Being Proactive

AMY YEAGER LMSW

Being Proactive Agenda

- COGNITIVE CHANGES in general
- Risks and challenges in individuals with Intellectual and Developmental Disabilities (IDD)
- Specific challenges and needs
- Proactive protocol for families, IDD agencies and other supports
- Key recommendations

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COGNITIVE CHANGES
can be caused by MANY things

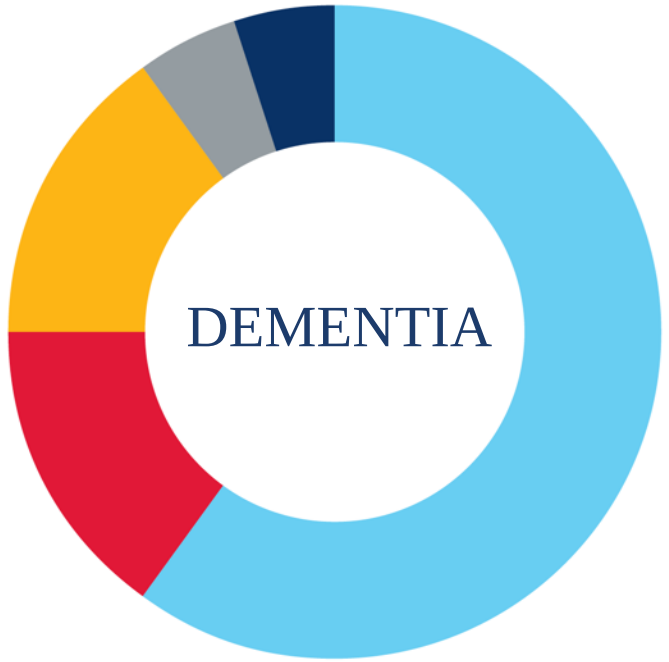
- Medication side effects
- Vitamin deficiencies
- Urinary tract infections
- Metabolic disorders
- Thyroid dysfunction
- Subdural hematoma
- Sleep disorders
- Sensory impairment
- Depression
- Substance abuse
- Hydrocephalus
- Vascular disease
- Brain tumors
- General infections

COGNITIVE CHANGES
should always be thoroughly EVALUATED

- BRAIN SCAN
- THOROUGH CLINICAL HISTORY
- LAB WORK
- PHYSICAL EXAMINATION
- BLOOD WORK
- SLEEP STUDY
- NEUROPSYCHOLOGICAL TESTING

DEMENTIA is not a specific diagnosis

ALZHEIMER'S DISEASE	60% - 80%
VASCULAR DEMENTIA/STROKE	15%
DEMENTIA WITH LEWY BODIES	15%
FRONTOTEMPORAL DEMENTIA	5%
PARKINSON'S DISEASE	5%



WHY does someone get Alzheimer's disease?

GENETICS:

- Familial variety of Alzheimer's disease approximately 10% of cases (APOE gene on chromosome 19)
- Sporadic varieties

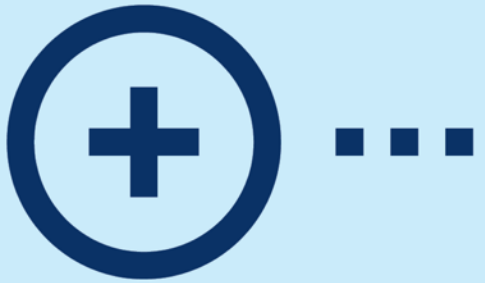
…continued RISK factors

Importance of EARLY DETECTION

SHIFTS TO APPROPRIATE INTERVENTIONS

PROVIDES OPPORTUNITY FOR EMOTIONAL SUPPORT

REDUCES BIAS



ALLOWS TIME FOR APPROPRIATE PLANNING

+ EARLY Stage

- Begins in the part of the brain that has to do with short term memory
- Depression early on is common
- Memory impairment very subtle, often missed by others
- Reduction of activities/involvements common
- May make comments/jokes about the forgetfulness to cover real concerns

