



# GLOBAL

DOWN SYNDROME FOUNDATION®

## Alzheimer's Dementia in Down Syndrome: A Clinicians Perspective

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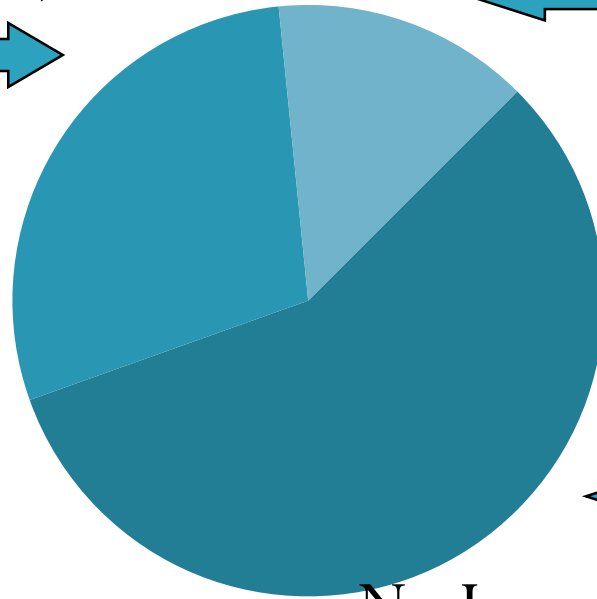
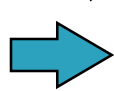
For the past 25 years

- \* At the Chicago ADSC & Denver Adult Down Syndrome Centers
- \* We have seen close to 6000 people
- \* & Diagnosed over 450 people with Alzheimer's Dementia

## Clinical Sample ADSC, all over 40; (n=298 )

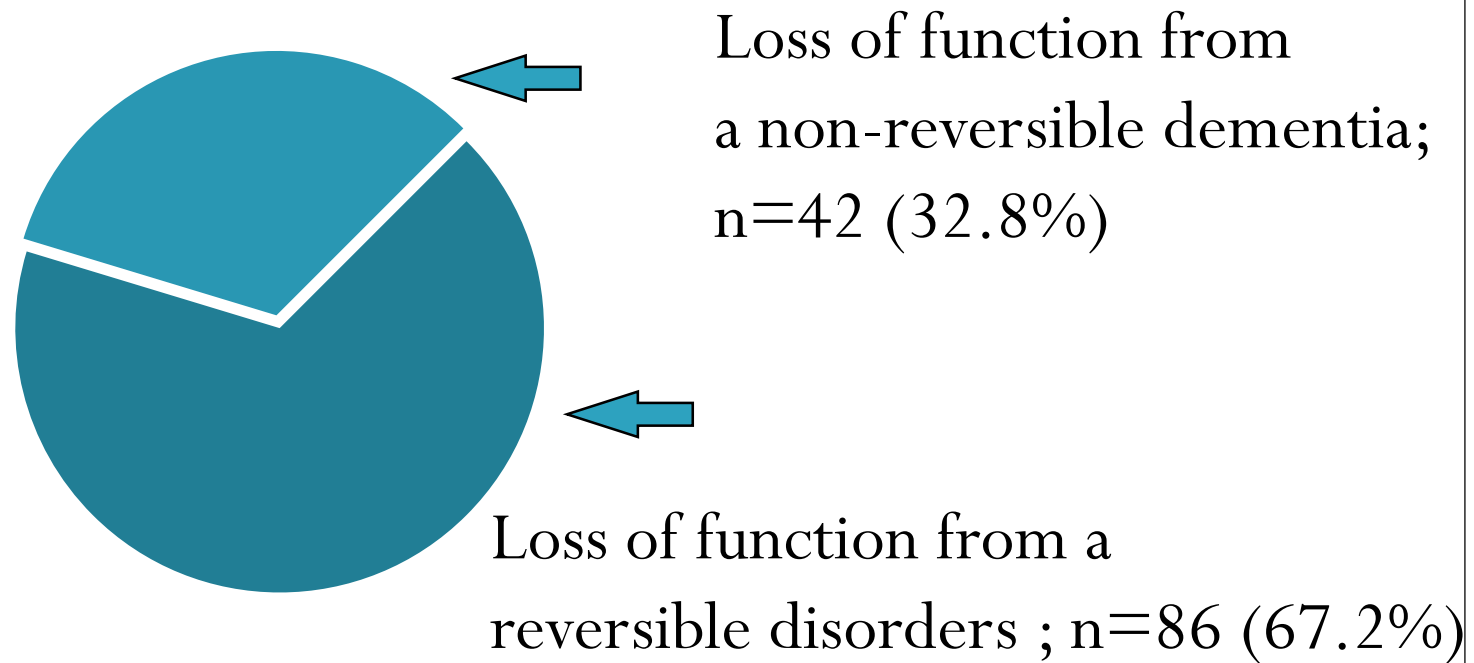
Loss of function from a  
reversible disorders;  
n=86 (29%)

