



Session Handouts for Caregivers





Session 1 – Key Caregiver Knowledge, Skills, and Outlook Handout

<p>Knowledge</p>	<ul style="list-style-type: none"> ✓ Knowledge about the dementia condition: what it does to the person; how it progresses; what it means for caregiving ✓ Recognize the needs dementia creates in the person (e.g., for security) ✓ Understanding of how much the person will rely on you ✓ Knowledge of strategies and techniques that can be employed to manage day-to-day life with the person ✓ Knowledge of what dementia does to a family ✓ Knowledge of what caregiving can do to the caregiver and of appropriate self-care techniques ✓ Strategies to engage others to assist in the care of the person
<p>Skills</p>	<ul style="list-style-type: none"> ✓ Skilled observation: recognize subtle differences from day to day ✓ Creating and sustaining a secure and comfortable routine for the person ✓ Management of day-to-day life with a minimum of disruptive behavior ✓ Identify and use effective responses should disruptive behavior occur ✓ Effective communication, given the effects of the disease ✓ Ability to think up tasks and activities that suit the person and that allow him/her to be enjoyably involved in them ✓ Ability to bring family into caregiving, as much as possible ✓ Recognition of the need for and use of strategies for self-care ✓ Effective interaction with your caregiving network
<p>Outlook</p>	<ul style="list-style-type: none"> ✓ Clinical – have a kind of detached view of the situation and influences to allow for accurate observation and informed planning ✓ Experimental – be able to try things and learn from the results of the trying (whether they succeed or not) ✓ Accepting – recognize that dementia cannot be denied or stopped and that fighting against it is a waste of energy ✓ Humorous – trying to see that there might be things to laugh about in day- to-day life



Tasks and Activities Grid

Stage	Description	Examples
Normal	Independent in all activities, including complex cognitive tasks requiring intact executive function	<ul style="list-style-type: none"> ▪ Managing a checkbook ▪ Making and following shopping lists ▪ Planning and taking a vacation ▪ Taking care of all daily needs (dressing, eating, toileting, hair care, etc.)
Early Stage	Independent in most daily activities, but may make errors in complex tasks. NOTE: Errors in complex activities are more serious, and often higher risk, than those in daily care activities.	<ul style="list-style-type: none"> ▪ Makes mistakes with finances (checkbook doesn't balance; impetuous purchases), where he/she used to be able to manage. ▪ Difficulties in complex activities (problems on trips or in unfamiliar places; difficulties navigating while driving in unfamiliar places; confusion carrying out complex tasks such as preparing a large meal), where he/she used to be able to manage. ▪ May need reminders (e.g., to come to dinner, wash up, comb hair, or get to the bathroom).
Early-Middle Stage	Able to participate in daily care and activities with cuing and direction. May be able to do some steps, with guidance, in more complex activities.	<ul style="list-style-type: none"> ▪ Cannot manage checkbook or finances reliably; cannot successfully plan complex activities. ▪ Occasionally becomes lost or confused in places outside normal routine. ▪ Makes occasional errors with daily care activities (e.g, spill food, make a mess, toilet accidents) ▪ Needs help starting or continuing with daily care tasks (e.g., prompt to keep eating; hand hair brush, washcloth, etc.) to him/her; reminders to finish brushing, eating, washing, etc.). ▪ May still perform overlearned activities well (knitting, gardening, letters).
Late-Middle Stage	Remains able to participate in everyday care activities, with increasing amounts of assistance and guidance.	<ul style="list-style-type: none"> ▪ Must be handed things (grooming objects, dinner utensils) to perform task. ▪ Needs prompting and cuing in a step-by-step way to complete tasks (remind person to do each step of the task; serve just one thing at a time at meals; remind person to finish the task). ▪ May need direct assistance (help finishing cleaning up after toileting; having food handed to him/her; having washing-up materials handed one at a time and being cued on their use). ▪ May still perform simplified, overlearned activities with cuing and support.
Late Stage	Able to enjoy passive engagement. May cooperate or be fully passive during care provided by others.	<ul style="list-style-type: none"> ▪ Can be passively engaged/involved in activities performed by others. ▪ May enjoy passive activities, such as listening to music, watching birds. ▪ May cooperate during everyday care (e.g., move head while being washed, having hair combed, having incontinence products changed, or while being fed by another). ▪ May give no response while someone else does his/her daily care activities

Note: Even in early stage, when the person seems to be performing well, issues of safety must be addressed. Caregivers can't take safety for granted at any time.



