Intellectual disability and Alzheimer’s disease: Advocacy Efforts

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Advocacy across the life span

- Health is….a state of complete physical, mental and social wellbeing, and not merely the absence of disease. * 
- Quality of life 
- Quality of care 

“I be an old man.”

Accelerated Aging-A little understood phenomena
Diagnosis of DAT 2006

November 2008

Rapid decline starting
December 2008

End of life February 2010
Looking Back

- Establish baseline long before disease onset
- Be informed about co-occurring conditions
- Seek medical practitioners that understand the complex nature of diagnosing/treating individuals with ID
Looking Back

- Understand “differential diagnosis”

- With diagnosis of Alzheimer’s disease: *
  - Educate
  - Anticipate
  - Accommodate
  - Accept

*Rosalyn Carter’s Institute for Caregiving
Some useful resources

What is DEMENTIA?

- Pamphlet created by Down’s Syndrome Scotland to use with adults with intellectual disabilities and explain dementia and its effects on their friends, relatives and parents.

The NTG FAQ: Some Basic Questions about Adults with Intellectual/Developmental Disabilities Affected by Alzheimer's Disease or Other Dementias

- Fact sheet in a question and answer format addressing common questions regarding dementia and intellectual disabilities.
  - Download at [http://aadmd.org/sites/default/files/FAQ-Table-v9.pdf](http://aadmd.org/sites/default/files/FAQ-Table-v9.pdf)
NTG Activities

A national early detection-screening instrument (NTG-EDSD)

Various language versions available

Access at www.aadmd.org/ntg

Practice guidelines

Community supports guidelines issued

- Health practices, social care, day-to-day services and practices
- CARF & national program standards

Training and education activities

- Training workshops
- Meetings with professional groups
- Promotion of Family information

Linkages

- Administration on Community Living
- National Assoc. of State Directors of Developmental Disabilities Services
- National Assoc. of Area Agencies on Aging
- National Association of Councils on Developmental Disabilities
The NTG’s recommended nine-step approach for assessing health and function.

- Taking thorough history, with particular attention to “red flags” that potentially indicate premature dementia such as history of cerebrovascular disease or head injury, sleep disorders, or vitamin B12 deficiency.
- Documenting a historical baseline of function from family members of caregivers.
- Comparing current functional level with baseline.
- Noting dysfunctions that are common with age and also with possible emerging dementia.
- Reviewing medications and noting those that could impair cognition.
- Obtaining family history, with particular attention to a history of dementia in first-degree relative.
- Noting other destabilizing influences in patient's life such as leaving family, death of a loved one, or constant turnover of caregivers, which could trigger mood disorders.
- Reviewing the level of patient safety gleaned from social history, living environment, and outside support.
- Continually “cross-referencing the information with the criteria for a dementia diagnosis.”
NTG Guidelines and recommendations for dementia-related health advocacy preparation and assistance that can be undertaken by provider and advocacy organizations.

The guidelines help caregivers recognize and communicate symptoms, as well as find appropriate practitioners familiar with the medical issues presented by aging adults with lifelong disabilities.

www.aadmd.org/ntg
Aging and Down Syndrome: A Health & Well-being Guidebook

Adults with Down syndrome, along with their families and caregivers, need accurate information and education about what to anticipate as a part of growing older, so they can set the stage for successful aging.

The purpose of this guidebook is to help with this process... it is intended to be helpful to a variety of users: families, professionals, direct caregivers or anyone concerned with the general welfare of someone with Down syndrome.

The goals of this guidebook are to:

• Provide guidance, education and support to families and caregivers of older adults with Down syndrome
• Prepare families and caregivers of adults with Down syndrome for medical issues commonly encountered in adulthood
• Empower families and caregivers with accurate information so that they can take positive action over the course of the lifespan of adults with Down syndrome
• Provide an advocacy framework for medical and psychosocial needs commonly encountered by individuals affected by Down syndrome as they age

www.ndss.org
Urgent needs of older caregivers…
Caregiver Crises

- Mrs. B
  Age 80+

- Husband 80+
  with dementia

- 50+ year old
  Daughter with
  physical and ID
  exhibiting
  further
cognitive
decline

Estimates suggest that roughly 75% of individuals age 40-60 with an ID live with aging family members

Provided by MP Janicki, PhD
Siblings
Compound Caregivers

Aging Father
Mother in Nursing Home*
Brother with Ds/Ad*

Jan*
Jan lives several hours from her parents and brother.

