Navigating the Middle Stages of Alzheimer’s Disease

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What is Dementia?

• A group of SYMPTOMS marked by changes in:
  – Memory
  – Language
  – Spatial abilities
  – Planning, problem-solving, judgment and reasoning
  – Personality changes
  – Changes in behavior

What is Alzheimer’s Disease?

• A type of dementia
• Gradual onset and slowly progressive course
• Accounts for 70% of the dementias of old age
• NOT part of “normal aging”
• Not due to another disease such as thyroid disorder or vitamin deficiency
Mid Stage AD

• Memory difficulties continue to worsen, significant personality changes may emerge, and affected individuals need extensive help with daily activities.

• At this stage, individuals may:
  – Lose most awareness of recent experiences and events as well as of their surroundings.
  – Recollect their personal history imperfectly, although they generally recall their own name.
  – Greater difficulty with communication including word finding, losing train of thought in conversation, naming objects.

Mid-Stage AD

• At this stage, individuals may:
  – Experience major gaps in memory and deficits in cognitive function emerge. Some assistance with day-to-day activities becomes essential.
  – Be unable during a medical interview to recall such important details as their current address, their telephone number, or the name of the college or high school from which they graduated.
  – Become confused about where they are or about the date, day of the week or season.
  – Have trouble with less challenging mental arithmetic; for example, counting backward from 40 by 4s or from 20 by 2s.
  – Need help choosing proper clothing for the season or the occasion.

Mid Stage AD

• At this stage, individuals may:
  – Occasionally forget the name of their spouse or primary caregiver but generally can distinguish familiar from unfamiliar faces.
  – Need help getting dressed properly; without supervision, may make such errors as putting pajamas over daytime clothes or shoes on wrong feet.
  – Experience disruption of their normal sleep/waking cycle.
  – Need help with handling details of toileting (flushing toilet, wiping and disposing of tissue properly).
  – Have increasing episodes of urinary or fecal incontinence.
Mid Stage AD

- At this stage, individuals may:
  - Experience significant personality changes and behavioral symptoms, including suspiciousness and delusions (for example, believing that their caregiver is an imposter); hallucinations (seeing or hearing things that are not really there); or compulsive, repetitive behaviors such as hand-wringing or tissue shredding
  - Tend to wander and become lost

General Behavior Management Tips

- Distract - Don’t argue
- Don’t speak in a condescending manner
- Don’t talk about the person in front of them
- VALIDATE: Respond to underlying emotions
- Be reassuring - You set the tone
- Keep the environment and instructions simple (one step commands if necessary)
- Talk to the person in a place that is free from distractions

General Behavior Management Tips (cont)

- Understand the “triggers”
- Don’t take behaviors personally
- Adapt environment to reduce distractions, sensory overload
- Choose your battles wisely
- Acceptance: if the behavior is not of harm to person with AD you may need to let it go!
Navigating Communication

- Speaking slowly and clearly in a gentle tone (louder does not help).
- Keep questions and answers SIMPLE
- Repeat questions if needed
- Be patient and supportive
- Offer a guess
- Look for the FEELINGS underlying the communication
  - Person may be anger, sad or frustrated
- Encourage unspoken communication
- Limit distractions
  - Turn off TV or radio, go to a quiet place

Navigating Communication

- Turn questions into answers.
  - Provide the solution rather than the question. For example, say "The bathroom is right here," instead of asking, "Do you need to use the bathroom?"
- Avoid confusing and vague statements.
  - Describe actions directly: "Please come here. Your shower is ready."
  - Instead of using "it" or "that," name the object or place. For example rather than "Here it is" say "Here is your hat."
- If you notice sudden changes in communication, make sure to contact the doctor, since this could indicate other medical issues or side effects of medication.

Navigating the Behavioral Changes

- Changes in behavior will occur!
  - Try to understand the immediate trigger to the behavior
  - Rule out pain as a source of stress
    - Pain can cause a person with dementia to act aggressively.
  - Focus on feelings, not the facts.
    - Rather than focusing on specific details, consider the person's emotions.
    - Look for the feelings behind the words or actions.
  - Don't get upset.
    - Be positive and reassuring. Speak slowly in a soft tone.
    - Limit distractions.
Navigating the Behavioral Changes

• Examine the person’s surroundings, and adapt them to avoid similar situations.

• Shift the focus to another activity.
  • The immediate situation or activity may have unintentionally caused the aggressive response. Try something different.

• Try a relaxing activity.
  • Use music, massage or exercise to help soothe the person.

Navigate the Behavioral Changes

• Decrease level of danger.
  • Assess the level of danger — for yourself and the person with Alzheimer’s. You can often avoid harm by simply stepping back and standing away from the person.
  • If the person is headed out of the house and onto the street, be more assertive.

• Avoid using restraint or force.
  • Unless the situation is serious, avoid physically holding or restraining the person. He or she may become more frustrated and cause personal harm.

Navigating the Behavioral Changes: Repeating

• Focus on the emotion, not the behavior.
  • Rather than reacting to what the person is doing, think about how he or she is feeling.

• Look for a reason behind the repetition.
  • Does the repetition occur around certain people or surroundings, or at a certain time of day? Is the person trying to communicate something?

