

Dementia Hospital Bag

What to Bring When Going to the Hospital

Positive Approach™ suggests bringing the following information and items to have available during a hospital stay:

PAPERWORK:

- Health care power of attorney (notarized)
- Advance directives (notarized)
- Copy of patient driver's license and insurance cards (or actual cards)
- List of primary contact and all care team members, including name, and contact information
- Copy of primary contacts calendar for the next few days and any additional important telephone numbers (for example: work or administrative assistant #'s) so staff know when and how to reach you
- A blank notepad or notebook for recording information or you want to keep track of or questions you want to ask
- It is recommended to create a **Personal Information Sheet** and bring multiple copies to the hospital to help to communicate the specific needs of a **Person Living With Dementia (PLWD)**. As the progression of dementia will impact a person's ability to communicate as staff might be used to, the goal is that this documentation is to quickly equip a hospital team to help. It should be typed or printed neatly and given to those in charge.

Personal Information Sheet:

1. Share the individuals *preferred name*
2. List of diagnosis or other medical conditions
3. List of current medications including: drugs, and over the counter items such as vitamins, herbs etc.
 - ✓ Bring bottles to hospital if available
 - ✓ Share allergies as well as any history of adverse reactions or sensitivities to medications, as well as any recent medication changes
 - ✓ Discourage the stopping of any ACIs if possible during the hospital stay (Aricept, Exelon, Reminyl)
4. Need for supportive aides such as glasses, dentures, or hearing aids
5. Describe the amount of help typically needed for daily living activities (for example: when getting ready in the morning my mother typically can... or needs help with...)
6. Describe current impairments/challenges including
 - ✓ Memory
 - ✓ Language
 - ✓ Understanding
 - ✓ Hand skills
 - ✓ Movement
 - ✓ Judgment
 - ✓ Impulse control
7. Important contact information
 - ✓ Include names and relationship to the person, favorite people, relationships or names to avoid (those who may induce stress for the PLWD) and pets
8. Describe work history
 - ✓ Jobs & preferences (old and recent)
9. Describe leisure history
 - ✓ What PLWD likes/liked, and what they dislike/disliked
10. Describe living history
 - ✓ Where they currently live, how long, and who do they live with
 - ✓ Where they are from originally
 - ✓ Where else they might have lived
11. Describe spiritual history
 - ✓ Describe comfort level with faith
 - ✓ Where they have, or still do, worship
12. What specific behavior or "cue" does the PLWD do to let you know when they are
 - ✓ Hungry
 - ✓ Thirsty
 - ✓ Tired
 - ✓ Hurting
 - ✓ Needing to urinate/pee
 - ✓ Have become wet/incontinent
 - ✓ Constipated or needing to have a bowel movement
 - ✓ Have had a BM

13. Describe daily schedule and behavior patterns as well as behavior concerns:

- ✓ Typical routines
- ✓ Details about what would be normal high activity and rest times
- ✓ Challenging times of day
- ✓ Wandering or elopement tendencies
- ✓ Anxiety/agitation
- ✓ Need/desire to move, difficulty being still for long periods of time
- ✓ Calling out or yelling
- ✓ Swallowing or eating challenges
- ✓ Fall risks or immobility
- ✓ Dis-inhibition, socially inappropriate tendencies
- ✓ Sensory sensitivities (for example: likely to resist medical protocols and play with or pull out tubes)
- ✓ Emotional high's and low's

14. How does the PLWD express these emotions

- ✓ Lonely
- ✓ Scared
- ✓ Angry
- ✓ Sad
- ✓ Happy
- ✓ Confused

15. Describe self-care preferences and patterns

- ✓ Grooming, bathing, exercise, dressing, amounts of help used

16. Describe any major life events

- ✓ Past experiences that may have greatly affected them either positive or negative
- ✓ Bad hospital stays from before

17. Describe “hot” buttons, helpful information for staff about

- ✓ Things that cause upset (for example: specific words, actions, or responses)

18. Food

- ✓ Favorite foods
- ✓ Comfort foods
- ✓ Disliked foods
- ✓ Sensitive to (for example: textures)
- ✓ Allergies