Session 1 – Cognitive Losses Worksheet

Area of Thought	Strengths/ Losses	Less Productive	Productive	Ideas
Memory				
Language				
Reasoning				
Judgment				
Perception				
Abstraction				
Attention				
Organization				



Session 4 – Structure and Support Handout

Stage	Structure (Set Up of a Task or Activity)	Support (Communication and Help)	Steps
Early Stage	<ul style="list-style-type: none"> • Can do many things independently • Consider removing complex parts • Think about breaking tasks apart and assigning parts • Check this, but should be able to move from place to place 	<ul style="list-style-type: none"> • Use fairly normal directions • Give verbal help; use notes or labels • Be ready to help with the next step or missing word • Watch for frustration and be positive and supportive 	4-6 Steps depending on complexity
Early-Middle Stage	<ul style="list-style-type: none"> • Can successfully participate in activities if you: • Take Over: do the planning for the task; establish a routine • Simplify: break larger and more complex tasks into parts • Structure: Get things ready and set them up • Make the environment work for the person by removing distractions • By the end of this stage, do the activity in one room 	<ul style="list-style-type: none"> • Begin to be more directive because reason and explanation may not work • Verbal help still works, but simplify and begin to use visual cues • Fill in with next steps and words • Be ready to help and redirect • Frustration and irritation very possible 	2-5 Steps Reduce the number of steps as the disease gets worse.
Late-Middle Stage	<ul style="list-style-type: none"> • Can participate in steps of an activity when: • You are in control; you are making decisions • Continue to simplify by breaking tasks into fewer and fewer steps • Set everything up • Only show the things needed to do the task • Do the task in one place • Remove distractions • Be prepared to do the task yourself 	<ul style="list-style-type: none"> • Help the person start and with each step • Use short verbal directions • Rely more on showing and physically guiding the person • Demonstrate the steps • Expect frustration; end the task and move on when you sense it • Do not force a step • Be positive and reassuring 	1-2 Steps or Passive
Late Stage	<ul style="list-style-type: none"> • Able to enjoy passive activities and observation • You are fully in control • Very simple, one-step tasks may be possible • Focus mainly on comfort and calm environment • Think about the senses: What might s/he like to watch, feel, smell, hear, or taste? 	<ul style="list-style-type: none"> • The tone of your voice will convey more than words • Your emotional tone is also likely to be picked up • Guide the person physically and use visual cues 	1 Step or Passive

