ADSC Clinical Findings (Behavior Health): 400 + Individuals Diagnosed with Alzheimer’s Dementia

For older Adults with Down Syndrome (Older than 40)

- Loss of function is due to reversible causes in a majority of cases
- Clinicians must to find any possible health or psychosocial causes of a loss of function
- Before making a diagnosis of a non-reversible dementia

Loss of function due to reversible and non-reversible disorders, all over 40; n = 128

Objectives

- Discuss health
- Mental health
- Interaction of health and behavioral health
- Discuss alzheimer’s Dementia in DS

A major reason for the success of the Center

- Multi-disciplinary
- Health &
- Behavioral health

Interaction mental and physical

- Physical changes may trigger behavioral health issues
- Behavioral health issues, may be a precipitant for physical changes

Change in Function The Team:

- Rule out health conditions (Hypo-thyroid; sleep apnea; Celiac; Gerd)
- Assess behavioral characteristics (self talk; grooves, visual memory)
- Assess supports (changes: family; peers)
- Assess Life stage changes & transitions: (leave school for adult life)
- Assess environmental stressors (home, school, work)

Depression: Behavioral strategies

Symptoms of withdrawal, loss of interest and participation
- Get people moving & active
- Don't let people sit at home
- Find activities that stimulate. etc
**Obsessive Compulsive Disorder**

- Reduce stressors (Environment; Treat health or other mental health problems)
- Do not try to STOP, “gently redirect”
- If stuck and rigid try a “visual cue” to reset

**Kathleen 45 year old women**

Living in a apartment with 5 others on a good campus environment

- Good support from family & agency staff
- Functional “grooves” (meticulous, organized, reliable in daily living & worksite tasks)
- Doing well in her work sites {office cleaning; assembly & and an art program}
- Participated in campus sport and recreation activities

**Kathleen 45 year old women**

Living in a good campus environment

- History of some Depression & compulsions: Associated with move to campus after loss of mother
- There are recent major stressors:
  - A Number of losses: roommate, brother in law, close staff, one sister moved away

**Recent symptoms: Depression**

- Loss of spark, life and vitality
- Loss of interest in music & sports which she “loved”
- Often refused to go to social or recreation activities she had enjoyed
- Restless sleep
- Fatigue and loss of energy

**Kathleen: Depressive symptoms**

- Crying spells
- Moody, tense & irritable
- Less tolerant (“can’t shake off daily irritations as before“)
- Some loss of self care skill (was meticulous)

**Kathleen: OCD & anxiety**

- Obsession, & rumination over one person
  - constant talk and worry about this person
- Wearing several layers of clothing
- Dragging & difficulty getting ready in morning
- She gets stuck on tasks, trying to make them “just right”

**Kathleen: Loss of function Leads to a concern for Alzheimer’s dementia**

- Ability to do daily living tasks is reduced due to her compulsions
She is so focused on making things “just so”
- Requires “prompting to complete tasks”
- Compared to her her normal meticulous appearance
- She is just not as careful with appearance

16 **Treatment strategy for Kathleen**

- Complete physical exam; (diagnosed an untreated hypothyroid problem)
- Behavior treatment Depression: Get her moving & active in sports and recreation again
- Anti-depressant medication:
  - to reduce sad mood; withdrawal, sleeplessness, irritable mood, fatigue, and skill loss.
  - to reduce OCD & anxiety: Obsession, worry and anxiety

17 **Treatment strategy for OCD**

Regarding obsession over housemate
- Staff & family told to nod but not to engage
- Divert attention whenever possible
Regarding difficulty getting ready in morning
- She was to use a checklist
- with a simple reward at the end

18 **Morning list:** **Earn a point for each task**

- Get up on time
- Take shower
- Get dressed
- Make bed
- Eat breakfast
- Take backpack with purse, & lunch
- Get on bus on time

19 **Sleep evaluation**

- On a home visit
- Her sister noted Kathleen was awake at (2 am) on several nights
- Napping and fatigue in the day
- Oversleep in morning and difficulty getting up
- Dr Chicoine recommended a sleep study

20 **Sleep evaluation**

- Sleep specialist consulted
Sleep study completed
- Difficulty with wearing the CPAP
- Use of behavioral incentives
- Use of sleep aid to encourage sleep (melatonin but not effective)
- Use of anti-depressant (trazodone not SSRI)

