



RUTGERS HEALTH

The Boggs Center
on Disability and Human Development
Robert Wood Johnson Medical School

An Overview: How to Support People with I/DD Age Well



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for The Arc of New Jersey

12/10/25

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Official Obituary of

Kathleen M. Graham

May 9, 1961 ~ February 16, 2025 (age 63)

Kathleen Graham Obituary

No one had a greater influence on my life and career than Kathleen and her parents, Ann and Jack. She and I met in the nursery (we were born hours apart, delivered by the same doctor). We were inseparable in early life and close buds until I left home for college. Stories of Kathleen have always been woven into my teaching around disability rights and inclusion and particularly on the power of the words we use to describe people. No one loved harder, better, truer, or more loyally than Kathleen.

—Margaret Gilbride

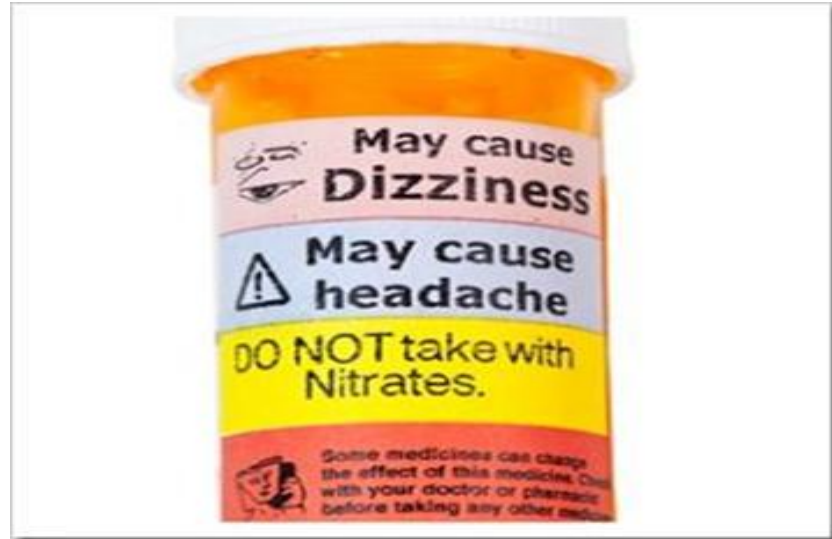
AGENDA

- Understand age-related changes
- ID home and community modifications
- Implement support strategies



Causes of Age-Related Changes

- Aging itself
- Life-long choices
- Environment
- Relationships
- Genetics
- Health



Early Onset of Aging DOES Occur

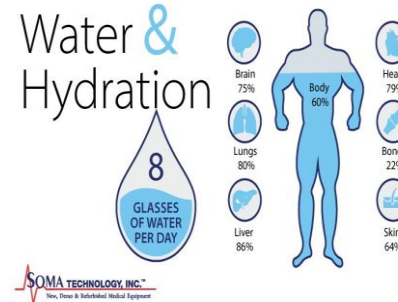
Those with Down syndrome, cerebral palsy, spinal cord injury and other significant disabilities experience

- Same age-related changes but earlier onset
- rate of change compressed



Physical Health and Wellness

- Vision/hearing
- Oral health
- Skin changes
- Gastrointestinal issues
- Taste/smell
- Sleep
- Musculoskeletal

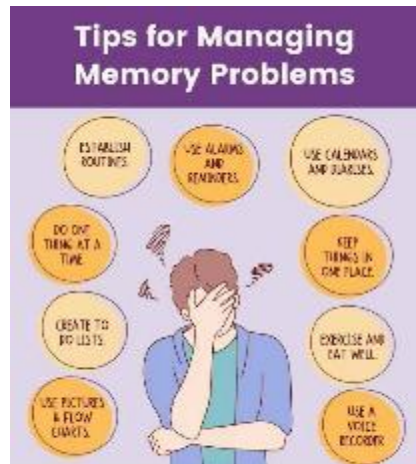


**Jimmy Jenson,
48.
Picture credit:
Best Buddies**



Cognitive, Mental and Emotional Wellness

- Memory
- Following directions
- Executive functioning
- Details
- Concentration
- Processing a/v
- Loneliness
- Isolation

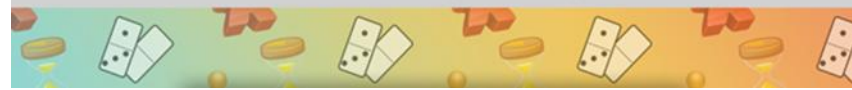


Strategies for Enhancing Focus



NJSAP Brain Games on Zoom!

