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360 Lexington Ave, New York, NY CARINGKINDNYC.ORG 646-744-2900



Understanding Dementia 101:

Caregiving Through Changing Abilities and Dementia Stages

Stephani Shivers, MEd, OTR/L & Anne Kenny, MD

Dementia 101 Series

Caregiving Through Changing Abilities and Dementia Stages Signs & Symptoms of Alzheimer's and other Dementias Adjusting to the Diagnosis & Life Changes







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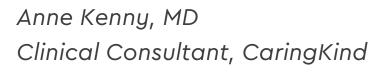
Previous Recordings & Upcoming Webinars



Our Speakers

Stephani Shivers, MEd, OTR/L Chief Innovation Officer, CaringKind

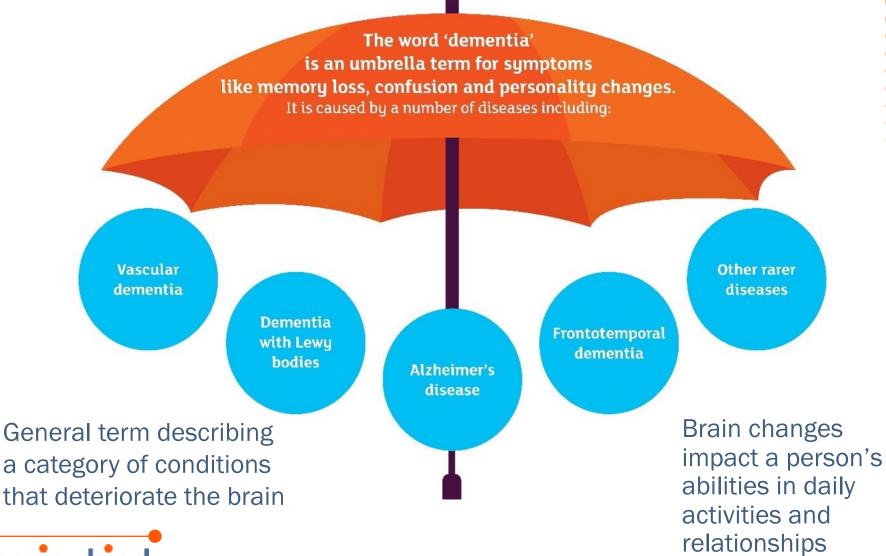








What is Dementia?



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of Alzheimer's and other Dementias

Stephani Shivers, Chief Innovation Officer



For More Information

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Changing Abilities:

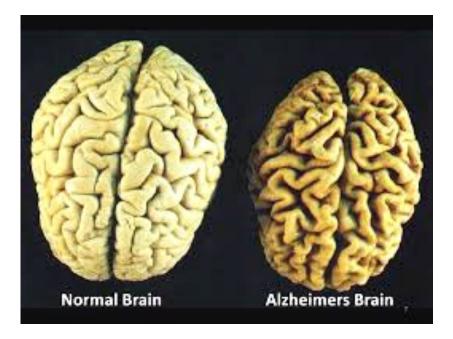
What abilities does dementia affect?

How do a person's abilities change as dementia progresses?

