

- 1 **ADSC Clinical Findings (Behavior Health): 400 + Individuals Diagnosed with Alzheimer's Dementia**
- 2 **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
- 3 **Loss of function due to reversible and non-reversible disorders, all over 40; n= 128**
- 4 **Objectives**
 - ⊙ Discuss health
 - ⊙ Mental health
 - ⊙ Interaction of health and behavioral health
 - ⊙ Discuss alzheimer's Dementia in DS
- 5 **A major reason for the success of the Center**
 - Multi-disciplinary
 - ⊙ Health &
 - ⊙ Behavioral health
- 6 **Interaction mental and physical**
 - ⊙ Physical changes may trigger behavioral health issues
 - ⊙ Behavioral health issues, may be a precipitant for physical changes
- 7 **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)
 - ⊙
 - ⊙
 - ⊙
- 8 **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

- 9 **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
 - ⊙
- 10 **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
- 11 **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
- 12
- 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
- 13
- 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)
 - ⊙
- 14 **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"
- 15 **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

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20 **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

21 **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)

22 23 **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)

24 **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

25 **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

26 **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

27 **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

28 **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 chosen)
- ⊙ 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
- ⊙
- ⊙
- ⊙

37 **Alzheimer's dementia: Key diagnostic issues**

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

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

- 1 ⊙ 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
- ⊙
- 2 ⊙ Social life: active in many social activities
- ⊙ Good work skills.
- ⊙ Supports: parents; excellent peer & staff
- ⊙ Stressors
 - parents move to Florida
 - brothers death

40 **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

- ⊙ lost track of time, of day and night (several times had dressed for work in the middle of the night)

41 **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"

⊙

42 **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

⊙

43 **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

⊙

44 **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)

⊙

45 **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
- ⊙

51 **Linda's dementia: last stage**

Not all negative

- ⊙ Linda still at times responsive to family (long term memory)
- ⊙ Music still stimulating (eg., Sister Helen's room)

52 **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

53 **Linda's dementia:**

- ⊙ Speech incoherent & babbling
- ⊙ Psychotic symptoms (talking and yelling at imagined people)
- ⊙ Dis-inhibition; some odd or disturbing behavior (eg smearing; nudity)
- ⊙ First seizures noted

54 **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 of awareness & ambulating reduces danger of wandering & other safety concerns
- ⊙ Self care requires total dependence on careproviders

55 **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
- ⊙
- ⊙

56

57 **One of the Joy's of Down syndrome is a love of activity**

- ⊙ Many people enjoy sports and recreation activities
- ⊙

58 **Research evidence that any activity is good stimulation**

- ⊙
- ⊙ Out to shopping centers
- ⊙ Movies
- ⊙ Restaurants
- ⊙ Cultural events
- ⊙ Walking the dog
- ⊙

59 **Two of the most important words in health promotion for people with Down syndrome**

- ⊙ Music
- ⊙ Dancing

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62 **Add movement to Music and.....**

- ⊙ Dancing: The exercise that doesn't feel like exercise

63 **Also**

- ⊙ People love to dress up and to look good!

64 **But...**

If the music is playing they will be dancing

65 **Who needs a partner? ...just dance**

66 **Acting and theater?**

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

67