkinson's with a comorbidity of Alzheimer's.

Lewy Body Dementia

Symptomology:

- Intention and resting tremor
- Fast breathing
- Difficulty chewing and swallowing foods
- Rigidity occurs when trying to elicit movement (stiffness)
- Speech is hard to understand
- Flat facial expressions
- Thinking problems
- Hallucinations
- Loss of mobility
- Syncopal episodes (fainting)
- Short, shuffling gait pattern
- Unable to sit in an upright position
- Insomnia issues (disrupted sleep patterns)

Diagnosis:

- 5 symptoms must be observed for diagnosis
- Can be detected with lumbar puncture and PET scans
- MRI and CT scans do not detect as easily

Medications:

- Anticholinergic, a medication often used for Parkinson symptoms, may increase hallucination, delusions, or confusion.
- Traditional antipsychotic medications that are used prescribed for Alzheimer's, such as haloperidol, should be avoided as these affect a brain with Lewy-body dementia differently.

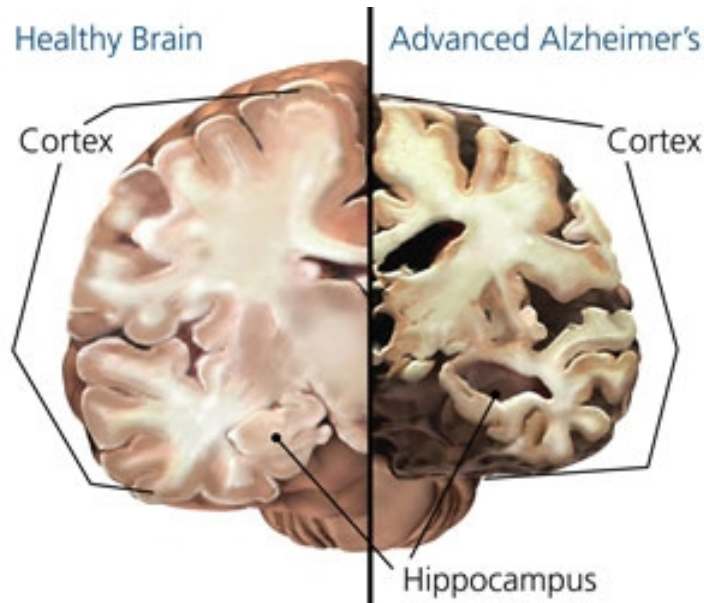
Caregiver Tips:

- Do not put them to bed right after eating; it messes up the digestive tract.
- Pay attention to their swallow
- Rapid short breathing patterns may be observed, so slow down and show them slow controlled breathing so they will mimic.
- Rhythmic, automatic movements are best
- Hypersensitivity areas include: hands, soles of feet, mouth, toes, genitalia
- Walkers and assisted devices that aid in guided ambulation increase the risk for falling

*See the Lewy Body Dementia Association page for additional information

Alzheimer's Brain Changes That Occur

- Loss of brain cells
- Shrinking of brain size
- Plaques and tangles damage nerve cells – plaques form from clumping of protein beta-amyloid



- Hippocampus shrinkage
- Cortex shrinkage
- Ventricles enlarged
- Words, language centers affected
- Temper, mood, and ability to control impulses affected

Alzheimer's Disease Specific Brain Changes

FRONTAL LOBE → reasoning, personality, movement, speech, alertness, safety

PARIETAL LOBE → perceptions, senses, language

AMYGDALA → emotions, anger, fear, sex

OCCIPITAL LOBE → vision, interprets information from eyes, position, movements

HIPPOCAMPUS → memory, short-term memory, stores new memories, learning processes

TEMPORAL LOBE → hearing, memory, language

CEREBRAL CORTEX → sensations, sights, sounds, problem solving, generating of thoughts, making plans, forming and storing memories, control voluntary movement

MRI Brain Imaging

- ❖ “In the autosomal-dominant forms of Alzheimer disease, the rate of atrophy of the medial temporal structures differentiates affected individuals from control subjects as early as 3 years before the clinical onset of cognitive impairment” (Ramachandran, 2016).
- ❖ “Although hippocampal volume has been shown in MRI studies to be associated with cognitive impairment in patients with Alzheimer disease, hippocampal texture has also been shown to be a predictor of conversion of mild cognitive impairment to Alzheimer disease, according to the Alzheimer's Disease Neuroimaging Initiative” (Ramachandran, 2016).
- ❖ MRI findings show the hippocampal volume was highly associated with Alzheimer's disease by stating, “Hippocampal volume was the best discriminator, although a number of medial temporal-lobe structures were studied, including the amygdala and the parahippocampal gyrus” (Ramachandran, 2016).