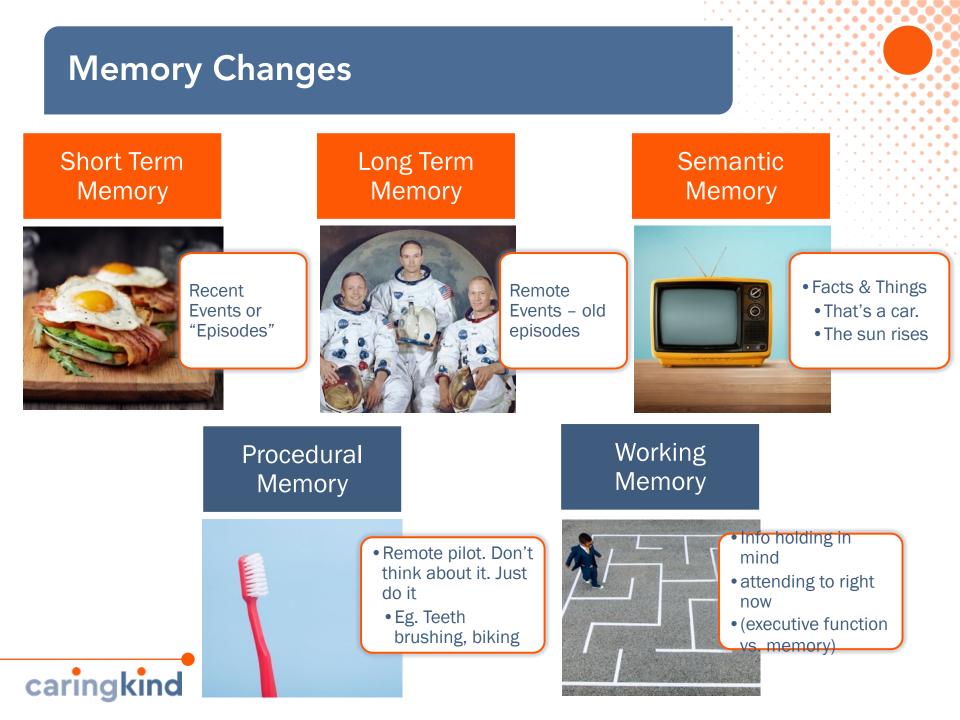


Changing Abilities: Thinking & Physical

- memory
- executive function
- language







Executive Function Changes

- Difficulty organizing; Inability to switch attention (multitask)
- Difficulty planning and initiation (getting started)
- Trouble planning for the future
- Difficulty understanding information, holding it in head, getting information out of head
- Mood swings
- Lack of concern for others
- Loss of interest in activities
- Socially inappropriate
- Inability to learn from consequences from past action
- Difficulty with abstract concepts
- Lack of awareness, denial of problems

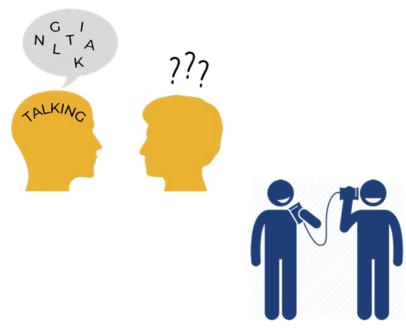






Language Changes

Expressive Language (Logic or word production)



Receptive Language (Understanding words)



Tip of the Tongue (eg. can't find name of thing



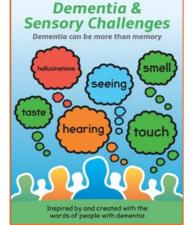
Related or Wrong Word (eg. 'brother' vs. 'husband')

Changing Abilities: Thinking & Physical



- visual spatial function
- processing
- sensory functions

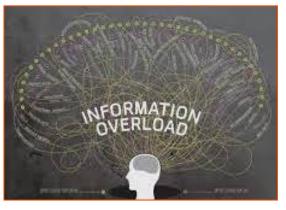




https://www.alzscot.org/sites/default/file s/2019-07/Sensory%20Leaflet.pdf







Changing Abilities: Thinking & Physical

- Balance
- Motor planning movement
- Physical movement
- Coordination









Instrumental Activities of Daily Living (IADLs)

- Shopping
- Meal Preparation
- Household Management
- Using phone, transportation
- Money Management
- Health & Medication
 Management

Activities of Daily Living (ADLs)

- Bathing, Dressing
- Toileting & Clothing Management
- Walking
- Transferring in/out of chair, bed, car
- Feeding oneself/eating

Changing Abilities: IADLs & ADL Function





What do changing abilities look like?

Memory loss	 Repeating questions, comments
Thinking challenges	• Problems with bills, taxes, remote control, computer
Problems planning & problem solving	Meal management; not taking care of things properly
Confusion	• Getting facts wrong; mixing up dates, times, etc.
Emotional regulation	Quick temper; Over-reactions
Apathy	 Not caring about result; dirty clothes, hair
Lack of awareness	 Don't recognize a problem or memory loss
Word finding challenges	Word substitution
Decreased balance, sensory	• Trips, dropping things. Eye complaints, new glasses.

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Dementia Stages:

What are "stages"? How are they determined? What do they mean?



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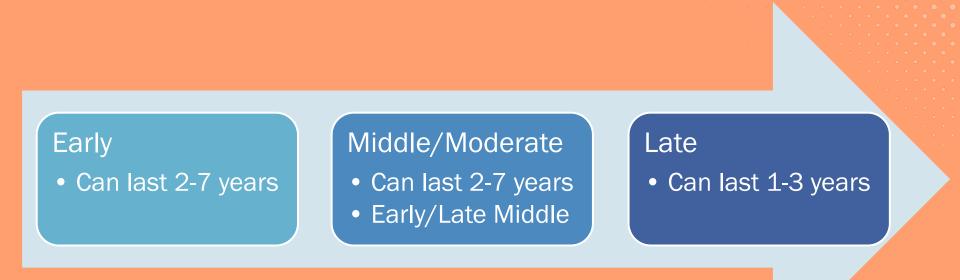
Staging – Pros & Cons

- Provide an idea of what abilities are and will be affected
- Guide for planning
- Baseline understanding of abilities for comparison
- Emphasize what is lost
- Focus on inabilities
- Focus on stage and not on person





"Stages"



Retain certain abilities in each stage

Leverage strengths to promote autonomy and quality of life



Cognitive Screens, Assessments & Staging Tools:

What are the common dementia tests? What are the differences? What do they mean for today or the future?



