

# **DUKE DEMENTIA FAMILY SUPPORT PROGRAM**

## **Caregiver Connections**

**An Educational Webinar Series With The Experts**

**The presentation will begin shortly.  
Thank you for your patience!**

**[dukefamilysupport.org](http://dukefamilysupport.org)**

**919-660-7510**

# **Life in the Middle Stage: Exploring what to expect in the middle stages of memory and thinking changes**

**Cornelia Poer, MSW, LCSW  
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- How do you know when the person living with dementia has gotten to the middle stage?
- What do you need to keep in mind as symptoms change and new symptoms develop?
- What is the impact of these changes on the role of care partners?
- What are some considerations for addressing today's needs and planning for the future?

# WHY DO YOU NEED TO KNOW IF YOU ARE IN THE MIDDLE STAGE?

For some, they do not necessarily need to know and they choose to take it day to day, which is OK.

Others may want to know because it helps them understand the person living with dementia:

- How their brain may be working now
- What they need
- Can inform the care provided
- Helps in planning for the future

Although there are tendencies for symptoms to occur at certain times during the journey of the disease, there is

- Not always a defined pattern
- No algorithm
- No prescribed length of time in each stage

Individuals travel this path at different rates.

## **Early, Middle, and Late**

**Keep in mind, there may be other medical and psychological conditions at the same time that can impact presentation and symptoms.**

- **For example, recurrent UTIs, cardiac issues, history of/or concurrent depression and anxiety.**

# HOW DO YOU EVEN KNOW WHEN THE PERSON WITH DEMENTIA HAS GOTTEN TO THE MIDDLE STAGES?

- It is important to remember
  - everyone does not experience every symptom
  - every symptom does not occur at a specific time
- Because the person living with dementia looks like themselves and sounds like themselves, it is easy to be deceived.

# WHAT DO YOU NEED TO KEEP IN MIND AS SYMPTOMS CHANGE AND NEW SYMPTOMS DEVELOP?

- Everyone is different. You know the person living with dementia the best.
- There are several considerations for addressing different changes in symptoms and needs, not an exhaustive list.
- Each of the changes could be a presentation on its own, this is just an **overview** of what you might observe.



# CHANGES IN THE EARLY STAGES BECOME MORE NOTICEABLE

## Early Stages

- Decreased social interactions
- Reduced verbal output
- Decreased spontaneous interest
- Loss of interest in hobbies, activities or events
- Lessened alertness
- Slowed movement
- Inattention
- Loss of motivation
- Change of judgment
- Apathy
- Altered concept of time
- Mild memory loss
- Work performance decline
- Change in language comprehension, finding words
- Slight changes in hygiene or neatness of dress
- Obvious changes in behavior
- Irritability
- Fear of leaving familiar places

**CONSIDER:** Increased need to accommodate changes

# LOSS OF SELF-HELP SKILLS

More difficulty with dressing, toileting, using eating utensils

## CONSIDER:

- Safety evaluation by Physical Therapy and/or Occupational Therapy
- Adapt clothing
- Type of bath; time of bath; hire a bath aide
- Fewer items on the plate or table; presentation; finger foods

# MOBILITY CHANGES

**Shuffling gait, balance issues, decreased endurance**

## **CONSIDER:**

- **Falls safety checklist**
- **Physical Therapy evaluation**
- **Use of assistive devices**

# LOSS OF MEMORY MORE PRONOUNCED

Forgetting conversations; increased repeating

## CONSIDER:

- May require more subtle suggestions
- Prompting, cueing, or reminders

# LONG PERIODS OF INACTIVITY

Often interpreted as less motivation

## CONSIDER:

- May have to become the “cruise director,” or hire one if you do not want that role
  - Companion
  - Adult day care program
  - Enlist the assistance of friends and family if available

# VISUAL CHANGES

The brains of persons living with dementia can develop problems processing visual information that can impact their understanding of the world around them; this can lead to feeling less confident, less independent, and more unsure. Some examples of changes include:

- Difficulty with spatial awareness and ability to judge distance
- Slower to adjust to change in light
- Changes in peripheral vision
- Misperceptions
- Misidentification
- Contributes to delusions, hallucinations

# VISUAL CHANGES

## CONSIDER:

- Unless it is a safety issue, may not be necessary to draw attention to mistakes. Being corrected can make confidence worse and increase reluctance to participate in activities or conversations
- Provide reassurance
- Introduce others and why they may be there; may even have to introduce yourself
- If reading is no longer an option, reading to person
- Evaluate lighting and reduce clutter.
- Be sure glasses are on if they have always worn them
- Describing food on the plate

# EXPRESSIVE AND RECEPTIVE LANGUAGE ISSUES

## Communication struggles including

- Difficulty finding words
- Losing train of thought
- Problems naming things
- Illogical conversation
- Loss of attention during conversations
- Challenges with understanding what words mean
- Struggling with directions
- Loss of speech