Session 5 – Suitable Mealtime Tasks Handout

Stage	Structure and Support Considerations	Suitable Mealtime Tasks
Early	<ul style="list-style-type: none"> ▪ Should be able to perform tasks involving moving about the home ▪ Should be able to do 4-5 step tasks ▪ Will likely keep the purpose of task in mind ▪ Provide clear verbal direction 	<ul style="list-style-type: none"> ▪ Getting things from other areas ▪ Arranging an area ▪ Measuring and mixing things together ▪ Taking things back to the kitchen and other areas ▪ Helping to cook
Early-Middle	<ul style="list-style-type: none"> ▪ Should be able to perform tasks involving moving about the home ▪ Should be able to do 3-5 step tasks ▪ Will likely keep the purpose of task in mind ▪ Provide clear verbal direction ▪ Check a few times; may have to remind 	<ul style="list-style-type: none"> ▪ Getting things from other areas ▪ Arranging an area ▪ Taking things back to the kitchen and other areas ▪ Measuring and mixing things together ▪ Sweeping or vacuuming under/around the table ▪ Doing and drying dishes ▪ Helping to cook; making sandwiches
	<ul style="list-style-type: none"> ▪ Needs a more contained area of work (e.g., the dining room) ▪ Can do a 2-4 step task; repetition is good ▪ Make sure materials are ready and out ▪ Give directions and visual demonstration; show end product if possible; help to start on task ▪ Check regularly; provide reminders to stay with the task; correct positively ▪ May need to be redirected 	<ul style="list-style-type: none"> ▪ Putting silverware and condiments on tables ▪ Making sandwiches ▪ Putting food in containers ▪ Preparing string beans; shelling peas ▪ Putting on napkins and/or tablecloths ▪ Putting water/juice on the table ▪ Putting flowers/other centerpieces on tables ▪ Taking things from the table ▪ Sponging down the table; drying dishes ▪ Rearranging the room
Late-Middle	<ul style="list-style-type: none"> ▪ Needs a task that is right within reach – a sit down task is best ▪ Can manage a 1-3 step task – needs repetition; likely won't recall purpose ▪ Demonstrate; visual directions; show end product; start on task ▪ Will need frequent checks to redirect and keep going on the task. 	<ul style="list-style-type: none"> ▪ Wrapping silverware in napkins ▪ Putting flowers into vases ▪ Peeling, shredding, chopping, and dicing ▪ Rewashing things ▪ Stirring; rolling (cookies) ▪ Cracking eggs into a bowl ▪ Buttering bread/toast
	<ul style="list-style-type: none"> ▪ Don't worry about quality, only involvement ▪ Keep task in sight and reach; remove distractions (face a wall at a table) ▪ Needs a very simple task ▪ Repeated visual demonstrations; hand object to person; give simple command ▪ Check back often for comfort and task 	<ul style="list-style-type: none"> ▪ Rolling (cookies) ▪ Simple folding (napkins in half) ▪ Stirring ▪ Frosting
Late	<ul style="list-style-type: none"> ▪ Likely can only enjoy passive activity ▪ May do single step task, if simple 	<ul style="list-style-type: none"> ▪ Wiping surface in front of him/her ▪ Spreading butter already placed on bread



Getting Washed Up in the Morning

Stage	Early	Early-Middle		Late-Middle		Late
Activity/Role	Able to wash up, shower and groom by self.	Able to wash up, shower and groom by self, but may lose track of the task at times.	Can perform the physical activities involved in morning washing up, but may need support to stay on task.	Able to perform discrete actions (wash, brush, etc.). Will need structure and support for keeping the goal and sequence in mind.	Able to perform gross actions (wash, brush, etc.). Will need assistance to be effective and not repetitive.	Might perform some gross tasks by self (e.g. using washcloth on face) with support. Can comfortably accept care.
Set-Up	Be sure the wash up area is accessible and ready.	Be sure the wash up area is accessible and ready.	Make the wash up area accessible and ready. Have materials (cloth, soap, tooth paste, toothbrush, comb, towel) laid out and remove distractions.	Make the wash area comfortable. Lay out specific materials (cloth, soap, toothbrush, towel, etc.), preferably in the order they'll be used. Remove distractions.	Make the wash area comfortable. Lay out specific materials (cloth, soap, toothbrush, towel, etc.), preferably in the order they'll be used. Remove distractions.	Make the wash area comfortable. Specific materials (cloth, soap, toothbrush, tooth paste, comb, towel, etc.) laid out for caregiver convenience.
Assistance	Able to do by self (unless another issue interferes); check back for task completion.	Give overall direction, check back more than once to redirect if necessary.	Set stage (it's time to wash up), give directions (okay, wash your face); return frequently to check and prompt.	Focus on the individual actions that make up the washing up task; remain with person to cue.	Each sub-task is an end in itself. Hand the equipment needed, start on task, refocus and redirect as needed.	Each sub-task is an end in itself. Person can do as much as able. Likely mostly done by caregiver.
Cues and Communication	Usual greeting and general direction: "Time to get going; I'll need your help with breakfast; wash up then come help me."	Specific direction (don't offer larger context): "It's time for you to wash up." Then specific cues: "have you... (washed, brushed, etc.)?"	Have all equipment laid out and in sight; provide reminders to stay on track; may need to direct for each sub-task.	Verbal and visual cues (pick up washcloth and hand it; say "wash your face," pointing to the face.) Take the person through all steps.	Verbal, visual, and tactile cues (pick up washcloth, hand it, say "wash your face," point to or touch face.) Help the person get started with hand over hand help. Take through all steps for each sub-activity.	Simple verbal cues with emphasis on visual and tactile. Hand over hand help may enhance participation. Communicate what is being done.