Peter 43 year old In a work setting
- Hobbies & interests (3 Stooges; oldies music; Star Wars and wrestling
- Participates regularly in sport and recreation activities
- Doing well in work transition (reliable & hard worker)
- Self talk but in a private space (positive)

Over 6 to 9 months his family are very concerned with the following
- Nightly tirades that escalate involving
- Negative and self critical self talk comments
- Content involve any teasing or negative comments by others toward him
- From any time in the past
- Replayed over and over
- He becomes more and more upset and self critical as the night wears on
- More inconsolable

Additional changes
- Depression: Loses interest in things he loved (music, movies, wrestling)
- Compulsions become more and more nonfunctional
  - He is more rigid about schedules and routines
  - He expands his need for things “just so” from his room to take in more of the whole house
  - Which becomes a safety concern

Alarming changes
- Loss of function (Alzheimer’s?)
  - Self care decreases dramatically
Examples of function loss:
  - Was meticulous with grooming and hygiene
  - Was able to make bed, brush teeth
  - Could get ready and out the door on time

Evidence of sexual molestation
- On the bus to work
- By another male “friend” (who also has an intellectual disability)
- No proof (reported by a 3rd student to her family)
- Family won’t prosecute
- Peter cannot verbalize the abuse

Memory interacts with other issues
- Compulsive need to replay the event
- At the same to blame himself (which happens to many victims)
- He does this by drawing on negative experiences from the past
- Expressing through self talk
- Escalates at night (when he not otherwise occupied)
- So self absorbed he cannot do self care tasks

29 Treatment
   ☐ Counseling to help reduce self blame
   ☐ Positive visual images to counter negative images ("change the channel")
   ☐ Consult with Dr. Chicoine re: health issues
   ☐ Medication?

30 MEDICAL EVALUATION
   History
   Physical
   Laboratory evaluation

31 Physical exam results
   ☐ Fatigue
   ☐ No diarrhea
   ☐ No constipation
   ☐ No weight loss
   ☐ Normal physical

32 Laboratory Evaluation
   ☐ Normal thyroid testing
   ☐ Elevated anti-gliadin IgA and IgG and anti-tissue transglutaminase antibodies (evidence of Celiac disease)

33 Diagnosis: Health & Behavioral health assessments
   ☐ Obsessive-Compulsive Disorder
   ☐ Post-traumatic stress disorder
   ☐ Celiac (presumed) (Parents decided against doing a small bowel biopsy)

34 Celiac
   ☐ Sensitivity to gluten-protein in wheat, barley and rye
   ☐ Small bowel biopsy (not choosen)
   ☐ Decision to eliminate all gluten in the diet
   ☐ Nutrition

35 Treatment
   ☐ Gluten-free diet
   ☐ Sertraline (Zoloft)
   ☐ Counseling

36 Outcome
Improved sense of well being

“Didn’t realize I felt poorly until I felt better”

Reduction in depression

Compulsions more functional

Evenings quieter

Alzheimer’s dementia: Key diagnostic issues

- Memory deterioration
- Loss of previously mastered skills
- Incontinence
- Walking difficulties
- Seizures
- (Not diagnostic) withdrawal & apathy

Skills prior to onset of Alzheimer’s dementia;
Linda, 57 year old woman with DS

Expressive language:
- Usually understood by all others
- adept at verbalizing feelings & concerns
- good sense of humor
- Independent in many daily living tasks
- Positive OCD; neat, organized, & meticulous

Social life: active in many social activities
- Good work skills.
- Supports: parents; excellent peer & staff
- Stressors
  - parents move to Florida
  - brothers death

Linda’s Dementia: Initial phase, an up and down course of memory deterioration

Beginning signs of Memory deterioration
- forgetful (lost keys, her lunch, glasses, etc)
- loss of concentration and difficulty completing tasks with multiple steps
- at times forgot how to do automatic tasks (setting table, brushing teeth etc)

Confusion/disorientation
- At times forgot location of bedroom or bathroom in house
② lost track of time, of day and night (several times had dressed for work in the middle of the night)

### Caregiver and Environmental Issues
- Growing sense of concern by people who really know her
- Changes are highly unusual for her
- Key: Because of superb visual skills and visual memory
- She never seemed to lose or forget anything
- Important early marker
- Example of “here after”

