

Dementia in Adults with Down Syndrome

A Supplemental Document to Session 3 in Webinar Series

Mild Cognitive Impairment

- Transitional early pre-clinical symptoms of dementia usually associated with early signs of Alzheimer's disease in the general population
- Early signs of subtle memory impairment assessed by psychometric tools
- Early decline in memory may also occur in the DS adult before other symptoms of AD appear

Depression

- Common in acute or chronic dementia, it is under recognized in clinical settings and mistaken for dementia, DS adults may be at high risk for diagnostic over-shadowing of Depression being misdiagnosed as Alzheimer's disease
- Symptoms - usually rapid and discrete onset while dementia symptoms are slow to develop
 - changes in sleep patterns
 - changes in appetite patterns
 - behavioral slowing or agitation
 - complaints of diminished ability to think or concentrate
 - poor effort of cooperation on assessment test
 - caregivers notices cognitive decline

Although there has been little research on MCI and depression occurring in the DS adult, it is possible they do occur but not noticed.

Considerations in Maximizing Independence	Examples
<p>Maximize their opportunity to live as full and healthy a life as possible</p> <p>Older DS adults with Alzheimer’s disease can continue to live in the community, if the right supports and assistance are provided.</p>	<ul style="list-style-type: none"> • Keeping up interests in: <ul style="list-style-type: none"> ○ work ○ recreation ○ friends and family • Maintaining: <ul style="list-style-type: none"> ○ good health, diet and fitness ○ regular medical checkups • Establishing specialty teams can provide advice and guidance to staff and families confronting care challenges. • However, since some adults affected by dementia may not be able to continue to live on their own, “dementia capable” housing and supports need to be developed.
<p>Once the suspicion of Alzheimer's disease has been clinically confirmed, the person's family, caregiver, or formal providers may need to make changes in the person's daily routine.</p>	<ul style="list-style-type: none"> • First and foremost, the person must feel safe and secure in his or her environment. • As a result of the complications associated with Alzheimer's disease, what may have been comfortable and familiar for the individual will become unrecognizable and may lead to unpredictable behavior

Managing Behavior Problems

- Remember Alzheimer’s disease in DS adults has a very rapid onset and a short duration. This means that changes in behavioral, ADL, memory associated with the disease process will occur sooner and will have a shorter time frame for interventions. **Many of these changes may be compounded (may worse) by their inability to communicate, express frustration, or negative interactions between staff or caregivers**
- The changes associated with the disease have been previously discussed. Their inability to communicate and/or express frustration, or negative interactions between staff or caregivers due to these change creates behavior problems that can and must be managed

Therapeutic Interventions

- Reality orientation therapy - Used to help maintain a person to the present time, skills and current memories of person and place. Not appropriate for adults with Alzheimer’s disease. Does not take into consideration regression in time, loss of skill knowledge or memories of person and place

Validation therapy - Appropriate therapy helps maintain a person to the time they have regressed in memory, skills and knowledge. Strongly suggested for adults with Alzheimer’s disease

Causes of Behavior Changes	Examples
Frustration from the loss of their abilities due to the following changes associated with the disease process	<ul style="list-style-type: none"> Short term memory loss Decrease in their current activities of daily living (ADL) abilities Confusion Disorientation to their surroundings Loss of learned skills (new skills first to be lost, older skills last)
Acting out behavior due to unnoticed or non-communicated personal discomfort or pain from physical changes	<ul style="list-style-type: none"> Rheumatoid or osteoarthritis of the joints Urinary tract infection (mainly females) Difficulty in urinating (mostly in males) Unreported or unnoticed menopausal symptoms pain Problems in hearing or vision Hungry or thirsty
Changes in their physical environment	<ul style="list-style-type: none"> Sundowning - time of day the sun is setting <ul style="list-style-type: none"> Can contribute to between 70-90% of late

afternoon behavior disturbance

- Changes in:
 - Roommate, meal partner, activities partner
 - Room, change in room set-up
 - Nursing aide or other personal
 - Changing any personal items in room (moving a picture)
 - Any regular routine
 - Family visit (when they arrive or leave)
 - List other possible changes that may cause behavior disturbances

Sensory Overload

- Too much activity at the same time - radio, TV conversation and other activities
- Too much activity around eating
- Instructions to complex - "sit down and eat"
- Fear of water - showers and bath
- Activities may be too overwhelming - field trips, group projects

The types of behaviors changes associated with disease, physical discomfort, environment, sensory overload include: agitation, anger, depression, frustration, pacing/wandering, striking out with food or fist, spitting, throwing food, and withdrawal not being involved with past pleasure.

