



Competence and Compassion: The Essentials of Dementia Responsive Supports

AAIDD Webinar

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Typical Aging

Normal aging involves gradual changes in functioning – changes in memory, concentration, vision, hearing, and in physical capabilities. Some health problems are more likely as we age. The effects of aging are highly individualized.

Dementia is NOT a normal part of aging.



Alzheimer's Type Dementia

◊ A slowly progressing , degenerative brain disorder characterized by memory loss, changes in personality, and loss of functional and motor capabilities.



Alzheimer's Risks in the General Population

- ◊ Advancing Age is the greatest risk
- ◊ Family history of Alzheimer's Disease is a risk factor
- ◊ History of TBI is a risk factor for Alzheimer's Disease



Risks for Individuals with I/DD

- Adults with I/DD are typically at no more risk than the general population.
- People with Down Syndrome are at increased risk.
- Estimated 25% of those in the late 30s/ early 40s and older are affected.
- 65% of those 60 and older affected.
- Approximately 9000 people with I/DD are affected; this number is expected to triple in the next 20 years.



The Down Syndrome Connection

- “Extra” genetic material
- Premature aging – signs of aging appearing 20 – 30 years early
- Earlier onset of dementia



AD is different for people with Down Syndrome

- Compressed progression
- Onset of seizure disorder
- Some cognitive changes may not be noticed
- Early onset (mid 40s – early 50s)
- May see significant changes in functioning (independence, communication, initiative)



Signs and Symptoms of Alzheimer's Disease

- Gradual onset and progression of 6 or more months
- Decline in memory for recent events
- Decline in functional abilities (self care and daily living)
- Confusion / disorientation
- Personality changes
- Inactivity or loss of interest
- Loss of emotional control



What Makes Diagnosis Difficult?

- Individuals with DD may not be able to report signs and symptoms
- Subtle changes may not be observed
- Most dementia assessment tools are not relevant for people with DD
- Difficulty of measuring change from previous level of functioning
- Conditions associated with DD may be mistaken for signs of dementia



What Should be Ruled Out?

- Thyroid abnormality
- Depression
- Vision & hearing loss
- Medication reactions
- Urinary tract disturbance
- Gastro-intestinal disturbance
- Nutritional deficiency
- Vitamin deficiency
- Head trauma
- Brain tumor
- Folic acid abnormalities in people taking anti-convulsants



Stages of Alzheimer's Disease

- **Onset** - difficulty finding right words, minimal memory loss, deterioration of work performance
- **Progressive** - distinct language problems, disorientation, confusion, loss of self-care skills, frustration
- **Terminal** - inactive, require complete 24-hour care, risk of pneumonia



Effects of Alzheimer's

- ◇ Memory Loss
- ◇ Confusion / Disorientation
- ◇ Decline in communication, personal care, and work skills
- ◇ Changes in personality and behavior
- ◇ Loss of mental abilities eventually resulting in total dependency for all activities

The "A's" of Alzheimer's

- ◊ Agnosia: inability to recognize or interpret visual information – faces, objects, etc.
- ◊ Anomia: inability to find the right word, name, label, or express an idea
- ◊ Aphasia: difficulty understanding or expressing – following instructions, conversing
- ◊ Apraxia: difficulty translating thoughts to actions – eating, toothbrushing



Behaviors Associated With Alzheimer's Disease

- Wandering, pacing
- Ingesting inedibles
- Agitation, combativeness
- Refusals of daily care
- Loud vocalizations
- Restlessness, irritability
- Fear, paranoia
- Sleep disturbances



We must honor the person she was, and embrace the person she is.