Ramachandran, T. 15 March 2016. Alzheimer's Disease Imaging. Retrieved from: <https://emedicine.medscape.com/article/336281-overview#a3>

**The only true way to detect Alzheimer's is an autopsy after death.

Stages of Alzheimer's

Early stage

- Forgets time and place
- Idiosyncratic behaviors (anxious, irritable)
- Falls asleep easy
- Communication issues surface
- Lack of engagement
- Memory and concentration issues arise (repeat questions, forgets history and names)
- Struggle planning things

Middle stage

- Needs help with appropriate dressing and toileting
- Steady need for caregivers
- Hygiene decline
- Hallucinations can be present
- Longest decline during this stage
- Often repeats routines over and over → needs cueing and daily support with daily routines
- Orientation to time, place, and location may not match reality
- Challenged by transitions
- Reacts to changes in the environment
- Aggressive behaviors → resident to resident conflict
- Pacing
- Wandering (1/2 of people with Alzheimer's Disease)
- Carry items around and set them down anywhere (ex. many residents carry baby dolls)
- Driving is a big challenge – you can say “I am sorry, I am worried and concerned so you do not get hurt.” VALIDATE FEELINGS- “**I am sorry** this is happening.” “**You are right**, I see your concern with this.”
- PERSON FIRST, DEMENTIA SECOND → protect relationships
- At the end of the middle stage, difficulty with chewing and swallowing may occur and may not understand what to do with food
- Fine motor in feet and lower extremities decline- lose balance and FALL, FALL, FALL!
- Pay attention to skin integrity

Late stage

- Complete deterioration/lack of functioning – no protective reactions, no appetite
- Cannot write or complete reading material → problems with gaze
- May become bedridden
- No voluntary movements
- Skin thinning
- Severe incontinence
- Sleeps more than usual due to sleep disruptions – let them sleep!
- Repetitive movements
- Hospice services needed → Learn the art of saying “letting go” rather than “giving up”
- Pneumonia/heart failure/diabetes/infections are causes of death during this stage → they may need you to say the words that it is okay to go

Tips for the Caregiver:

- ❖ Apathy (suppression of emotions of passion, motivation, excitement, interest) is a problem within all stages
- ❖ Learn to go with the flow
- ❖ Choose your battles
- ❖ Protect relationships and focus on the person within
- ❖ Learn to say “I am sorry” and “You are right”
- ❖ Do not bark commands – Ex. Do not say “Brush your teeth” but “here is your toothbrush” and move your hand like a toothbrush if they need cueing
- ❖ Do not be negative – Ex. “You cannot wear that!” but say “Could you wear this shirt? I love this one!” (Help them feel good about the decision you are wanting.)
- ❖ Enter into their reality!! Picture yourself in their world!
- ❖ All behavior has meaning so identify the triggers and outline an activity/plan
- ❖ Redirecting behaviors are helpful with catastrophic reactions
- ❖ Reduce lighting is helpful at night
- ❖ Be creative in conversation
- ❖ Do not say, “I can’t let you” – they need to know you have respect for them
- ❖ Write things down! – Example→ keep a schedule/calendar
- ❖ When you are experiencing frustration with a loved one: step back, respond-do not *react*, be flexible with making a plan, control the environment, take care of yourself)
- ❖ Do not argue or get angry with them, or even raise your voice- they understand that emotion and it will only heighten the circumstances. Do not ask if they remember something, simply validate what they are telling you.
- ❖ Majority of people live 4-8 years with Alzheimer’s Disease, but can even last up to 20 years.
- ❖ In the end stages of dementia, strong muscle groups will overpower and cause the body to curl in (arms curl in, head down, crossed legs, hunched back) - although this may look painful, do not pry them open → when washing them wash from the back and reach underneath arms
- ❖ In the end stages of dementia, their body does not want food and whether you give them food or not it isn’t processing like it should so it doesn’t really matter → learn to cope with this thought- the body is shutting down

**Thinking, memory, communication, and mood are all affected by catastrophic reactions, which are strong emotional reactions, a person with dementia experiences.