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Montreal Cognitive Assessment (MOCA)

- 18–25 points: Mild cognitive impairment.
- 10–17 points: Moderate cognitive impairment.
- Fewer than 10 points: Severe cognitive impairment.

A person's level of educational attainment may affect their score.



https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5662994/

Mini-Mental State Examination (MMSE)

Patient's Name:

Date:

Instructions: Score one point for each correct response within each question or activity.

Maximum Score	Patient's Score	Questions
5		"What is the year? Season? Date? Day? Month?"
5		"Where are we now? State? County? Town/city? Hospital? Floor?"
3		The examiner names three unrelated objects clearly and slowly, then the instructor asks the patient to name all three of them. The patient's response is used for scoring. The examiner repeats them until patient learns all of them, if possible.
5		"I would like you to count backward from 100 by sevens." (93, 86, 79, 72, 65,) Alternative: "Spell WORLD backwards." (D-L-R-O-W)
3		"Earlier I told you the names of three things. Can you tell me what those were?"
2		Show the patient two simple objects, such as a wristwatch and a pencil and ask the patient to name them.
1		"Repeat the phrase: 'No ifs, ands, or buts.'"
3		"Take the paper in your right hand, fold it in half, and put it on the floor." (The examiner gives the patient a piece of blank paper.)
1		"Please read this and do what it says." (Written instruction is "Close your eyes.")
1		"Make up and write a sentence about anything." (This sentence must contain a noun and a verb.)
1		"Please copy this picture." (The examiner gives the patient a blank piece of paper and asks him/her to draw the symbol below. All 10 angles must be present and two must intersect.)
30		TOTAL

https://www.researchgate.net/publication/351948858/figure/fig1/AS:10286345675243 52@1622257000164/Mini-mental-state-examination-questionnaire-Note-Figure-1-shows-MMSE-test-a-30-point.png

Mini-Mental State Examination

- 24-30: No cognitive impairment
- 19-23: Mild cognitive impairment
- 10-18: Moderate cognitive impairment
- 0-9: Severe cognitive impairment

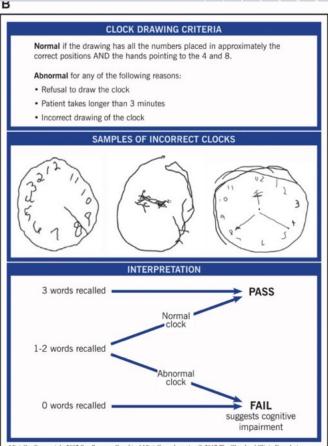


Mini-Cog Screen

• Three Word recall

Clock
 Drawin
 g Test





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Comparison of staging scales

Each scale has its own focus and strengths:

- Global Deterioration Scale (GDS) focuses more on cognitive decline
- Clinical Dementia Rating (CDR) assesses both cognitive and functional domains
- Functional Assessment Staging Tool (FAST) emphasizes functional abilities and activities of daily living



Global Deterioration Scale (Reisberg)



Reisberg's Stages (also called Global Deterioration Scale)

No Cognitive	2 c	Very Mild	5 Mild	A Moderate
Decline		ognitive Decline	Cognitive Decline	Cognitive Decline
 No complaints of memory problems No evidence of cognitive deficits 	problems objects o names • No evid	s of memory s, like misplacing or forgetting ence of issues k or social is	 Impaired concentration Difficulty with work tasks Some denial and anxiety about the deficits 	 Trouble remembering personal history Trouble traveling or handling finances Reduced expression of emotions Withdrawal from situations that are challenging
5 Moderately		Severe		7 Very Severe
Cognitive D		Cognitive Decline		Cognitive Decline
 Some assistance Evidence of shormemory loss Lack of orientation to time, place, or one May need assistance Alzheimersdisea 	t-term on late ance with wear		oundings ily living may ce ontinence and or ces behavior changes nallucinations, anxiety,	 Significant personality and behavior changes Loss of speech and ability to hold a conversation Difficulty moving, eating, and swallowing Loss of bladder and bowel control Unable to do daily activities without assistance