# EXPRESSIVE AND RECEPTIVE LANGUAGE ISSUES

## CONSIDER:

- **Make eye contact; call by name**
- **Be aware of your tone of voice; how loud you are talking; your body language**
- **Repeat as necessary**
- **Be respectful; do not talk down, talk to them like they are children, or talk about them. Persons living with dementia are still adults with adult emotions.**
- **Encourage, or jump start, the conversation**
- **Even if difficult to understand, listen, convey interest, be patient**
- **Consider a speech therapy evaluation if you have not already done so, or have another if necessary**

# INCREASED CONFUSION

## CONSIDER:

- **Modify the environment as needed including lighting, temperatures, sounds/noise (TV)**
- **Use communication techniques (less information, reassurance, redirection)**
- **When possible, maintain a regular schedule**

# DISORIENTATION TO PERSON, PLACE OR TIME

## CONSIDER:

- Reorient – work it into the conversation
- White board may be helpful

# HALLUCINATIONS

Hearing (voices, music), seeing (people, objects), smelling (smoke, perfume), feeling (bugs), tasting (food is off, metallic) things that are not really there

## CONSIDER:

- Assess for medical causes such as dehydration, infection, constipation, which can cause delirium
- Calmly explain, reassure, repeat as often as necessary
- Avoid arguing or trying to convince person living with dementia they are wrong because it can make situation worse

# DELUSIONS

Information can be fragmented and/or mixed with other memories leading to incorrect conclusions or false beliefs that feel real, are real to the person living with dementia.

## CONSIDER:

- Calm, reassuring approach; if afraid, provide comfort
- Redirect
- Consider the environment
- For everyone's safety, secure weapons, or anything that could be used as a weapon

# PARANOIA

Feeling threaten, suspicious – belief that others are trying to harm them, they are being watched, others are mean to them, they are being lied to

## **CONSIDER:**

- Listen
- Acknowledge feelings
- Try to understand their reality
- Avoid arguing; remain calm if accused
- Reassure, including that their concerns are taken seriously
- Provide brief explanation as needed
- Redirect

# CHANGES IN SLEEP HABITS

From sleeping too much to not sleeping and being up all night

## CONSIDER:

- Daily exercise
- Light exposure
- Limit naps
- Higher energy activities earlier in the day, when possible
- Reduce or limit caffeine
- Relaxing activities in the evening; low lighting; lower levels of noise; soothing music
- Keep routine sleep schedule: go to bed at the same time each night

# “NON-COMPLIANT” BEHAVIOR

What is perceived as “non-compliant” may be difficulty with the changes previously identified

## CONSIDER:

- Assess the cause (confusion, time of day, language issues, visual changes, delusions, paranoia, personal preference, communication problem, fatigue, etc.)
- Less may be more; avoid asking for too much at a time
- Avoid rushing, if possible, go at the pace of the person living with dementia; or start earlier
- Always respect dignity and modesty



# WANDERING

This symptom is not a given but you should be aware of the possibility

## CONSIDER:

- Routine exercise and structured activities
- Assess for patterns
- Is the person living with dementia hungry, thirsty, do they need to toilet?
- Avoid congested places
- Technology such as GPS, alarms, cameras
- Silver Alert as needed

# INCREASED RISK OF INFECTION

Increased difficulty expressing symptoms; recurrent conditions such as UTI's

## CONSIDER:

- Healthy, nutritious meals
- Drink (hydrate)
- Assess for constipation
- Assist with personal hygiene as needed
- Avoid being around individuals known to be sick
- Vaccines (flu) as needed

# WHAT IS THE IMPACT OF THESE CHANGES ON THE ROLE OF CARE PARTNERS?

Increased needs will lead to care partner adding to their role, also becoming a caregiver

## CONSIDER:

- Learn to ask for help and accept it
- The time is now to get help, do not wait until you think you need help
- Find ways to have personal time/down time, which will not only benefit you, but can help the person living with dementia get used to others in their lives
- Assume the attitude of “good enough for now,” you do not have to be strong and correct all the time
- Support groups
- Seek professional help as needed

## CONSIDER:

- **Committee to Take Care of the Person Living with Dementia**
  - You are the chairperson, or co-chair, who ultimately makes the decisions
  - Involve the person living with dementia in decision making when possible/appropriate
  - Who can you bring to the table to help navigate these changes and increased needs
    - doctors, caregivers, volunteers, support groups, faith based groups, friends, etc.
  - Like all committees, members change as needs and demands change.

# WHAT ARE SOME CONSIDERATIONS FOR ADDRESSING TODAY'S NEEDS AND PLANNING FOR THE FUTURE?

- **Establish a Contingency Plan of Care**
  - Whether you are caring for someone at home, have companions/caregivers, or the person living with dementia is in a long term care facility, you need to have contingency plans of care in the event of unexpected changes
  - Who provides care if you are not able to do so temporarily or permanently?
  - When will higher levels of care be needed?
  - How will you cover the costs?



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