**Identifying, understanding, and responding are ways the brain changes that are affected by sensory inputs of people with dementia.

**Use your senses: visual, auditory, tactile touch

Gems Brain Change Model by Teepa Snow

Sapphire ~ True Blue ~ Optimal Cognition, Healthy Brain

- True to self: personal preferences remain basically the same
- Can be flexible in thinking and appreciate multiple perspectives
- Stress/pain/fatigue may trigger Diamond state: back to Sapphire with relief
- Able to suppress and filter personal reactions: chooses effective responses
- Selects from options and can make informed decisions
- Processes well and able to successfully transition
- Aging doesn't change ability: processing slows, more effort/time/practice needed

“My brain is healthy - true blue. If I am aging normally or distressed, it may be hard for me to find words. I can describe what I am thinking so you understand. I may talk to myself because I am giving myself cues and prompts. I can learn new things and change habits, but it takes time and effort. Honoring my choices and preferences, when possible, is important. I need more time to make decisions. Give me the details and let me think about it before you need an answer. I am able to remember plans and information but supports are helpful. I may like specific prompts such as notes, calendars, and reminder calls. Health changes in vision, hearing, balance, coordination, depression, anxiety, pain, or medication may impact my behavior, but my cognitive abilities remain the same.”

Diamond ~ Clear and Sharp ~ Routines and Rituals Rule

- Displays many facets: behavior and perspective can shift dramatically
- Prefers the familiar and may resist change: challenged by transitions
- More rigid and self-focused; sees wants as needs, when stressed
- Personal likes/dislikes in relationships/space/belongings etc, become more intense → controls important roles and territory
- Reacts to changes in environment; benefits from familiar; functional/forgiving
- Needs repetition and time to absorb new/different information or routines
- Trusted authority figures can help: reacts better when respect is mutual
- Only 20% of individuals are diagnosed at this stage.

“My overall cognition is clear and sharp. When happy and supported, I am capable and shine in my abilities. When distressed, I can be cutting and rigid and may see help as a threat. I have trouble seeing other points of view and may become less aware of boundaries or more possessive about my relationships, personal space, and belongings. I have many facets so people see me differently depending on the situation. This can cause conflict among my family, friends, or care team as it’s hard to tell if I am choosing my behavior or truly have limits in my ability. I can socially engage and have good cover skills. People will vary in their awareness of what is happening to me. I want to keep habits and environments as they have always been, even if they are problematic for me or others. I am often focused on the past, personal values, or finances. I will need help to make changes in my life; it’s hard for me. I can be in a Diamond state for reasons other than dementia.”

Emerald ~ Green and On the Go With a Purpose ~ Naturally Flawed

- Sees self as able and independent, with limited awareness of changes in ability
- Lives in moments of clarity mixed with periods of loss in logic/reason/perspective
- Understanding and use of language change: vague words and many repeats
- Cues and support help when getting to/from places and doing daily routines
- Awareness of time, place, and situation will not always match current reality
- Strong emotional reactions are triggered by fears, desires, or unmet needs
- Needs to know what comes next: seeks guidance and assistance to fill the day

“I am flawed; it is part of being a natural emerald. I tend to be focused on what I want or need in this moment and may not be aware of my own safety or changing abilities. I can chat socially, but I typically miss one out of every four words and cannot accurately follow the meaning of longer conversations. I won’t remember the details of our time together, but I will remember how your body language and tone of voice made me feel. I may hide or misplace things and believe someone has taken them. My brain will make up information to fill in the blanks, which makes you think I am lying. If you try to correct me or argue, I may become resentful or suspicious of you. I am not always rational, but I don’t want to be made to feel incompetent. My brain plays tricks on me, taking me to different times and places in my life. When I am struggling, I may tell you, “I want to go home.” To provide the help and assistance I need, you must go with my flow, use a positive, partnered approach, and modify my environment.”