+ As the disease progresses…

…it affects the part of the brain that impacts speech

- Word finding difficulties
- Word substitution
- Concentration errors
- Short term memory continues to worsen
- Visual spatial deficits emerge
- Challenges with numbers
- Individuals often keep note pads and other memory aides with them to manage the memory changes
- Driving issue needs to be addressed

// EARLY…HELPFUL STEPS

1. Alterations in compensatory adaptions
   - Visual cues
   - Employment accommodations
   - Adjustments in procedural task completion
2. Technology
   - Cameras
   - Safety supports (stove, medications, falls, door ajar alarms, smart locks)
3. Education
4. Emotional support

+ MIDDLE Stages

- Part of the brain that controls executive function becomes impaired
- Logic becomes circular
- Insight diminishes
- Judgment/decision making impaired
- High risk for exploitation/victimization
- Psychosis may appear–paranoia very common
- Emotional lability as center of feelings impacted

+ MIDDLE Stages continued…

- Altered sleep/wake cycle
- Loses initiation/motivation
- Sundowning
- Increasingly self absorbed
- Internal ‘map’ destructs

+ As the disease progresses…

- Short term memory absent, and long-term memory affected
- Frontal lobe area of the brain is impacted
- Disinhibition
- High risk for environmental changes provoked by above
- Loses the ability to filter noises
- Less interested in television
- Lower frustration threshold
- More dependent on cues from environment to convey whether one is okay

+ As the disease progresses continued…

- Misperceives things in the environment
- Sweet tooth lives
- Unable to convert physical messages to action
  i.e. keeps walking/pacing even when fatigued, eats when has just eaten, etc.
- Incontinence
- Requires help with all activities of daily living

// MIDDLE…HELPFUL STEPS

5. Matching capacity and expectation
   - Support for things they can do
   - Adequate support for things they can no longer do
   - Environmental supports/transitions
6. Structured engagement
7. Active treatment for depression

END Stages

- Eventually the disease affects walking
- People become unsteady on their feet
- Less and less verbal, eventually mute
- Requires total care
- Can see a new or increase in behavioral issues
- Begins to have swallowing difficulties
- Often see weight loss
- Infectious process, pneumonia, etc.
  is typically the demise of someone with the illness
- Seizure activity

// END…HELPFUL STEPS

8. Clarity and advocacy for individual philosophy and quality of life

9. Actively addressing depression, anxiety and other neuropsychiatric issues

10. Hospice

KEY FACTS regarding Intellectual and Developmental Disabilities

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KEY FACTS regarding IDD

Genetic link in individuals with Down syndrome (DS) – Chromosome 21 – Amyloid Protein buildup

Role of cardiovascular risk factors

Individuals with IDD other than DS may be as much as 5x more at risk for AD in older years than older adults without IDD.

(Developmental disabilities 34(6):1881-1885 · April 2013)

Role of psychiatric contributors

+ HIGHER RISK Population

- African Americans have 2x as great a risk
- Individuals with Down syndrome
- Individuals with other forms of IDD
- *Individuals with persistent mental health issues*
- *Some studies have indicated risk with early life trauma/life stress/PTSD*
- *Some studies indicate individuals with long term financial insecurity–access to health care issues*

+ Complications in recognizing early cognitive changes in IDD

- Cognitive and communication issues that impact standard testing
- Support individuals with long term comparative information not always available
  - Staff turnover
  - Individuals with IDD more likely to enter new settings when family absent or severely disabled
- Challenges in formal provider interpretation
- Symptoms can be the same with different etiology

- Co-competence in both IDD/dementia has not yet caught up with growing aging population in IDD community
- Baseline limitations
- For some, less insight about changes
- Constellation of formal supports
- May become more entrenched with same/less able to cope with changes
- Shifts in job coach involvement
- Alterations in support tasks

Something NEW

DIFFERENT BEHAVIOR

DIFFERENT RESPONSE

DIFFERENT REACTION

AGING ISSUES in individuals with Down syndrome

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+ Aging Issues in Individuals with Down syndrome