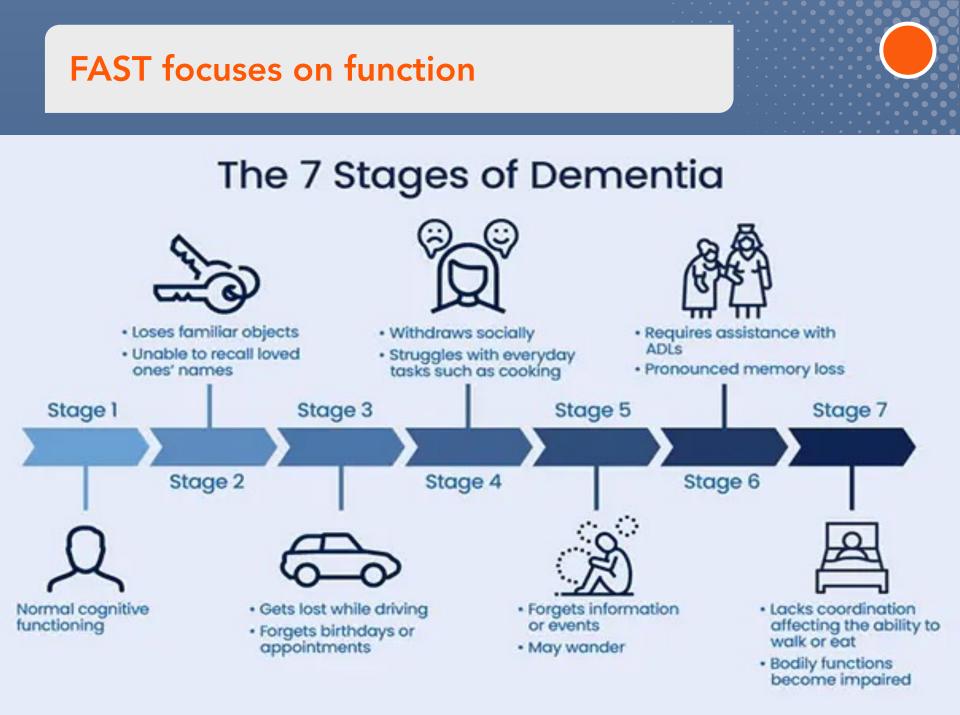
Clinical Dementia Rating (CDR)

Score	Memory	Orientation	Judgement Problem Solving	Community Affairs	Home and Hobbies	Personal Care
0	No memory loss or slight inconsistent forgetfulness	Fully oriented	Solves everyday problems well; judgement good	Independent function at usual level in job, shopping, business, financial, volunteer and social groups	Life at home, hobbies, intellectual interests all maintained	Fully capable of self care
0.5	Mild consistent forgetfulness; partial recollection of events	Fully oriented with slight difficulty with time	Slight impairment in solving problems, similarities and differences	Slight impairment in these	Life at home, hobbies, intellectual interests slightly impaired	
1	Moderate memory loss; interferes with everyday activities	Mod diff w time; oriented for place and person at exam but may have some geographic disorientation	Moderate difficulty in handling complex problems, social judgment usually maintained	Unable to function independently at these although may still be engaged in some; appears normal to casual inspection	Mild but definite impairment of function at home, chores abandoned, more complicated hobbies and interests abandoned	Needs prompting
2	Severe memory loss; only highly learned materials retained	Sever difficulty with time; usually disoriented to time, often to place	Severely impaired in handling problems; social judgment usually impaired	No pretense of indep function outside of home; appears well enough to go to function outside of family home	Only simple chores preserved; restricted interests, poorly maintained	Requires assistance in dressing, hygiene, keeping personal effects
3	Severe memory loss; only fragments	Oriented to person only	Unable to make judgments or solve problems	Appears to ill to be taken to functions outside of home	No significant function in home	Requires much help with personal care; frequent incontinence

Functional Assessment Staging Tool (FAST)



Stage	Stage Name	Characteristic	Expected Untreated AD Duration (months)	Mental Age (years)	MMSE (score)
1	Normal Aging	No deficits whatsoever		Adult	29-30
2	Possible Mild Cognitive Impairment	Subjective functional deficit			28-29
3	Mild Cognitive Impairment	Objective functional deficit interferes with a person's most complex tasks	84	12+	24-28
4	Mild Dementia	IADLs become affected, such as bill paying, cooking, cleaning, traveling	24	8-12	19-20
5	Moderate Dementia	Needs help selecting proper attire	18	5-7	15
6a	Moderately Severe Dementia	Needs help putting on clothes	4.8	5	9
6b	Moderately Severe Dementia	Needs help bathing	4.8	4	8
6c	Moderately Severe Dementia	Needs help toileting	4.8	4	5
6d	Moderately Severe Dementia	Urinary incontinence	3.6	3-4	3
6e	Moderately Severe Dementia	Fecal incontinence	9.6	2-3	1
7a	Severe Dementia	Speaks 5-6 words during day	12	1.25	0
7b	Severe Dementia	Speaks only 1 word clearly	18	1	0
7c	Severe Dementia	Can no longer walk	12	1	0
7d	Severe Dementia	Can no longer sit up	12	0.5-0.8	0
7e	Severe Dementia	Can no longer smile	18	0.2-0.4	0
7f	Severe Dementia	Can no longer hold up head	12+	0-0.2	0