Live, interactive board games with the NJSAP Team for you to test your creativity and knowledge and to have fun!
Join us on Zoom every Thursday at 1PM!



Alzheimer's Disease and PWDS

- All people with DS develop the neuropathological lesions associated with AD
- Amyloid plaques, neurofibrillary tangles, are present by age 40, ***though not all people with DS will develop AD***



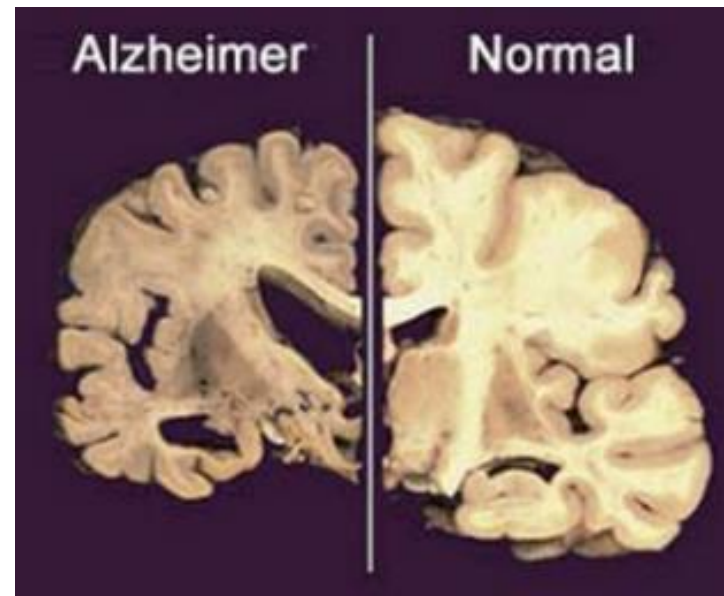
Alzheimer's Disease (AD)

General Population

- >65: 10.3% have AD
- >85: 47.2% have AD
- Average age of onset = 72
- Course: ~15 years; up to 25

People with Down syndrome

- >60: 56% have AD
- Average age of onset = 52
- Course: often 5 years usually 7-10





NTG-EDSD

The NTG-early Detection Screen for Dementia (NTG-EDSD) can be used for the early detection screening of these adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff and family caregivers to note functional decline and health problems and record information useful for further assessment, as well as to serve as part of the mandatory cognitive assessment review that is part of the Affordable Care Act's annual wellness visit for Medicare recipients. This instrument complies with section 2.8 of the US National Plan to Address Alzheimer's Disease.

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down Syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities who suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for one or more months) such as a family member, agency support worker, or a behavioral or health specialist using information derived from observation or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 40 minutes. Some information can be drawn from individual's medical health record. Consult the NTG-EDSD Manual for additional instructions (www.aadm.org/ntg/ some).

File #: _____ (2) Date: _____

Name of person: (3) First: _____ (4) Last: _____

(5) Date of birth: _____ (6) Age: _____

(7) Sex: ☐ Female ☐ Male

(8) Best description of level of intellectual disability

<input type="checkbox"/> No discernible intellectual disability
<input type="checkbox"/> Borderline (IQ 70-75)
<input type="checkbox"/> Mild (IQ 55-69)
<input type="checkbox"/> Moderate (IQ 40-54)
<input type="checkbox"/> Severe (IQ 25-39)
<input type="checkbox"/> Profound (IQ 24 and below)
<input type="checkbox"/> Unknown

(9) Diagnosed condition (check all that apply)

<input type="checkbox"/> Autism
<input type="checkbox"/> Cerebral palsy
<input type="checkbox"/> Down syndrome
<input type="checkbox"/> Fragile X syndrome
<input type="checkbox"/> Intellectual disability
<input type="checkbox"/> Prader-Willi syndrome
<input type="checkbox"/> Other: _____

Instructions:
For each question block, check the item that best applies to the individual or situation.