- Seizure activity
- Sleep apnea
- Sensory deficits including risk of vision and hearing issues
- Hypothyroidism
- Increased risk of dental/gum issues
- Digestive issues such as higher risk for GI reflux and increased risk for aspiration
- Mental health issues (anxiety, depression, OCD, ADD)
- Increased risk of diabetes
- Higher risk of osteoporosis
- Higher risk of mitral valve prolapse
- Increased incidence of trauma
- Delays in pain reporting
- Long term established routine
- Communication Issues
- Higher risk of obesity

Down syndrome + DEMENTIA

- Earlier and more observable pain protocols
  - Higher risk of behavioral issues secondary to unreported pain
- Regular assessment of anti depressant and/or other psychotropics
- Attention to diet/need for special diets
- Attending to length of time in bed/positions
- Attention to indicators of past trauma/often unreported
- Historical context for “security blankets”
- Thorough diagnosis important
- Integrate long term language choices into present
- Attention to anti cholinergic medications
- Monitor wax buildup in ears/hearing issues
- Find ways to maintain long standing relationships from the Down syndrome community
- Openly celebrate successes– be consistent with past pattern of affirmation
- Shifts in job coach involvement
- Alterations in support tasks

AGING ISSUES in individuals with Autism

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+ Aging Issues in Individuals with Autism

- Sensory Sensitivities—
  oral, tactile, auditory, and visual
- “Melt Down”
- Increased prevalence of
  depression, anxiety
- Social errors
- Perseveration/Fixation on certain
  topics or experiences
- Less able to adapt to changes
  in schedule/environment—Rituals
- Often limited support network,
  especially those with
  mild/moderate severity
- Literal interpretations
- Many never diagnosed
- Smaller range of interests
- Higher risk for sedentary
  lifestyle and consequences

Autism + DEMENTIA

- Area for calming
- Cautious medication reaction when melt downs occur
- Clear history on presence of meltdowns, triggers, how handled
- Bridge conversations with others
- Implications on activity schedule building
- Keep to schedule— do what you say you will do
- Monitor for rise in anxiety and depression
- Know preferences for touch, sound and material
- Integrate visual cues earlier
- Know something about the topics of heightened interest– maintain balance but integrate ‘security’ topics therapeutically
- Celebrate successes
- Shifts in job coach involvement
- Alterations in support tasks

AGING ISSUES in individuals with Cerebral Palsy

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+ Aging Issues in Individuals with Cerebral Palsy

- Limitations in weight bearing–“overuse syndrome”
- Increased fall risk
- Earlier incontinence
- Higher risk of osteoarthritis/degenerative arthritis
- Risk for depression goes up with age
- Decreasing social supports
- Higher risk of vision issues

Cerebral Palsy + DEMENTIA

- Critical integration of physical therapy/movement regimen ongoing
- Monitor and treat anxiety/depression
- Bridge conversations with other–
  keep the person connected
- Build activities and structure around any
  sensory challenges such as vision impairment.
- Celebrate successes

Being Proactive Protocol

FOR FAMILIES

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// *Being Proactive Protocol*

FOR FAMILIES

COMPLETE NTG EDSD FORM ANNUALLY

- Individuals with Down syndrome (DS) starting at age 35
- Individuals with an IDD, other than DS, starting at age 50

PROVIDE A COPY TO

- Key IDD providers
- Successors
- Primary Care Providers
- Neurology if at point of baseline

BASELINE DEMENTIA EVALUATION

- Individuals with DS at age 35
- Individuals with an IDD other than DS, if change noted on EDSD

FOLLOW UP

- Individuals with DS, Annually after baseline
- Individuals with an IDD other than DS, annually or more often after diagnosis, depending on need and practitioner

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FOR SERVICE PROVIDERS

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// Being Proactive Protocol
FOR SERVICE PROVIDERS