FAST Stage 6 for Moderately-Severe

- Improperly putting on clothes without assistance or cueing
- Unable to bath properly (not able to choose proper water temperature)

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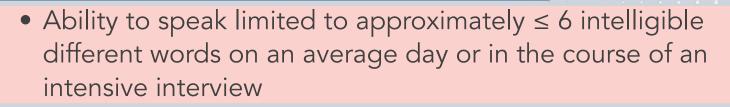
- Inability to handle mechanics of toileting

 (e.g., forget to flush the toilet; does not wipe properly
 or properly dispose of toilet tissue)
- Urinary incontinence

• Fecal incontinence

FAST Stage 7 Severe

B



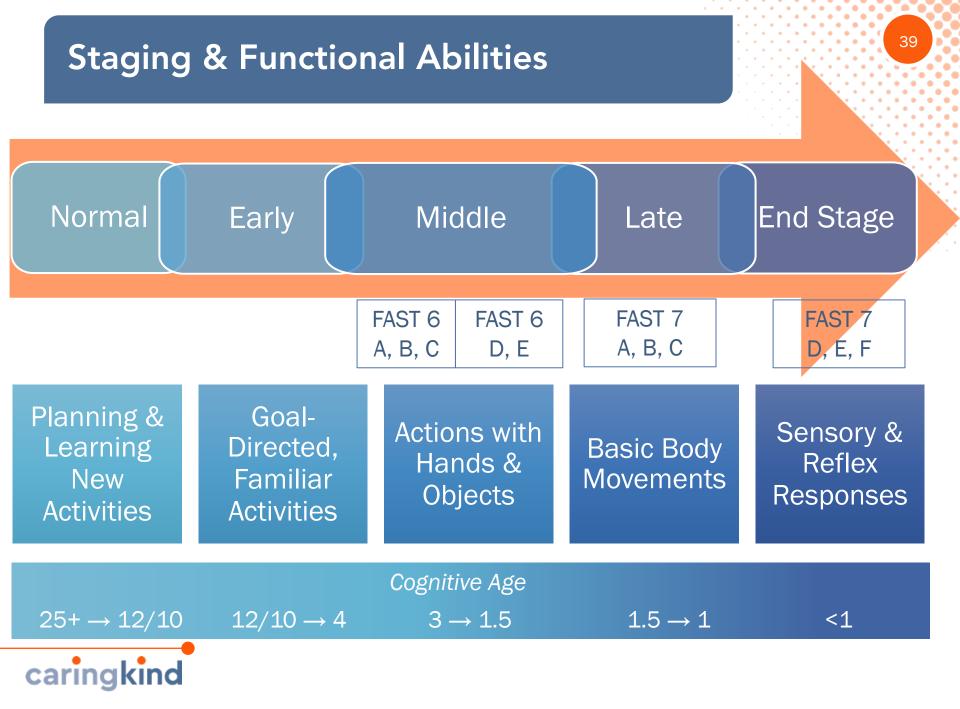
- Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview
- Ambulatory ability is lost (cannot walk without personal assistance)
- Cannot sit up without assistance (e.g., the individual will fall over if there are not lateral rests [arms] on the chair.)
- Loss of ability to smile

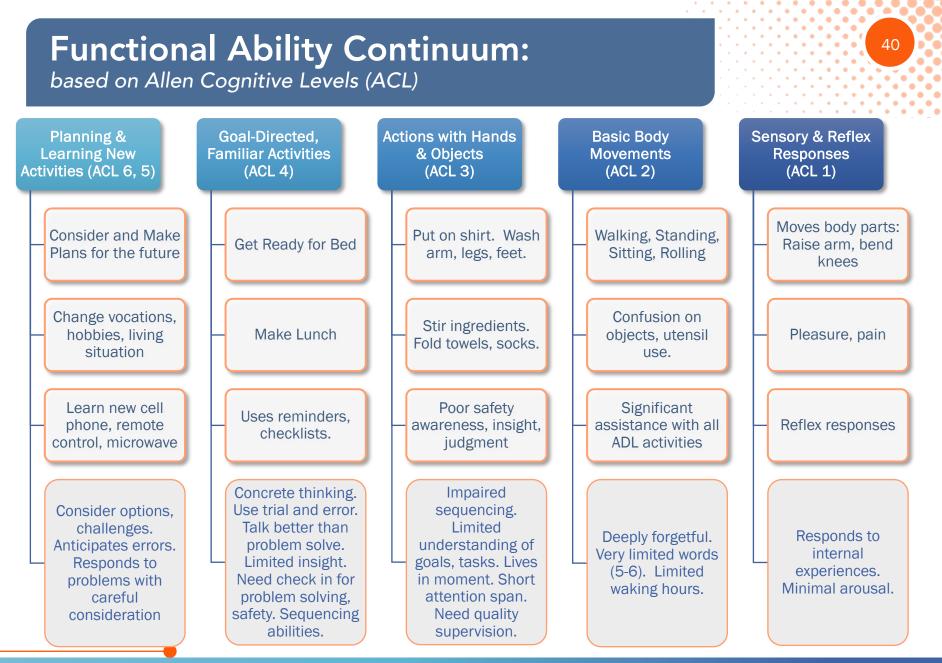
• Loss of ability to hold up head independently