Behavior Management

Examples

Frustration from the loss of their abilities due to disease (memory, skill loss and confusion)

- Demonstrate by example
 - lay out clothes on order of dressing
 - show how to dress
 - verbal clues for ADL/IADL
 - Show how to use utensils to eat
- Keep repeating instructions as needed
- Keep environment simple - no clutter
- Do not keep reminding the person

Acting out behavior due to unnoticed or non-communicated person discomfort or pain from physical changes - notice any change in activities that may be related to pain or discomfort slowing in movement (bending, walking, standing up, movement of hands interfering with skills, stiffness), problem with seeing or hearing (withdrawal, making mistakes), problems with doing every day activities (opening doors, turning on faucets)

Changes in environment or communication of need or frustration

- Have open bottles of water easily available
- Have food (fruits, low sugar candy, etc) easily available
- Look for any stress or pain in face or body action when during activities (walking, sitting, getting up, using hands) - pain and anti-inflammatory medications may be used under doctors direction
- Modify environment - chairs that are easy to sit or get up, door knobs, faucets, large objects
- Sundowning behavior
 - Bright lights in afternoon
 - Pull shades or curtains shut
 - Play music
 - Have activities to distract
 - Area for safe pacing or wandering
- Reduce sensory overload
 - Reduce background noise (TV, radio, conversations, activities)
 - Small groups with one on one attention
 - Reduced confusion at meal, going to mall, large group activities
 - Too many instructions
- Avoidance of circumstance causing behavior outburst-do not argue
- Use temporary distraction to avoid outburst
- Try to determine the cause of outburst - look for patterns
- Keep environment simple
 - Reduce the number of different foods dish (many servings) also on number of utensils – one at a time
 - Room uncluttered
 - Structure of day - simple but structured
 - Communicate in simple words and make instruction simple - one word (sit, eat, stand)
- Memory board outside of room with their picture (picture of time frame of memory they are currently in)

Reducing caregiver burden of family

- Last skills and information learned first to be lost (need to look at earlier skills and information learned)
 - Emotional support - Support groups, individual counseling, family counseling
 - Services - informal and formal supportive services
 - Day programs
 - Respite care
 - Visitation
 - Transportation - home delivered meals
 - Caregiver services
 - Knowledge and skills training for caregiver
 - Learning about the disease
 - Resources available
 - Coping with symptom
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Possible Causes of Symptoms

Symptoms	Examples
Functional Decline	<ul style="list-style-type: none"> • Side effects of Medication • Stroke • Thyroid (hypo-hyper) • Depression • Cardiac (hyper-hypo tension) • Diabetes • Arthritis (rheumatoid/Osteo) • Incontinence • Anorexia • Sensory Loss <ul style="list-style-type: none"> ○ Vision ○ Hearing • Pain • Environmental Design • Dehydration • Fatigue (Infections/Fever) • Nutritional Deficiency • Vitamin B12 • Iron
Dementia-like Symptoms	<ul style="list-style-type: none"> • Medications • Dehydration(hot days) • Hypothyroidism • Poor nutrition • Low blood pressure • Sensory loss • Personal loss • Change of environment • Sleep reduced or interrupted

Behavior Changes

- Depression/anxiety
- Infections
- Medications
- Sensory loss / environment
- Early dementia or progression
- Changes in environment
- Attention seeking
- Dehydration
- Personal loss
- Problems with urination
- Unreported pain/discomfort
- Sleep reduced or interrupted
- Menopause

Assessment Checklist / Level of Assessment

The three levels of assessment include:

- Level 1 – Staff observations and reporting
- Level 2 – Neurological assessment
- Level 3 – medical assessment diagnosis.

