

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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