

# Dementia and Intellectual and Developmental Disabilities

## Caregiving in Action: Case Studies and Practical Tips

**Presented by Julie A. Moran, DO**

Geriatrician, Aging and Intellectual/Developmental Disabilities Specialist

Consultant, Tewksbury Hospital and Massachusetts Department of Developmental Services

Clinical Instructor of Medicine, Harvard Medical School



Massachusetts Dept.  
of Developmental  
Services (DDS)

Produced on behalf of DDS by the Center for Developmental Disabilities  
Evaluation and Research (CDDER)



# What Would You Do Differently?

*D.K. is a 58 year old man with DS and AD. At day program, he enjoys playing with beads, sorting and placing them in buckets. Another client, Suzie, attempted to pick up one of his beads and he became angry and dumped the whole bucket on the floor. His day program staff immediately reprimanded him: “D.K., I told you yesterday that is not how we behave here. That was not nice. Suzie was only looking to play with you. Now we have a mess all over the floor and I will wait until you pick them all up.”*



# What Would You Do Differently?

*P.M. is a 48 year old man with Down syndrome and early Alzheimer's Disease. He participates in a workshop but is becoming more frustrated with his work. He frequently pushes away from the table and attempts to walk out into the hallways or into other rooms.*

*His supervisor has tried repeatedly to correct this behavior, saying: "P, it's not time for break yet. I don't want you going out into the other rooms right now unless you have someone with you, it's not safe. Why don't you go back to your chair and settle down. We'll have lunch in about an hour."*



*P.M. was led back to his chair, but he yelled and resisted. He threw the items he was working on at his work station and then re-attempted to leave the room.*



# On a Related Note...

- ❑ When the ability to understand and interpret language is progressively impaired (aphasia), we rely more on EMOTIONAL clues to interpret what is being communicated
- ❑ Be extremely mindful of the emotional tone of your words!
- ❑ Adults with dementia will commonly react in a way that mimics the emotion that is presented



# Think About How the Peanuts Characters Interpreted Adult Voices...



Copyright Peanuts Worldwide, LLC, Iconix Brand Group, Charles M. Schulz Creative Associates



# Minding our Emotions

- ❑ Volume and tone of voice often matters more than the words themselves
- ❑ Negative, reprimanding, or scolding tones can escalate a reaction or lead to a negative or fearful response

## What To Do

- ❑ Keep your tone of voice positive and calm, try to keep your facial expression calm and kind
- ❑ Accentuate the positive
- ❑ Positively distract to a new activity



# General Principles for Dementia Caregiving

- ❑ **Increase amount of time** spent with individual with AD
- ❑ Avoid boredom
  - ❑ **Structure the day** with recreational and social activities that are enjoyable and appropriate for their ability and comfort level
- ❑ Create a **failure-proof environment** that maintains skills and fosters self-esteem
- ❑ Use a **person-centered approach**
  - ❑ **Tailor** to the person's needs and preferences



# General Principles for Dementia Caregiving

- ❑ Look for **patterns** and try to identify triggers for behaviors
- ❑ **Substitute** pleasurable activities during stressful times
- ❑ Create a **soothing, calm, predictable** atmosphere
- ❑ **Establish eye contact** when communicating
- ❑ Expect to **repeat yourself** when speaking
- ❑ **Slow down** and **speak clearly**



# General Principles for Dementia Caregiving

- ❑ Approach from the front and make face-to-face contact when speaking. Smile
- ❑ Validate worries and fears and provide reassurance
- ❑ Avoid using the word “NO”
- ❑ Use as much sensory input as possible when communicating
- ❑ Use simple one-step instructions. Prepare to show AND tell instructions



# General Principles for Dementia Caregiving

- ❑ Avoid social isolation
- ❑ Continue daily involvement in meals, routines, activities as much as possible
- ❑ Make an effort to help housemates understand what is happening
  - ❑ Encourage them to participate in helping



# Webinars on Aging with DD

## General Aging in Intellectual and Developmental Disabilities

- Understanding Age Related Changes
- The Role of Polypharmacy
- Identifying and Assessing Pain
- Behavior Related Changes and Aging in Adults with IDD
- Health Promotion and Aging in Adults with IDD
- Mobility and Aging in Adults with IDD
- Aging with Down Syndrome
- Aging and Cerebral Palsy

## Dementia and Intellectual and Developmental Disabilities

- Introduction to Dementia and Aging with IDD
- Early Evaluation of Dementia and Alzheimer's Disease
- Stages of Alzheimer's Disease
- Applying the Knowledge to Dementia Caregiving and Caregiver Support
- Caregiving in Action: Case Studies and Practical Tips



# Additional Aging with IDD Resources

*Massachusetts Department of Developmental Services (DDS)*  
*[www.mass.gov/eohhs/gov/departments/dds/aging-with-id.html](http://www.mass.gov/eohhs/gov/departments/dds/aging-with-id.html)*

*Center for Developmental Disabilities Evaluation & Research*  
*[http://shriver.umassmed.edu/cdder/aging\\_idd\\_education](http://shriver.umassmed.edu/cdder/aging_idd_education)*



***Training produced by the  
Center for Developmental Disabilities  
Evaluation & Research (CDDER) on behalf of the  
Massachusetts Department of Developmental Services  
(DDS)***

***cdder@umassmed.edu***