### Linda’s dementia: Additional signs in first stage
- Prompting and some hands on assistance needed for completion of basic self care tasks
- Some Incidence of Incontinence
- Mood still positive
- Loss of energy & fatigue
- Loss of interest and motivation to do activities she had enjoyed (especially in morning)
- Eating & sleeping still OK

### Caregiver and Environmental Issues: Early Up and Down Course
- Some days on (focused, sharp, plugged in);
- Some days off (unfocused, confused)
- May lead many to believe the changes noted are behavioral (oppositional or willful)
- In fact: they are typical of AD course

### Caregiver and Environmental Issues: Denial
- Very difficult for many significant others
- Safety issues may need to be stressed
- Wanderers (alarms needed on doors)
  - Close monitoring in public places
- One benefit/deficit of DS (compared to GP):
  - Existing depth perception problems worsen (Less likely to wander; more difficulty getting in vans etc)

### Caregiver and Environmental Issues: Inappropriate settings
Individuals with moderate level of skills are often already in supervised settings
Interesting problem: Individuals with high levels of skill and independence
- Live independently (are at great risk)
  - We need to stress safety concerns
- Work in higher level jobs (begin to fail)

46 Linda’s Dementia: mid phase
- Memory deterioration worsens (Groove gone)
- She had a set place for her personal items, now hardly aware
- She had set rituals and routines in daily life, now hardly aware
- Often lack of recognition of how to do routine tasks (setting table, brushing hair etc)

47 Caregiver and Environmental Issues mid stage: Level of Care Questions
Wide range of environments: (Not judgemental)
- Families/Agencies who can continue to care
- Families/Agencies who cannot or will not
At this stage even families/agencies who can
- Need to assess plan B and C (when they believe they cannot care)
- Some families and agencies are there to the end

48 Caregiver and Environmental Issues mid stage: Level of Care Questions
Some families or agencies are there to the very end
- Increasing paid/volunteer caregivers
- Other adaptations made
Some families or agencies cannot
- Look to nursing homes
- Chicago alternatives (near ADSC and in local communities)

49 Linda’s Dementia: mid phase
Confusion/disorientation more pronounced
- danger of wandering requires close monitoring
- recognition of home and work environment very limited
- Difficulty recognizing others, especially those who are not immediate supervisors evident.

50 Linda’s dementia: last stage
Hands on assistance needed even for basic self care tasks.
- Incontinence becomes a daily problem
- Mood labile: (irritable especially when caregivers try to have to have her do any activity)
- Distant, unresponsive & even "mask-like" in appearance
- Increased sensitivity to environment: heat or cold; noises etc
- Little energy or motivation for any tasks or activity
- Eating still OK

Linda’s dementia: last stage
- Not all negative
- Linda still at times responsive to family (long term memory)
- Music still stimulating (e.g., Sister Helen’s room)

Linda’s dementia:
- Sleeping disturbed; a reversal of day and night sleeping
- Walking very difficult (stairs are almost impossible; walks extremely slow and leans forward when walking)
- Safety concerns: Risk of falling and wandering
- Some difficulty with swallowing

Linda’s dementia:
- Speech incoherent & babbling
- Psychotic symptoms (talking and yelling at imagined people)
- Dis-inhibition; some odd or disturbing behavior (e.g., smearing; nudity)
- First seizures noted

Dementia: Final phase of deterioration for Linda
- Limited to vegetative functions; Sleeps most of the day and night, appetite still good
- Recognition & responsiveness even to close family members very limited
- Lack or awareness & ambulating reduces danger of wandering & other safety concerns
- Self care requires total dependence on caregivers

Dementia: final stage
- Seizures increase
- No ability to walk
- Swallowing problems worsen leading to aspiration and pneumonia
- (As in general population) Death often caused by pneumonia

One of the Joy’s of Down syndrome is a love of activity
- Many people enjoy sports and recreation activities

Research evidence that any activity is good stimulation
Two of the most important words in health promotion for people with Down syndrome

- Music
- Dancing

Add movement to Music and........

Dancing: The exercise that doesn't feel like exercise

Also

People love to dress up and to look good!

But...

If the music is playing they will be dancing

Who needs a partner? ...just dance

Acting and theater?

- Many with creative talents
- "Ham" "MC" weddings and social events