19. Music

- ✓ Bring favorite or helpful ambient sound
- ✓ Plan to use it

20. Activity

- ✓ Bring preferred things to touch and hold (for example: familiar blankets, pillows, stuffed animals, or cushions)
- ✓ Bring preferred things to look at (for example: posters, pictures of family, request room with a window)
- ✓ Bring preferred things to do (for example: books, magazines, cards)
- ✓ Inquire with staff about available massage, recreation, or volunteers available to help decrease boredom

THINGS TO PACK:

- An extra set of clothing for the PLWD, pick favorite and comfortable clothes
- An extra set of pajama's gown in case the hospital gown is bothersome
- A set of clothes for yourself, especially if you may need to go directly to work from the hospital
- Morning personal care items for yourself and PLWD, familiar mouth care and grooming items helpful
- Cell phone and electronic chargers
- *Familiar and comforting SMELLS*: favorite lotions, perfumes, colognes, after shaves, herbs, room fresheners, oils (for example: lavender is calming and citrus is energizing (familiar and comforting smells))
- *Familiar and comforting THINGS TO LOOK AT*: favorite pictures or posters, photo albums (or copies of pictures and include a 'cheat sheet' of details for staff), picture books (for example: coffee table books), other objects that have meaning and comfort that have been included in your personal information sheet

- *Familiar and comforting THINGS TO LISTEN TO:* a cd player or speaker and favorite cd's or created music compilations (childhood, adolescence, or young adulthood can be particularly comforting if dementia is progressing), ambient or soothing white noise sounds (to help reduce hospital noise and support sleeping), head phones (in case there is a roommate), a hymn book with 'favorites' marked, song books with 'favorites' marked, books on tape of favorite readings or stories, create a recording of a favorite person sharing a story or share expressing their love
- *Familiar and comforting THINGS TO FEEL:* bean bag filled weighted pillows or hot packs, favorite blankets, pillows or covers or clothing items, stuffed animals, cloth samples to explore
- Snacks and favorite things to eat or drink (may need to confirm with staff any dietary restrictions while in the hospital), packaged snacks or drinks, sealable bags for leftovers or small portions for between meals or missed meals, drink mixes to add to water (if it helps to keep the person hydrated), cups to improve ability to drink (standard Styrofoam or paper cups may be difficult to use)

ENGAGEMENT/ACTIVITY IDEAS:

Engagement “needs” during a hospital stay will change as dementia progresses. Here are some ideas based on Teepa’s Gem™ level dementia ability classification model.

Diamonds: *Early stage mild cognitive impairment, PLWD will still be clear and sharp, may become rigid (especially under pressure), may become protective or territorial, may repeat self, will struggle holding onto new information, socially capable, will be experienced differently by different people*

- ✓ Familiar and interesting lap or table activities including: crossword puzzles, word searches, hand work (crochet or knitting), letter or card writing, journaling, positive reading materials that may include inspiring pictures (Reader’s Digest, National Geographic, Smithsonian, LIFE, Woman’s Day, Sports Illustrated, and hunting, fishing, or car magazines), newspapers, favorite books or books on tape, spiritual or inspirational reading, card games, board games (Scrabble, Checkers, Chess, Chinese checkers, Yahtzee, category games, or 100-300 jigsaw piece puzzles, electronics only when someone is familiar with or has been using for a while (I pads, kindles, laptops)

Emeralds: *A moderately progressed dementia causing changes in comprehension and communication ability, language may be more vague, PLWD will tend to respond to what is visually suggested or “cued” instead of what they are told, may want to move and prefers to stay active or busy, may do things by mistake but will typically be unable to correct them, may lose their sense of time or begin to time-travel to other history or places, may ask questions repeatedly (what, where, why, how), may need help but will resist being “controlled” and may react emotionally, will respond well to simple choices (either/or), may be at higher risk for becoming lost due to the need to move or wanting to move away from frustrations (purposeful movement)*