Finding Strengths as Function Changes:

What strengths remain to support ongoing connection and engagement in meaningful activities?







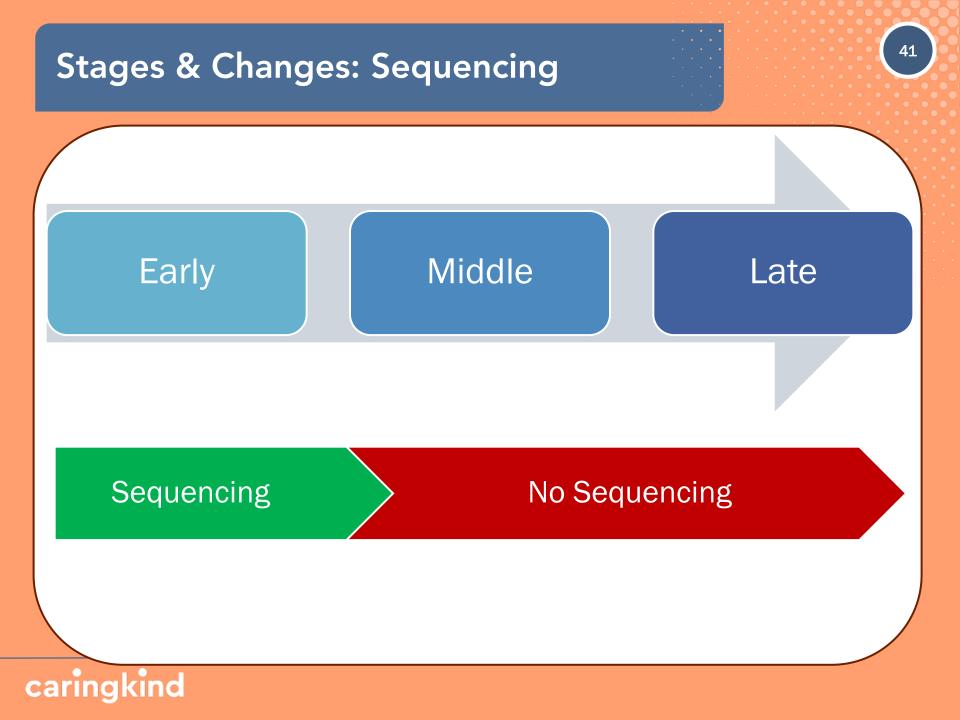
Set Up **Minimum Assistance** 25+-12/10 Cog Age

 $12/10 \rightarrow 4$

Moderate Assistance $3 \rightarrow 1.5$

Maximum Assistance $1.5 \rightarrow 1.1$

Dependent <1



Cueing

CUEING TECHNIQUES

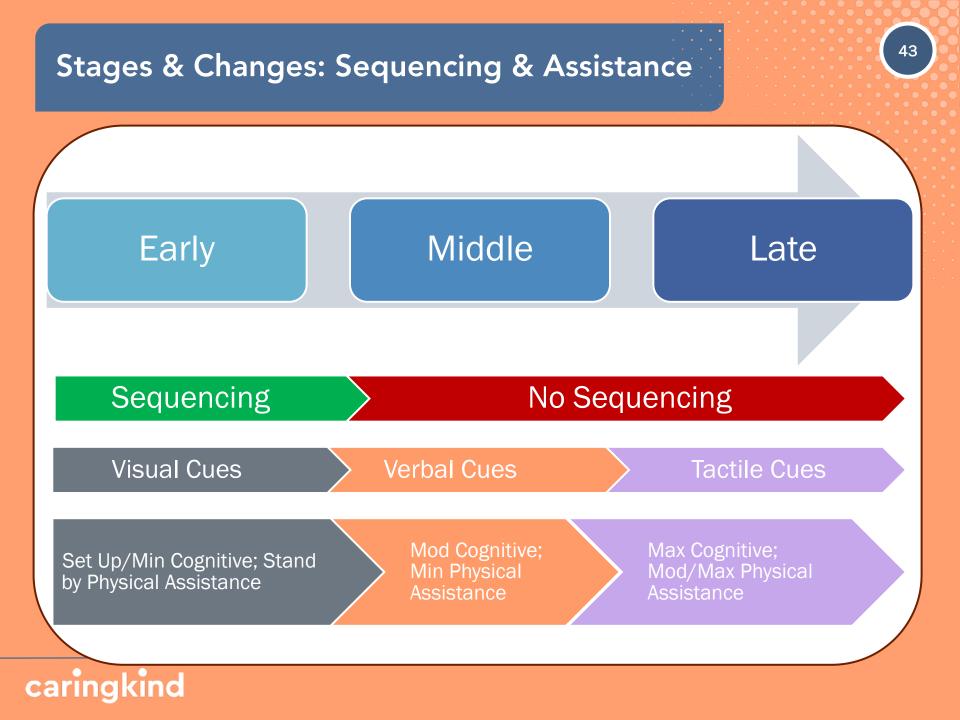
- •Use signs (key words with location and identifiers)
- •Place objects in view
- •Use gestures (point or movement)
- •Use demonstration