Current living arrangement of person:

<input type="checkbox"/> Lives alone
<input type="checkbox"/> Lives with spouse or friends
<input type="checkbox"/> Lives with parents or other family members
<input type="checkbox"/> Lives with paid caregiver
<input type="checkbox"/> Lives in community group home, apartment, supervised housing, etc.
<input type="checkbox"/> Lives in senior housing
<input type="checkbox"/> Lives in congregate residential setting
<input type="checkbox"/> Lives in long term care facility
<input type="checkbox"/> Lives in other: _____



ntg

National Task Group on Intellectual
 Disabilities and Dementia Practices

<https://www.the-ntg.org/family-caregivers>

Early Detection Screen for Dementia in People with IDD

<https://www.the-ntg.org/ntg-edsd>



These are live, interactive events to promote healthy living for adults and students with intellectual and developmental disabilities. We will be holding events on Zoom every Wednesday at 11 AM and Fridays at 1 PM on a variety of topics relating to healthy living!

Healthy Lifestyles Project (HLP)



New Jersey Self-Advocacy Project

A program of The Arc of New Jersey since 1983

Promoting Advocacy and Independence for People
with Intellectual and Developmental Disabilities

WEEKLY ZOOM SERIES Wednesdays & Fridays



An interactive Zoom series created by the New Jersey Self-Advocacy Project
as part of our Healthy Lifestyles Project

Enhancing Accessibility in the Home

- Structural changes
- Environmental Adjustments
- Assistive technology



Day Programs

- Adapting activities to accommodate changing physical and cognitive abilities
- Arts, music, social
- Focus on wellness
- *Staff training



Thanks to Supported Living staff, clients can participate in activities like the Special Olympics. Gregory Maxwell, an experienced skier and racer, competed in the advanced slalom and advanced giant slalom at the 2024 Special Olympics Games in Indiana.





Support Activity

Aerobic Exercise 3-4 times/week

- Walking
 - Inside or Outside
- Dancing
 - Chair dancing counts
 - Add props/movements
 - Intersperse with other activities
- Cycling
 - Stationary/trails



Support Musculoskeletal System

- Have “strength training” 2-3 times/week
 - Light weights more often (plastic bottles filled with sand, soup cans, inner tubes, person’s own body weight, walls)
 - Include Weight-bearing exercises



Fitness Centers

- Ensure physical accessibility-routes, space, bathrooms, showers, pool
- Inclusive and adaptive activities
- Inclusive machines/equipment
- *Staff training



Places of Worship

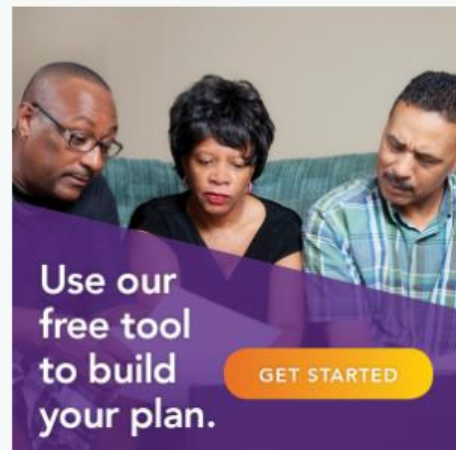
- Physical accessibility
- Sensory accommodations
- Social connections
- Valued roles



The Arc's Center for Future Planning

- Daily routines, needs, supports
- Living arrangements
- Finances
- Doctors' contact information
- Medical history
- Decision-making support
- Details about employment, hobbies, religious beliefs, music, interests, and important relationships.

<https://futureplanning.thearc.org/pages/learn/future-planning-101>



Future Planning: It's Possible

Future planning is possible regardless of income.



Welcome to our Community of Learning

Charting the LifeCourse is designed to be used for your own life, for your family members, or in the work you do. The framework and tools will help you organize your ideas, vision, and goals, as well as problem-solve, navigate, and advocate for supports.



You can use LifeCourse with your family or for yourself

- Learn more about yourself or your family
- Organize your thoughts and speak out for what you or your family wants and needs
- Problem-solve and plan for taking action in your life or on behalf of a family member
- Direct services and supports
- Advocate for change



Professionals use LifeCourse in the work that they do every day

- Educating others on possibilities
- Facilitating planning for now and the future
- Problem-Solving
- Coordinating Integrated Services and Supports
- Conflict Resolution and Advocacy

Website here



Leaders use LifeCourse to drive policy, practice, and cultural change

- Reframing Expectations at All Levels
- Training and Coaching Staff
- Education and Outreach Activities
- Driving Policy, Practice and Cultural Change
- Transforming organizations and communities

Focus on Aging here



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Everyone desires long
life, not one old age.

Jonathan Swift

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