Grown children/ grandchildren
Husband *

*Numerous medical issues
Common Themes

- Lack of information
- Fear about future
- Difficulty formulating long term plan
- Struggle to access coordinated care
- Difficulty partnering with medical community
- Overwhelmed by demands of caregiving
- Isolation and abandonment
- Profound sense of **Loss** with further diagnosis
- End of life issues
George

Age 61
Advocacy Efforts

- Remember that *behavior is communication*
- Observe, monitor and record changes over time
- Trust your knowledge as the “historian” and informed observer
- Think outside of the box
Carl
Coordination of Care

Model Developed by Kathleen Srsic-Stoehr, MSN, MS, RN, NEA-BC

3/18/13 Version
The Three C’s

• Communication
• Coordination
• Collaboration
Understanding Aging in Place

“Aging in place” requires a commitment to:

- On-going caregiver training
- Increasing staff
- Creating a calm, safe, “enabling” environment
- Person centered planning
- Supporting peers/family
- Monitoring quality of life for all involved
Challenges of Change
Advocacy Efforts

- Communicate, collaborate and coordinate for a smooth transition
- Foster a connection…Help new community know the “person”
- Advocate for informed, compassionate and respectful care
- With each transition have a distinct presence
- Strive for Balance for the Caregivers
Irma

Palliative care is more than pain management care. It is:

- Person and family/caregiver centered care
- Designed to optimize the quality of life
- Focused on anticipating, preventing, and treating suffering that may be caused by physical, intellectual, emotional, social, and spiritual needs.
- Coordinated through team collaboration of the person, family, caregivers, and health care providers.

Age 70
Joel

Diagnostic overshadowing

- Dehydration
- Fractures
- UTI
- Adverse Drug Reactions (ADR’s)
- Sleep deprivation
- Co-occurring medical conditions
Robin

Age 58
Advocacy Efforts

- Develop a **Support System**
- Access community resources
- Identify caregiver characteristics
  - Engaging
  - Attentive
  - Observant
Richard
Advocacy Efforts

- Promote options for
  - Alternative Day Programs
  - Long Term Care Options
- Recognize depleted coping mechanisms
- Consider Respite Care
Changing life time role…

60+ years of caregiving
Witnessing life-altering changes…
Joey

Availability of Hospice and End of Life Care
The overlooked 4th “C”
Looking Ahead

Training for family and staff related to:

- Aging with Intellectual Disability
- Alzheimer’s disease
- Adapting day programs
- Challenging behaviors
- Creation of Safe and Enabling Environment
- Long term care
- Caregiver Support
What is needed:

- Education
- Implementation of best practices
- Long term planning
- The "3 C’s"
- Leadership and...
The Promotion of...
Additional Resources

**Understanding Difficult Behaviors** by Anne Robinson, Beth Spencer and Laurie White, Alzheimer’s Education Program, Eastern Michigan University
Phone: 734-487-2335  [www.emich.edu/alzheimers](http://www.emich.edu/alzheimers)

The Guide to Good Health for Teens and Adults with Down Syndrome by Brian Chicoine, M.D. and Dennis McGuire, Ph.D., Woodbine House Press 2010

Mental Wellness in Adults with Down Syndrome: a Guide to Emotional and Behavioral Strengths and Challenges by Dennis McGuire, Ph.D. and Brian Chicoine, M.D., Woodbine House Press 2006

The 36-Hour Day by Nancy Mace and Peter Rabins, Johns Hopkins University Press, 2008

The Picture Communication Symbols, DynoVox, Mayer and Johnson LLC Boardmaker