Amber ~ Caught in a Moment of Time ~ Caution Required

- Focused on sensation: seeks to satisfy desires and tries to avoid what is disliked
- Environment can drive actions and reactions without awareness of safety
- Visual abilities are limited: focus is on pieces or parts, not the whole picture
- What happens to or around an Amber, may cause strong and surprising reactions
- Enters others' space and crosses boundaries attempting to meet own needs
- Has periods of intense activity: may be very curious or repetitive with objects or actions
- Care is refused or seen as threatening, due to differences in perspective and ability

“Like a particle trapped in an amber, I am caught in a moment of time. It may surprise you to see how I take in the world around me. I may not know you or see you as a whole person. I react to you based on how you look, sound, move, smell, and respond to me. I like to do simple tasks over and over and may need to repeatedly move and touch, smell, taste, take or tear items apart. While it may exhaust or frustrate you, it soothes me. I don't recognize danger; you will have to safeguard my environment. I'm intolerant to discomfort because my mouth, hands, feet, and genitalia are highly sensitive due to changes in my nervous system. Therefore, activities like eating, taking medication, mouth care, bathing, dressing, and toileting may distress me. Please notice my reaction and stop if I am resisting. I can't help myself, and one or both of us may get hurt emotionally and/or physically. If this happens, wait a few minutes, connect with me, and try a different approach; possibly substituting one area of focus for another.”

Ruby ~ Deep and Strong in Color ~ Others Stop Seeing What is Possible

- Makes use of rhythm: can usually sing, hum, pray, sway, rock, clap, and dance
- When moving can't stop; when stopped can't get moving: needs guidance and help
- Big, strong movements are possible, while skilled abilities are being lost
- Danger exists due to limited abilities combined with automatic actions or reactions
- Tends to miss subtle hints, but gets magnified facial expressions and voice rhythms
- Can mimic actions or motions, but will struggle to understand instructions/gestures
- Able to pick up and hold objects, and yet not know what to do with them

“As the deep red of a ruby masks detail, my obvious losses make my remaining abilities harder to notice. Although my fine motor skills have become very limited, remember that I am able to move and do simple things with my hands. You will need to anticipate, identify, and respond to all of my needs, even though I may not be aware of them. Plan to create a supportive environment, help with the details of care, and structure my day. Just as a crossing guard directs traffic, you will need to guide my movements and transitions. I can rarely stop or start on my own and switching gears is a challenge. Move with me first, then use your body to show me what you want me to do next, going one step at a time. Hand-under-Hand™ assistance helps me to feel safe and secure and to know what to do. Danger is part of my life, due to losses in visual skills, chewing abilities, balance, and coordination. You can reduce the risks to me, but not eliminate them. I can still have moments of joy when you are able to provide what gives me pleasure.”

Pearl ~ Hidden Within a Shell ~ Beautiful Moments to Behold

- Will frequently recognize familiar touches, voices, faces, aromas, and tastes
- Personhood survives, although all other capabilities are minimal
- Understanding input takes time: go slow and simplify for success
- In care, first get connected by offering comfort then use careful and caring touch
- Changes in the body are profound: weight loss, immobility, systems are failing
- As protective reflexes are lost, breathing, swallowing, and moving will be difficult
- Care partners benefit from learning the art of letting go rather than simply giving up

“While hidden like a pearl in an oyster shell, I will still have moments when I become alert and responsive. I am near the end of my life. Moments of connection create a sense of wholeness and value between us. Use our time together not just to provide care, but to comfort and connect with me. To help me complete life well, it’s important to honor my personhood when making medical or care decisions; please don’t talk about me as though I am not still here. I respond best to familiar voices and gentle rhythmic movements. I am ruled by reflexes and will startle easily. My brain is losing its ability to control and heal my body. Be prepared to see me having difficulty breathing or swallowing. My body may no longer desire food and drink as I prepare to leave this life. I may not be able to stop living without permission from you. Your greatest gift at this time in my life is to let me know that it is okay to go.”

Taken directly from:

Snow, T. (2018). The Gems: Brain Change Model. Retrieved from:
<http://teepasnow.com/events/teepas-gems/>

Triggers of Catastrophic Reactions

- Environmental
 - Stimulation
 - Familiarity with environment
 - Lighting
- Internal
 - Medication side effects
 - Depression
 - Fear
 - Confusion
 - Dependency
 - Loss of control
 - Frustration
- Caregiver
 - Are you comfortable and familiar with the caregiver?
 - How much assistance are you offering?
 - Are you paying attention to their desired routines and preferences?
(Age and gender can be a potential cause for reaction)
 - Are you maintaining dignity and respect for the individual?