Essential Components of a Dementia Responsive Program

- ◊ Environmental Design
- ◊ Interaction Techniques
- ◊ Specialized Activities
- ◊ Individualized Plans of Care
- ◊ End of Life Support



Physical Environment

- ◇ Keep changes to an absolute minimum
- ◇ Maintain consistency in personal space
- ◇ Eliminate clutter and distractions
- ◇ Eliminate ambient noise (loud and multiple conversations, tv, radio)
- ◇ Keep traffic paths clear
- ◇ Good lighting, non-glare glass, attention to figure ground contrast
- ◇ Use symbols and signs in the environment

Daily Routines

- ◇ Regular, predictable schedule
- ◇ Consistent approach to each activity of the day
- ◇ Simplify routines
- ◇ Reduce choices, but continue to offer them
- ◇ DO EVERYTHING POSSIBLE to maintain skills

General Interaction Tips

- ◇ Come into the person's visual field and at an appropriate distance
- ◇ Speak slowly and clearly / Introduce yourself (every time)
- ◇ Keep verbal requests simple
- ◇ Use a quiet, low frequency tone
- ◇ Use facial expressions, smile
- ◇ Use body language and gestures
- ◇ Incorporate symbols or signs familiar to the person
- ◇ Use the person's name frequently
- ◇ Know the person and individualize your approach



The *Don'ts* of Interactions

- ◇ Talk from a distance or shout across the room
- ◇ Engage in side conversations within hearing of the person
- ◇ Begin an activity without explaining what is happening next
- ◇ Argue or confront
- ◇ Initiate interactions on the go (Drive by Interactions)
- ◇ Abandon people (leave a person without an explanation – even for a few minutes)



Leisure and Social Activities

- ◇ Being with people is more important than the actual activity (*spending time provides reassurance and combats confusion and fear*)
- ◇ Simplify activities and focus on individual interactions
- ◇ Fewer materials, fewer steps, forget about rules and outcomes



Self Care

- ◇ Personal Care and Meals ARE Activities
- ◇ Slow down... PATIENCE
- ◇ Support INDEPENDENCE to preserve dignity
- ◇ Use simple instructions, do one step at a time
- ◇ Simplify – smaller steps or portions, fewer choices
- ◇ Minimize distractions and clutter
- ◇ Absolute consistency across staff and shifts



Challenging Behaviors

- It's not about you
- It sometimes seems entirely unpredictable
- Every moment is a new opportunity
- Break some rules you have always followed (be willing and creative)
- Anticipate and solve problems
- Re-direct, re-direct, re-direct
- Keep safe but don't restrict or restrain

Person Centered Plans

- ◇ Knowing and honoring the person
- ◇ As a team, try different techniques and systematically evaluate effectiveness
- ◇ Develop an individualized, written, user friendly plan (adaptive equipment, specific approaches and words to use, preferred people, activities, times of day, etc.)
- ◇ Develop plans for each difficult activity: Bathing plan, Mealtime plan, Transportation plan...
- ◇ Commit the strategies to writing , educate each other, insure consistency – DO IT THE SAME WAY, EVERY TIME – EXCEPT when you don't!



Knowing and Honoring the Person

- Who was she and who is she now
- Helping her connect with important aspects of her past
- Accepting the “new” person – be open to changes
- Balancing respect for family/friends and the person
- Creating room for conversation and connecting while protecting against “20 questions”

Making Life Stories or Conversation Books

- Know the person / learn the history
- Collect actual photos or reminders of important aspects of the persons life
- Make videos, photo boxes, binders, etc.
- Holding or touching pictures or objects is helpful
- For multiple users, new friends, volunteers, it's helpful to put info on the back
- Use only to stimulate conversation and reflection; not for quizzing or questioning



Hospital Stays

- ◊ Continuous cueing about the new environment
- ◊ Explain procedures and apologize each time discomfort is caused
- ◊ Watch for non-verbal signs of pain
- ◊ Try to maintain routine and regular activity level
- ◊ As much as possible, maintain consistent staff
- ◊ Avoid groups of staff or visitors
- ◊ Avoid restraints – falls are not prevented and sometimes result from restraint
- ◊ Avoid room changes
- ◊ Keep television off unless requested by the person
- ◊ Continue to provide dentures and glasses



Grief and Loss – the long goodbye

- Progressive dementia causes us to lose people over a period of time; often the person we knew is “gone” long before they die
- For family and friends who have watched a person work so hard to become independent and successful, it is particularly painful to witness the loss



End of Life Issues

- ◊The right and opportunity to acknowledge the end of life
- ◊Making deliberate choices and plans
- ◊Receiving the same array of services and supports as everyone else (palliative care / comfort measures)
- ◊Affirming the value of each life
- ◊Grieving the end of each life, the loss of each friend

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