• Turn the action or behavior into an activity.
  • If the person is rubbing his or her hand across the table, provide a cloth and ask for help with dusting.

• Stay calm, and be patient.
  • Reassure the person with a calm voice and gentle touch.
  • Don’t argue or try to use logic. Alzheimer’s affects memory, and the person may not remember he/she asked the question already.
Navigating the Behavioral Changes: Repeating

- Provide an answer.
  - Give the person the answer that he or she is looking for, even if you have to repeat it several times. If the person with dementia is still able to read and comprehend, it may help to write it down and post it in a prominent location.
- Use memory aids.
  - If the person asks the same question over and over again, offer reminders by using notes, clocks, calendars, or photographs, if these items are still meaningful. Accept the behavior and work with it.
- Engage the person in an activity.
  - The individual may simply be bored and need something to do. Provide structure and engage the person in a pleasant activity.
- If the behavior isn’t harmful, don’t worry about it. Find ways to work with it.

Navigating the Memory Changes

- Stay calm.
  - Although being called by a different name or not being recognized can be painful, try not to make your hurt apparent.
- Keep explanations SIMPLE.
- Show old photos and other reminders.
  - Use photographs and other thought-provoking items to remind the person of important relationships and places.

Navigating the Memory Changes

- Travel with the person to where he or she is in time.
  - If the person’s memory is focused on a particular time in his or her life, engage in conversation about recollections with an understanding that this is his or her current reality.
- Offer corrections as suggestions.
  - Avoid explanations that sound like scolding. Try: “I thought it was a fork” or “I think she is your granddaughter Julie.”
- Try not to take it personally.
  - Alzheimer’s disease causes your loved one to forget, but your support and understanding will continue to be appreciated.
Navigating Retiring from Driving

- Signs of unsafe driving
  - Forgetting how to locate familiar places
  - Failing to observe traffic signs
  - Making slow or poor decisions in traffic
  - Driving at an inappropriate speed
  - Becoming angry or confused while driving
  - Hitting curbs
  - Using poor lane control
  - Making errors at intersections
  - Confusing the brake and gas pedals
  - Returning from a routine drive later than usual
  - Forgetting the destination you are driving to during the trip

- Driving requires many thinking abilities that are affected in AD
- Reinforce medical diagnoses and directives.
  - Ask the physician to write a letter stating that the person must not drive. Or ask the physician to write a prescription that says, "No driving." You can then use the letter or prescription to reinforce the conversation.
- Consider an evaluation by an objective third party.
- Have a PLAN in place for when the person can no longer drive.

Navigating Wandering

- 6 out of 10 persons with AD will wander
- Safe Return bracelet is a MUST EVEN IN EARLY STAGES or Comfort Zone (a GPS tracking device)
- Establish a DAILY ROUTINE early on in the course of the disease and stick to it!
- Reassure the person if he or he feels lost, abandoned or disoriented.
  - If the person with dementia wants to leave to "go home" or "go to work," use communication focused on exploration and validation. Refrain from correcting the person. For example, "We are staying here tonight. We are safe and I'll be with you. We can go home in the morning after a good night's rest."
Navigating Wandering

- Ensure all basic needs are met.
  - Has the person gone to the bathroom? Is he or she thirsty or hungry?
- Avoid busy places that are confusing and can cause disorientation.
  - E.g. shopping malls, grocery stores or other busy venues.
- Place locks out of the line of sight.
  - Install either high or low on exterior doors, and consider placing slide bolts at the top or bottom.

Navigating Wandering

- Provide supervision.
  - Never lock the person with dementia in at home alone or leave him or her in a car without supervision.
- Keep car keys out of sight
  - Person with dementia may drive off, even if they DON'T have a licence
- Camouflage doors and door knobs
  - Painting them the same color as the walls, or cover them with removable curtains or screens. Cover knobs with cloth the same color as the door or use childproof knobs.
- Use devices that signal when a door or window is opened.
  - This can be as simple as a bell placed above a door or as sophisticated as an electronic home alarm.

Medications for Cognitive Symptoms of Alzheimer’s Disease

- FDA-approved cholinesterase inhibitor to treat early to severe Alzheimer’s disease
  - Donepezil (Aricept), approved 2006
  - Rivastigmine (Exelon) available in a patch
  - Galantamine (Razadyne)
Medications for Cognitive Symptoms of Alzheimer’s Disease

FDA-approved glutamate receptor antagonist to treat moderate to severe Alzheimer’s disease
• Memantine (Namenda) approved in 2003

Navigating Caregiving

• The time to make a plan is NOW!!
  – Plan for the future while the person w/AD can be a part of the plan.
• GET support
  – Support groups through Alzheimer’s association.
• Get Educated:
  – Meeting of Minds Conference – March 2, 2013
  – Alz.org Website
• Take care of you!!
  – All caregivers NEED RESpite
  – Find resources for respite in the community
  – Ask family members to help

Alzheimer’s Association Resources

• 24/7 Information Helpline: 1-800-272-3900
• Websites:
  – www.alz.org (HAS lots of information for caregivers for EVERY stage of disease)
  – www.alz.org/mnnd
• Care Consultation
• Support Groups
• Medic Alert + Safe Return®
• Family and Professional Education
• Advocacy
• Research