MAINTAIN RECORDS OF COMPLETED NTG EDSD ASSESSMENT PROVIDED TO YOU BY FAMILIES

INCORPORATE IN STANDARD PRACTICE WITH SPECIFIC ANNUAL REVIEW

ENCOURAGE FAMILIES TO COMPLETE AND TO SHARE WITH SUCCESSORS

COMPLETION OF NTG EDSD ASSESSMENT ANNUALLY IF FAMILIES UNAVAILABLE OR HAVE LIMITED DIRECT INVOLVEMENT

- Individuals with Down syndrome (DS) starting at age 35
- Individuals with an IDD, other than DS, starting at age 50

PROVIDE A COPY TO

- Successors
- Primary Care Providers
- Neurology if at point of baseline

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FOR HEALTH CARE PROVIDERS

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// *Being Proactive Protocol*
FOR HEALTH CARE PROVIDERS

COLLECT NTG EDSD ASSESSMENT AS PART OF ANNUAL WELLNESS VISIT

SCAN INTO MEDICAL RECORD

BASELINE DEMENTIA EVALUATION

- Individuals with DS at age 35
- Individuals with an IDD other than DS, if change noted on EDSD

DEMENTIA EVALUATION

- Review of NTG EDSD
- Neuropsychological Testing
  - Down Syndrome Mental Status Exam (DS-MSE)
  - The Cued Recall Task
  - Completion of Dementia Questionnaire for People with Learning Disabilities (DLD)
- Sleep study as indicated
- MRI if changes noted or score of concern

// *VALUE of the Protocol*

OBJECTIVE ASSESSMENT

OPPORTUNITY TO ADVOCATE

PROVIDES GUIDANCE TO HEALTH CARE PROVIDERS

ALLOWS APPROPRIATE INTERVENTIONS

// CURRENT Treatments

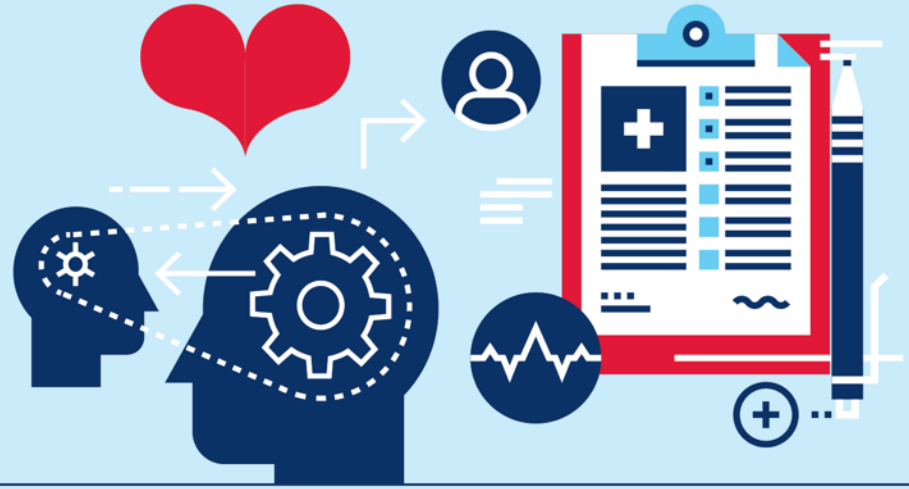
1. Aricept
2. Exelon
3. Razadyne
4. Namenda
5. Management of psychiatric complications
6. Non pharmacological interventions

LECANEMAB (**LEQEMBI™**)?

NO ONE with
Down syndrome
is included in the trials

// KEY RECOMMENDATIONS in CARE and SUPPORT

- Physical activity
- Vital attention to depression/anxiety
- Communication strategies to match person
- Range of strategies to connect with others
- Interpretation of affirmation
- Benefit of consistency multiplied



- Looking holistically at the person
  - Individual presentation of the intellectual/developmental disability
  - Personality/Individual elements
  - Role of past supports/formal resources
  - Alzheimer's disease

One is not more significant than the other.

> HOW we remember,
> WHAT we remember,
> and WHY we remember
> form the most personal map
> of our individuality.