- •Use 1-step directions (step by step, break it down)
- •Use yes/no questions
- •Use simple words and phrases
- Provide positive feedback (praise and encourage)



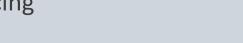
- •Use a handshake when greeting
- Talk less
- •Guide by touch (hand over hand)
- Gently touch to get attention





Abilities

- Early Stages:
 - Routine, familiar tasks
 - 1-3 step directions
 - Sequencing
- Middle Stages:
 - Step-by-step instructions
 - Cuing: physical and gestural
- Advanced Stages:
 - Single step instructions
 - Use of hands, some larger movements
 - Connect through sensory experiences







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Goal-Directed, Familiar Activities (ACL 4)

Person is able to complete many routine and familiar tasks with someone checking in for safety and to problem solve.

 Check in daily by phone, weekly in person. Create safe home environment. Engage in social, creative, learning opportunities. Establish new routines, relationships, roles that will be beneficial long term.

Person can sequence through an activity with an identified goal; new learning is possible if the activity is highly valued

 Provide simple – task specific instruction. May use checklists, labels, charts, lists, alarms. Engage in social, creative, learning opportunities. Establish new routines, relationships, roles that will be beneficial long term.

Person can follow step by step instructions through an activity to accomplish a task;

• Break activities into steps. Provide 1-3 step instructions with verbal and/or or visual cues. Set up tasks in order.

May live independently with someone checking in to provide intermittent support.



Manual Actions with Hands & Objects (ACL 3)

Person is able to use their hands and move their body parts in familiar patterns with fine and gross motor movements:

• Use familiar items to trigger long term, procedural memory. Start physical action and cue intermittently as necessary.

Able to use hands to hold and manipulate objects, follow 1 step commands to be sequenced, notes cause and effect, better fine motor coordination, strong long-term memory

- Compensatory Intervention Ideas
 - Provide safe, familiar supplies
 - Break familiar activities into single steps
 - Sequence through steps using 3 types of cues
 - Wait for response
 - Encourage gross and fine motor participation
 - Complete activity as needed to avoid frustration
 - Praise participation

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Basic Body Movements & Late Stages (ACL 2, 1)

Person is able to use their hands for tactile and sensory pleasures. May have some gross motor movement

- Use instructions with single steps;
- Use multiple types of cuing (verbal, gestural, tactile);
- wait for a response;
- eliminate distractions;
- may need hand over hand to initiate, continue actions

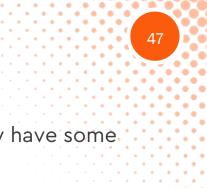
Person is able to connect to sensory stimulation - especially hands and face

- Use familiar/preferred items for pleasurable sensory experiences.
- Provide hand over hand movements and promote range of motion.
- Remember I am here, I am me.

