Aging with Down Syndrome
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Objectives
Down Syndrome and Intellectual Disabilities
Know what happens after age 35
Unlock the mystery of dementia and Alzheimer’s disease
Master early detection
Be prepared for future care and planning
Objectives:
Be able to distinguish Alzheimer’s Disease (AD) in individuals with Down Syndrome and Intellectual Disabilities (ID) (average IQ=45; mental age 6-12 years old) from The general population (sporadic AD) (average IQ=100; SD +/- 15)

Trisomy 21 Down Syndrome:
- Earlier age onset
- Age faster
- More rapid progression through AD stages

Objectives:
Know the PHYSICAL SIGNS of Alzheimer’s Disease

Physical signs:
Beta-amyloid → Tau
Objectives:
Know the PHYSICAL SIGNS of Alzheimer’s Disease

**Longitudinal Study**
- 15 subjects with Down Syndrome
- Ranging in age from 21 to 65
- Followed over a 2.87-year period of time
- Identifying serial biomarkers of
  - β-amyloid and tau tracers
- Post-mortem brain autopsy case study

**METHODS OF DETECTION**
Radiolabeled probes
2-(1-{6-[2-fluorine 18-labeled fluoroethyl]methylamino}-2-naphtyl)ethyldiene)malononitrile ([18F]FDDNP)
Progression to Dementia Non-demented

Fig. 1

FDG PET FDDNP PET

Logan graphical analysis with cerebellar grey matter as reference

Fig. 2
NeuroQuant: MRI volumetric Brain Imaging:

Physical signs of Alzheimer’s
- Includes brain atrophy

Subject with Down Syndrome from a cohort followed as part of the longitudinal study

Frontal Lobe Disruption
Objective
ASSESSMENT OF CLINICAL SYMPTOMS OF ALZHEIMER'S DISEASE

NORMAL AGING
in Down Syndrome

Objective
ASSESSMENT OF CLINICAL SYMPTOMS OF ALZHEIMER'S DISEASE

DEMENTIA
by Stage of Alzheimer’s Disease in Down Syndrome
Objectives:
Know the signs and symptoms of Alzheimer’s Disease

Clinical symptoms by STAGE & AGE OF ONSET:

1. Conversion into Alzheimer’s Disease (35-45 YRS.)
2. Stage 1 (45+)
3. Stage 2 (50’s)
4. Stage 2-3: BRAAK & BRAAK (50-60’s)
5. Stage 3 (END STAGE)

Prevalence of Dementia in Down Syndrome

Lai, F. Williams, R. 1989 Archives of Neurology; Cooper, SA. 1997
There is wide variation in:
- Skills
- Mental ability
- Cognitive levels
- Personality style
ASSESSMENT OF SYMPTOMS OF ALZHEIMER’S DISEASE
GET A BASELINE...AT ANY AGE.

Pre-Alzheimer’s Screening Tools

ASSESSMENT OF SYMPTOMS OF ALZHEIMER’S DISEASE

Testing the Patient Directly

ASSESSMENT OF SYMPTOMS OF ALZHEIMER’S DISEASE

Caregivers as “Examiners”
ASSESSMENT OF SYMPTOMS OF ALZHEIMER’S DISEASE

Structured Interview: Chronology of CHANGE
Medical HX
Psychiatric ONSET
HX Form: Patient Information Form
Tests: Neuropsychology Behavior and Affect Profile-Dementia
Status BEFORE / NOW
Dementia Screening Questionnaire for Individuals with Intellectual Disabilities: NEW SX / Worsening SX

WHEN IT’S NOT ALZHEIMER’S
✓ MILD HEAD INJURY
✓ VITAMIN DEFICIENCY
✓ DELIRIUM
✓ UTIs
✓ DEPRESSION
✓ OCCASIONALLY SEARCHES FOR WORDS
✓ MEDICATION SIDE EFFECTS
✓ HYPOTHYROIDISM
✓ ENVIRONMENTAL CHALLENGES
✓ SENSORY IMPAIRMENTS
✓ SLEEP PROBLEMS

Objective
Learn about care and treatment for Alzheimer’s Disease
Learn about care and treatment for Alzheimer’s Disease

Medication

Purpose:
- Slow rate of progressive COGNITIVE decline
- Reduce PSYCHIATRIC symptoms

Handout from the Alzheimer’s Association

Learn about care and treatment for Alzheimer’s Disease

Types of Treatment Facilities

Purpose:
Aging in Place is optimal care until....

Learn about care and treatment for Alzheimer’s Disease

Care during Disease Progression

STAFF : PATIENT RATIO by AD STAGE in DS:
- (Stage 1) IHHSS
- (Stages 1-2) Group homes
- (Stages 2-3) Assisted Living
- (Stage 3) Skilled Nursing
- (Late Stage 3) Hospice
Learn about care and treatment for Alzheimer’s Disease

Care during Disease Progression

RESIDENTIAL PLACEMENTS by AGE in DS:
(40-45 y/o) IHHSS
(21 and over ) Group homes
(45+) Assisted Living
(45+) Skilled Nursing
(45+) Hospice

RESIDENTIAL PLACEMENTS by SX in DS:
(dementia) IHHSS
(dementia) Group homes
(incontinence; mute; wandering) Assisted Living
(stroke; seizure; pulmonary) Skilled Nursing
Hospice
HOW DO WE DETECT ALZHEIMER’S DISEASE?

10 WARNING SIGNS
[IN ORDER OF HOW THEY APPEAR IN LIFE]

1
BEHAVIOR CHANGES

2
EMOTIONAL CHANGES
3
TROUBLE WITH LEARNING

4
COMMUNICATION PROBLEMS

5
TROUBLE WITH JUDGEMENT
6

MEMORY GETTING WORSE

7

NO LONGER ABLE TO DO SIMPLEST OF TASKS

8

CAN’T TAKE CARE OF SELF ANYMORE
9

DOESN'T RECOGNIZE FAMILIAR PEOPLE

10

EXTREME LOSS OF BODILY FUNCTIONS
(PHYSICAL, VASCULAR, NEUROLOGICAL)

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34 exceptional individuals with Down Syndrome

and

to the 34 exceptional individuals with Down Syndrome who gave so much for the sake of Science.

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