Loss of function from  
non reversible dementia;  
n=42 ( 14%)



No Loss of function; n=170 (57%)

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



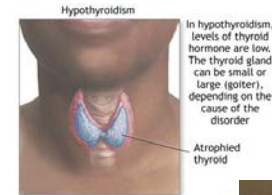
# For older Adults with Down Syndrome (Older than 40)

## Alzheimer's is a Diagnosis of exclusion

- Loss of function is due to reversible causes in a majority of cases (@ 60%)
- Clinicians must find any and all possible health or psychosocial causes of a loss of function
- Before making a diagnosis of a non-reversible dementia

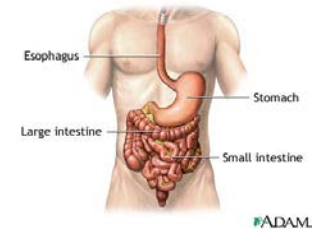


# Change in Function : Alzheimers. Dx of exclusion



Hypothyroidism

In hypothyroidism, levels of thyroid hormone are low. The thyroid gland can be small or large (goiter), depending on the cause of the disorder



## Rule out

- Health conditions (Hypo-thyroid; sleep apnea; celiac; etc)
- Mental Health ( depression, OCD, trauma, etc)
- Life stage changes & transitions: Loss of significant others etc.
- Environmental stressors (home, school, work)



# Process of excluding other causes is not an easy task: Huge overlap Depression & Alzheimer's

Symptoms of withdrawal, loss of interest and participation in activities

For example: Is he not brushing his teeth...?

- Depressed & does not care?
- Or cannot remember how (Memory?)





# “Stubborn-Compulsive Behaviors “Grooves”

- Set patterns of behavior
- Can be very adaptive
- Under stress a ‘groove’ can become an ‘**obsession or compulsion**’
- Can be very odd and unusual
- Easily misinterpreted as alzheimer’s
- But Obsessions or compulsions **are conduits For any stressors**
- Health, mental health, Life change





# All over the internet “In people with DS changes in overall function, personality and behavior...”

- | May be more common early signs of Alzheimer's
- | Than memory loss or forgetfulness
- | “Behavior or Personality changes”,
- | Are indicators
- | Of every other problem or issue
- | Those causes representing 60% of the loss of function



# Cognitive Testing is also of limited value

- Results of Cognitive assessment tools
- Are normed on general population
- “Minimum value” floor effect” in the tests which affect most people with DS



For most people with DS

Results Do not distinguish differences in person's ability below that minimal value/score.

But (in 27 years of practice ADSC)  
Found an interesting finding: People with  
DS have **Photographic visual memory**

- | People remember past people,  
places and events in great detail
- | And in living color





# Best Diagnostic “Instrument” for Alzheimer’s Dementia in Persons with DS:

- Have an experienced clinician ask
- Person/s sharing the day to day life with person with DS
- About this “photographic memory”



Example Linda 57: Had excellent expressive & adaptive skills prior to onset of Alzheimer's dementia

## Linda's unusual early memory changes

- Forgetfulness (lost keys, her lunch, glasses, etc)



# Caregiver and Environmental Issues



- Growing sense of concern by people who really knew her
- The changes observed were highly unusual for her
- Because of her **superb visual memory**
- She never seemed to lose or forget anything
- **Important early marker**
- Example of the “here after”



# 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):  
Existing depth perception problems worsen (Less likely to wander; but also more difficulty getting in vans etc)

# Most effective care: “Anchors”

- Small group of caregivers
- Providing one on one care

We found that:

- People maintained skills longer
- This greatly helps to minimized anxiety, fear & anger