Understanding and Recognizing Changes from Baseline may Indicate Onset of Chronic Dementia

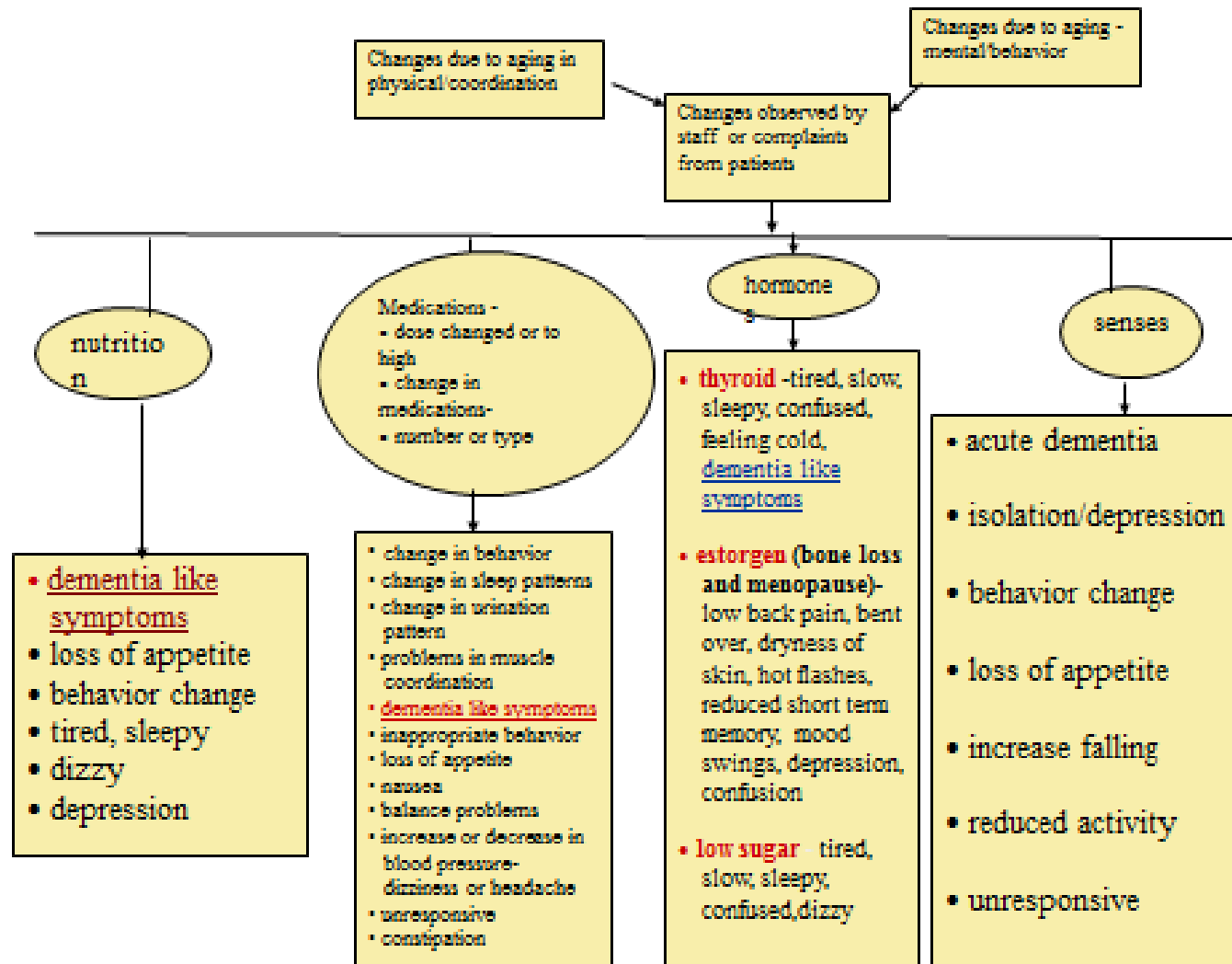
The beginning assessment for Alzheimer's disease starts when a gradual change is noticed from baseline clinical history that includes: change in routine behavior; noticeable steady decrease in ADL; personality change; loss of learned skills; loss or decline in learning new skills or information; reduced cognitive function; loss of social or job skills; withdrawal from past pleasurable activities

Conducting Assessments/Evaluation

To properly assess for Alzheimer's disease, it is necessary to observe a well-documented progression of symptoms. The family and carers of a person with Down syndrome should keep a record of changes they notice in: mood, personality, behavior, learning, and/or memory or skills in doing everyday activities. This information should be passed on to the social and health care professionals.