Getting Dressed in the Morning

Stage	Early	Early-Middle		Late Middle		Late
Activity/Role	Able to dress by self; able to choose own clothes and put them on without error or assistance	Able to dress self; able to choose and put on clothes, but may make poor choices (e.g., want to always wear same thing or not dressing for the weather).	Can perform the physical activities involved in dressing, but may need support to stay on task.	Can perform discrete actions (put on items) but may need structure and support for keeping the goal and sequence in mind	Able to perform gross actions (putting on clothes), but may need assistance to be effective (e.g. managing zipper) and not repetitive	Might perform some gross task (e.g. putting arms into a shirt) with support, and visual cues. Can comfortably accept care.
Set-Up	No set up really necessary	Consider beginning to simplify clothes closet to limit choices and avoid confusion	Focus on clothes closet. Simplify, hang outfits together	Set out the clothes in order of putting on. Remove or greatly limit choice. Close the closet door.	Set out the clothes in order they will be put on. Don't offer choices.	Set out the clothes in order of putting on. Hand each in order.
Assistance	Able to do by self (unless another issue interferes); check back	Able to dress with overall direction. Check back more than once to redirect if necessary	Able to dress with structure and support. Set stage ("It's time to dress"); give directions ("Put on your pants."); return frequently to check and prompt	Able to perform the individual actions that make up the task of dressing. Remain with person to cue through steps.	Able to perform individual steps in dressing process. Each sub-task is an end in itself. Hand the garment, start on task, refocus and redirect as needed	May be able to perform some individual steps with help. Each sub-task is an end in itself. Help the person to take part, as able. Likely done primarily by caregiver.
Cues and Communication	Usual greeting and general direction: "Time to get dressed now." However, person may not need cue at all.	Specific direction (don't offer larger context): "It's time for you to dress." Then specific cues: "Are you dressed yet?"	Might need to have clothes laid out and in sight; provide reminders to stay on track; may need to direct for each part of getting dressed	Verbal and visual cues (pick up garment, hand it; and say "put this on," perhaps mimic the action.) Take through all steps.	Verbal, visual, and tactile cues (pick up garment, hand it, say "put this on," Mimic action.) Get them started with hand over hand help. Take through all steps for each sub-activity.	Simple verbal cues with emphasis on visual and tactile. Hand over hand help may enhance participation. Communicate what is being done



Session 6 – Barriers and Aids to Successful Family Caregiving

Directions: Consider each of the following barriers and aids to your current family situation. Planning ahead is a helpful strategy for many caregivers. Write down ideas that relate to you and your person.

Denial. Is there anyone in the family who does not believe that the person has a dementia illness? Or that the problem isn't as serious as you see it to be?

Lack of Role Flexibility. Are you willing to ask your family for help? Are there reasons why they cannot help? Are there reasons why you haven't asked for help? Or, are there family members who want to uphold family traditions or ways of interacting but are not willing or able to make adjustments that are needed given your person's illness?

Lack of Experience. Are there members of your family who don't understand what dementia illnesses look like or what your person is like? Do you think any family members are frightened by your person's dementia (or too sad to be around him/her)?

Knowledge and Skill. What kinds of information about the disease or how to care for the person would help family members to be more a part of the situation and more able to help?

Having a Plan. Can you think of two or three caregiving tasks that you could delegate to other family members? Given the family situation and the person's condition, what are a couple of ways in which you could ask for specific help?

A Menu of Activities. Can you think of 2 to 4 tasks or activities that you could tell a helping friend or family member to do with the person over a 2- to 3-hour span of time?

Recipes for Helpers. Take one of the activities from the menu and describe how you set it up for the person. How would you get him/her involved with the activity? What kind of help you expect to give? How you give that help?

Communicating with Goals in Mind. Think about one of the tasks you feel you could ask for help with. Now develop a specific plan for communicating this to that family member. Tell him/her: what you want him/her to do with the person, what kind of Structure and Support to provide (and how to do that), and what to expect and look for. Give the person specific advice on what to do if the person becomes distracted or distressed. Set helpers up for success!
