

Dementia and Intellectual and Developmental Disabilities

Applying the Knowledge to Dementia Caregiving and Caregiver Support

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)



Applying the Knowledge to Caregiving

- ❑ Keep in mind: Forgetfulness and memory impairment are a hallmark of dementia
- ❑ Early deficit = inability to learn new information
- ❑ Behavioral approaches that require an understanding of cause-and-effect or consequences are generally not useful because they require learning!



Applying the Knowledge to Caregiving

- ❑ Strategies that require “carry over” of information over an extended period of time may no longer be useful or effective
- ❑ Examples
 - ❑ Rewards and consequences, delayed gratification
 - ❑ Attempting to “teach a lesson” when correcting a behavior
- ❑ Let go of the expectation of *learning* or carrying over new rules



Applying the Knowledge to Caregiving

- ❑ Disorientation is common
 - ❑ Increased confusion in familiar places
 - ❑ As dementia progresses, adults become even more dependent on structure, familiarity, predictability, and routine
 - ❑ A change in environment can be **extremely** confusing and emotionally upsetting
 - ❑ Flexibility of the environment is crucial to optimizing the care of a person with Alzheimer's Disease or other forms of dementia



Applying the Knowledge to Caregiving

- ❑ Communication/language difficulties are common
- ❑ Decreased ability to express oneself (*expressive* aphasia) and to understand what is being said (*receptive* aphasia)

What To Do

- ❑ Avoid long verbal explanations
- ❑ Avoid attempts to verbally reason with an adult with DS and AD as this can be extremely unproductive



Applying the Knowledge to Caregiving

- ❑ Disorientation/confusion contributes to resistance to change and transition
- ❑ General difficulty in interpreting and adapting to the day-to-day flow
- ❑ Adults with DS crave routine and structure. This becomes more pronounced with dementia

What To Do

- ❑ Anticipate transition times
- ❑ Aim to provide the most calm, predictable, and reliable routine possible
- ❑ Adapt routines to fit individuals' needs



CAREGIVER SUPPORT



Massachusetts Dept.
of Developmental
Services (DDS)

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



Rule 1

To provide good care, you must
practice good self-care



Rule 2

When in doubt,
refer to Rule 1



Caregiver Support

- ❑ Know your limitations
- ❑ Ask for help. Create a support network
- ❑ Use resources available through Alzheimer's Association, DDS, local senior service providers or community support agencies
- ❑ Consider involvement of hospice during the later stages of the disease



Additional Webinars on Aging with IDD

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

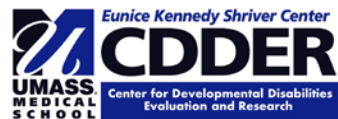
- ❑ Introduction to Dementia and Aging with IDD
- ❑ Early Evaluation of Dementia and Alzheimer's Disease
- ❑ Stages of Alzheimer's Disease
- ❑ Applying the Knowledge to Dementia Caregiving and Caregiver Support
- ❑ Caregiving in Action: Case Studies and Practical Tips



Additional Aging with IDD Resources

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

Center for Developmental Disabilities Evaluation & Research
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