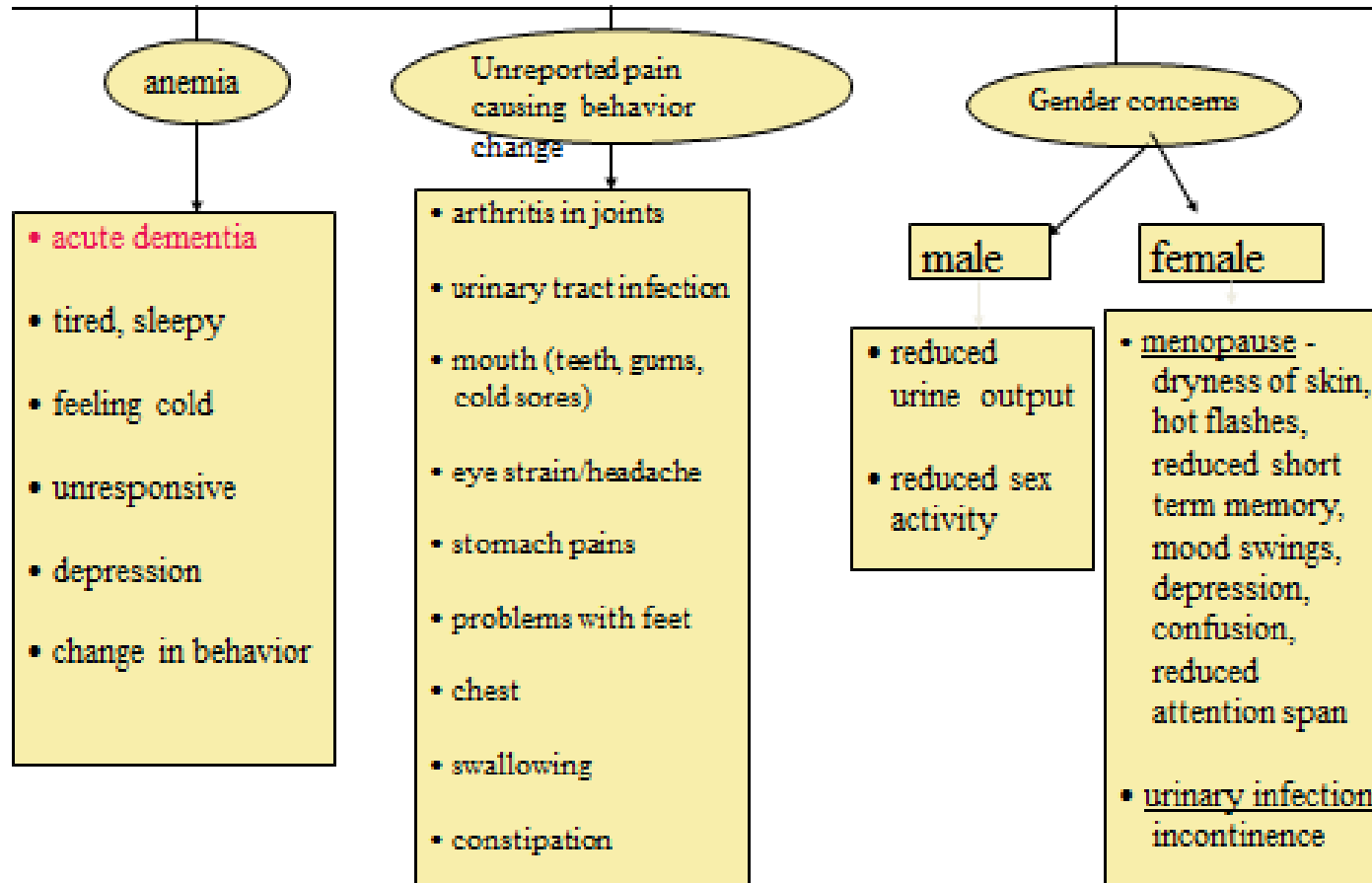
Differential Diagnosis Checklist:

Combing Changes Affecting Functional Level with Their Possible Causes - Graph 1



Differential Diagnosis Checklist:

Combining Changes Affecting Functional Level with Their Possible Causes - Graph 2



References

- Shoumitro Deb, et.al. 2007. Symptoms of Dementia Among Adults with Down Syndrome. Journal of Intellectual Disabilities. 51(9):727-739
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- Vineland 2 (psychometric): <http://ags.pearsonassessments.com/group.asp?nGroupInfoID=aVineland>
- Shoumitro Deb, et.al. 2007 Dementia Screening Questionnaire for Individuals with Intellectual Disabilities. British Journal of Psychiatry.190: 440-444
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