Christine Baldwin

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Research and Support Programs

1

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Down Syndrome Dementia Clinic

The Down syndrome Dementia Clinic at the University of Kansas Health System is a comprehensive, multidisciplinary clinic for individuals with Down syndrome that are experiencing cognitive changes. Education and support are provided by our social work team.

ANNE ARTHUR APRN, Lead Provider

call 913.588.0983

2ND FRIDAY OF THE MONTH

Indicate you want to schedule appointment in the Down syndrome Dementia Clinic.

For IDD other than Down syndrome, call 913.588.0970 – request Anne Arthur

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2

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Community Information and Support Services

- Dementia and IDD information, individual questions and needs assessment and emotional/resource direction and support
- Do not have to be a KU patient

COGNITIVE CARE NETWORK

AMY YEAGER LMSW, Lead IDD/Cognitive health social worker
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3

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Current Research

Become a Research Hero Today

Call 913.588.0555 option 1

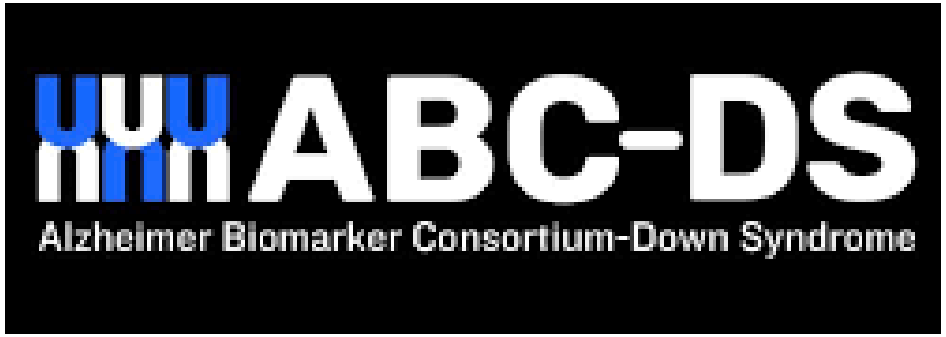
+ Current Research

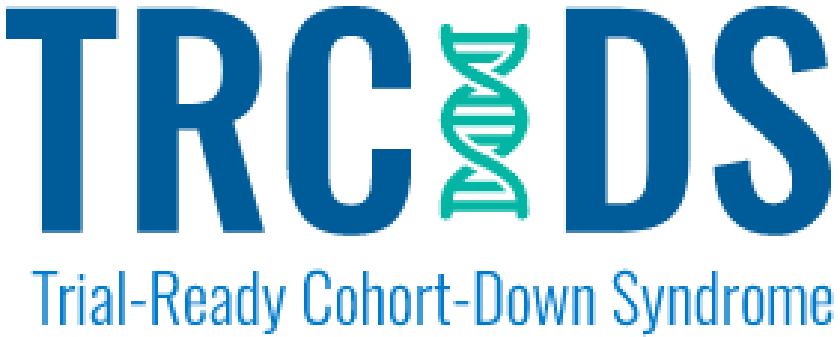
Brain Health in Down Syndrome Program

- Monthly newsletters related to Brain Health, specially for individuals with Down syndrome
- Access to caregiver support groups
- Opportunities to participate in a cutting-edge research
- Opportunity to join a long-term Brain Health study and get feedback on brain health at no cost

+ Current Research

Longitudinal Trials





+ Current Research

Brain Outcomes with Lifestyle change in Down syndrome (BOLD)

+ Current Research

ABATE…just launched!

One of the first anti-amyloid drug studies for individuals with Down syndrome

+ Other Resources

- Down syndrome innovations **kcdsi.org**
- Kansas Center for Autism Research and Training (KCART) **sswindler@kumc.edu**
- American Academy of Developmental Medicine National Task Group **aadmd.org/NTG**
- NDSS/Alzheimer's Association/NTG –
  "Alzheimer's and Down syndrome – A Practical Guidebook for Caregivers"
- Mood and Behavioral Challenges Guidebook

kuadrc.org/MoodBehavioralGuide

Dementia CareAssist app

iPhone **Android**

Questions?

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