- ✓ Familiar lap or tabletop activities that offer visually stimulating things to look at, talk about, or do with someone else including: cards, familiar or favorite magazines or books (may include books of faith), photo albums, newspaper sections, picture books, famous quotes, short stories, word games, recipe books, sorting supplies for manipulating and organizing (for example: colored index cards, foam shapes, poker chips, coins, hardware items like nuts, bolts, washers, beads or buttons, swatches of material) simple interactive game activity (Checkers, cards, matching games, Scrabble tiles for making words not playing formally), simple word games (books available), cutting coupons (blunt tip scissors recommended), tearing out or cutting out of pictures for collages or creative projects, 24-64 piece jigsaw puzzles, cd's or music collections (old radio programs, favorite speakers, stories, sing-a-long books or scripture readings), if PLWD is time traveling they may benefit from props, pictures, or activities that will match up to where they are experiencing themselves (early adulthood, early career, early family life)

Ambers: A middle stage progressed dementia requiring supervision in a hospital environment for safety, PLWD will be in the moment and busy exploring with fingers and hands, may be touching, tasting, fiddling, doing, “checking out” much of what they come in contact with in the environment, may resist or dislike restraints or limits, may react intensely to negative stimulation or sensory experiences (hospital environment sounds, patient vitals protocols, needed medical care) most of the time will typically not be able to make specific needs or preferences known (**personal information sheet** particularly helpful for this reason), can become hyper-focused (won’t want to be interrupted) or very distractible (hard to keep their attention), has ability to copy or imitate, typically respond well when caregivers model desired task or activity along-side of them, slow step-by-step approaches and low tones of voice are helpful when interacting

- ✓ Familiar lap or tabletop activities that provide the sensory need to manipulate, handle, fiddle with, put together/take apart items including: the applying of stickers around a border, sorting supplies for manipulating by color (cards, foam shapes, swatches of materials), cause and effect activities (putting coins in a piggy bank, or container, hinging clothespins to a sheet of cardboard, lacing shoestrings through holes in cards, bags with things inside to discover), stimulating or de-stimulating cd’s or playlists, song books, hymnals, soothing sensory experiences such as hand, back or foot massages with scented lotions, aromatherapy scented cloths in sealed bags

Rubies: A later stage progressing dementia when physical fine motor ability stops (refined skills in mouth, eyes, fingers, and feet), gross motor abilities and action are retained (strength and larger movement), engagement will be mostly quiet and interactive, PLWD will be capable of watching and copying large movement and desired actions if modeled by someone, may try to move a lot even though skill ability is minimal, may have longer drowsy periods and will need extra transition time into activity, will also need transition time and support from activity back to being still, may be restless if required to stay in bed or seated for long periods of time, may need more “interaction” and connection from you than from “things” you bring or offer to PLWD, can get overwhelmed and will react quickly and strongly (may surprise you), typically will not be interested in food or drink most of the time

- ✓ Personal interactive connection with familiar people may include: touch and contact to help the person stay where they need to be (multiple seating options helpful), rearranging of room in order that PLWD can see you and reach you, use of music to help calm and rest or to increase attention and focus, PLWD may prefer watching of what others to doing something, offering of something to hold (small pillows, weighted or favorite blankets, stuffed animals or doll)

Pearls: This is the final dementia state of being and typically means PLWD is nearing end of life, will be less alert or responsive, will typically respond better to familiar tones of voice, faces, or touch, may be unable to sit up or move without assistance, may be reflexive and sensitive to movement, touch, noise and temperature, muscular contractures are typically forming, and weight loss may be extreme

- ✓ Personal connection with familiar people may include: soft reassuring voices (expressions of love, quiet singing, quiet reading of poetry or scripture), gentle but firm touch (not a lot of movement but instead reassurance with palm of hand, flat fingers and pressured strokes or circular movement), holding of a hand and pumping the palm, stroking of hair, pressure of hand on a shoulder, application of a lip balm, relaxing music most of the time, arousing music perhaps before meal times, providing of extra warmth (socks, head cover, shoulder/arm covering, mittens or gloves, light weight and warm covers/blankets, warm head covers)