General tips for Preventing Catastrophic Reactions:

- ❖ Feelings remain intact even though memories and skills decline.
- ❖ Caregiving should be a shared process
- ❖ Do not discount the person's new reality; simply address their feelings that they are experiencing.
- ❖ Nourish the soul- love and support
- ❖ Give cues and allow plenty of time for response
- ❖ Consider the four "F's" for environment: friendly, familiar, functional, forgiving
- ❖ Consider also the four "S's" for environment: space, sensation, surfaces, and social experiences

Defusing a Catastrophic Reaction

SPACE- limit the number of people that address the reaction

APPROACH

REALITY- enter their reality

FEELINGS- fidgeting, pacing, shouting, and singing are all key cues to notice

TRIGGERS- chronic pain can be a trigger

COMMUNICATION- low tone of voice; short, simple commands

RE-APPROACH- if there is no potential of harm, step away and give them 10-15 minutes or time to finish an activity if they have started on a new activity already

REASSURE/REFOCUS- engage in activity, offer a snack or drink

Meaningful Activities

#1: Productive Activity (Work)

- Cooking/baking
- Gardening
- Laundry

#2: Leisure Activity

- Music
- Reading the newspaper
- Puzzles

#3: Self-Care Activity

- Brushing teeth
- Toileting
- Dressing
- Showering

#4: Rest and Relaxation Activity

- Spiritual renewal
- Personality preferences, ex. Time to themselves if introverted

**As a caregiver you need to be aware of these for your loved one as well as yourself.

Snow, Teepa. (2018). Meaningful Activities. Retrieved from:

<http://teepasnow.com/resources/teepa-tips-videos/meaningful-activities/>

General tips during activities:

- ❖ Use step-by-step instruction with demonstration
- ❖ Keep it simple
- ❖ Let them be as independent as possible and do all they can no matter how long it takes~ BE PATIENT
- ❖ Do not be upset with the person; be upset with the disease.
- ❖ Repetition is key
- ❖ Explain exactly what you are doing, especially during self-care activities.
- ❖ Allow and encourage self-expression activities
- ❖ Use previous interests to engage in activity
- ❖ Connect with others through activity
- ❖ Stimulating activities that stir memory are good activities
- ❖ Help them feel productive!

INTERVENTION ACTIVITIES FOR THE 24-HOUR CAREGIVER

- Family Picture Puzzle → memory; processing; visual
- Yoga (chair and standing poses for grading) → exercise
- Making a memory box → craft, meaningful memory activity
- Music → sensory stimulation while brushing teeth, dressing, showering
- Baking cookies or favorite recipe → following directions; occupational work
- Get a whiteboard with days of the week to place important dates on → planning/scheduling, developing routine
- Household tasks → sense of accomplishment and improving sense of self are integral activities for individuals in early to mid stage of Alzheimer's (laundry, cleaning, sweeping) ***SAFETY IS A PRIORITY-** Ex. cleaning supplies can become a safety hazard if too much confusion is occurring
- Animal day → sensory stimulation; increased expression; psychosocial benefits
- Activities with young children → psychosocial benefits, re-establishing roles
- Making a birdfeeder out of popsicle sticks to go outside their window → meaningful sensory and leisure activity
- Tend to the garden/help pick weeds/plant flowers
- Spa day for the ladies → psychosocial benefits- continuing to find value in hygiene and self-care
- Toolbox with nuts and bolts for men to fidget with ***use judgment for safety concerns** → meaningful work and leisure activity
- Hand under hand technique to initiate eating → purposeful activity

INTERVENTION ACTIVITIES FOR VISITING A LOVED ONE AT A FACILITY

- Family Picture Puzzle → memory; processing; visual
- Yoga (chair and standing poses for grading) → exercise
- Read the newspaper and/or magazine → leisure, orientation to time
- Have them read a small portion of their favorite book if able → cognition, attention, leisure activity
- Take a walk outdoors, if appropriate → leisure, sensory
- Bring grandchildren → psychosocial benefits
- Bring in a family puppy → sensory
- Make a card for someone → meaningful leisure activity
- Talk about old memories → relaxation technique
- Hand under hand technique to initiate eating → purposeful activity