Will need someone living with them to provide extensive assistance





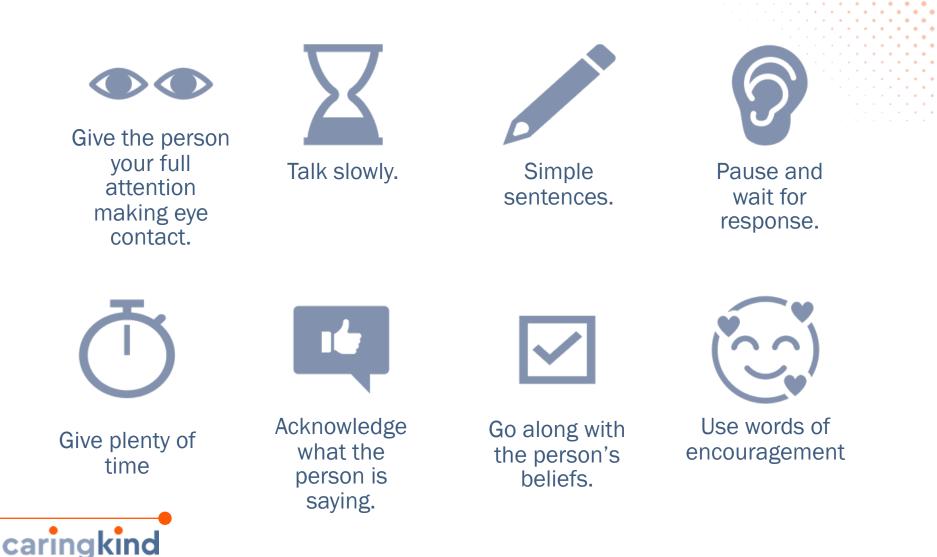


Adaptive Strategies for Activities of Daily Living:

What are some tips to support a person's independence and autonomy?



Simplify Communication



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Just Right Challenge

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Task = Abilities

Partner correct support

Task too complicated Partner over helps or under helps







Simplify the Task





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LIST RECIPE STEPS 1. **Boil Water** 2. Add pasta & set timer for 10 minutes 3. Heat sauce and meatballs in separate pan ŧ. Cover and cook for 20 minutes 5. Drain pasta 6. Set pasta on plate 1. Cover pasta with sauce & meatballs 8. Sprinkle with cheese & basil **©** TRANSITION ABILITIES

Visual Cues

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Using Visual Cues To Help Clients With Dementia



Using Cues: Visual, Verbal, Tactile







 Use a handshake when greeting 53

- Talk less
- Guide by touch (hand over hand)
- Gently touch to get attention

TACTILE



Activity or Task

- Make sure activity is Meaningful (or at least enjoyable).
- Find stimulating activities
- Break the task into parts.
- Set out the items in advance.
- Arrange the items in the order they will be used.
- Allow more than enough time.
- Label objects or places (cabinets, drawers)
- Consider environment warm, comfortable, good lighting
- Establish routines repeat the same steps daily



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LIVE WEBINAR

Monday November 25, 2024 • 6-7:15 pm EST

EDUCATION SEMINAR

individuals, families and professionals

A free learning event for

Home Safety & Adaptive Solutions

Practical tips and tools

Living with dementia presents unique cognitive and physical challenges that can impact an individual's ability to maintain independence and a meaningful life. These challenges can be greater when a person's home environment and daily routines aren't modified to leverage their retained strengths. At CaringKind we often hear things like...

- Yes, I have Alzheimer's! But I'm still walking, talking, and going out on my own. I
 don't want to be dependent on someone else until I really can't do things on my
 own.
- Mom lives alone now, and I worry about her cooking and falling when no one is around.
- John got dressed in a sweater and long pants today and it is in the 80s outside.
- Ifeel like I have to tell him how to do everything now... He can't do anything...

Join us for this informative seminar to learn tips, tricks and effective strategies that individuals and their partners in care can use to maximize independence and enhance safety at home.

Speaker: Melissa Smith, MSOT, OTR/L

Melissa is the Director of Programs at Memory Care Home Solutions. She ensures seamless team management, program delivery, evaluation, and community partnerships to improve dignity and quality of life for people living with dementia and their families by transforming evidence-based interventions into accessible healthcare solutions. Melissa's extensive experience in nonprofit leadership, combined with clinical expertise as an occupational therapist, contributes to her dedication to improving care and advocacy for vulnerable populations.

TO REGISTER: 646-744-2900 caringkindnyc.org/education

For More Information

Home Safety & Adaptive Solutions

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EDUCATION SEMINAR

A free learning event for individuals, families and professionals

LIVE WEBINAR

Creative Connections

Meaningful Engagement Across the Stages of Dementia

When Alzheimer's or another form of dementia progresses and a person's abilities change, finding enjoyable activities that a person can still do can be challenging. Frustrations and conflicts often arise amidst couples and families when typical activities, tasks and hobbies become more difficult.

Join us for this seminar to explore:

- Ways to engage a person in the early, middle and later stages of Alzheimer's or another dementia
- Creative and adapted activities that are meaningful and matched to a person's current abilities
- Strategies that foster connection, communication and quality of life for both the person living with dementia and their families and partners in care

Speaker: Olivia Cohen, MS, MT-BC, LCAT, CDP

Olivia Cohen is the Director of Early-Stage and Engagement Services at CaringKind. Olivia is a board-certified music therapist and licensed creative arts therapist with over 12 years of experience working in long-term care, healthcare, and with individuals living with Alzheimer's and dementia. Her work has been featured in publications such as The New York Times, Huffington Post, Chasing News, and Aging Today. Additionally, she has co-authored a chapter in the book "Creative Arts Therapies and the LGBTQ Community.

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