Dementia Capable Care of Adults with Intellectual & Developmental Disabilities & Dementia

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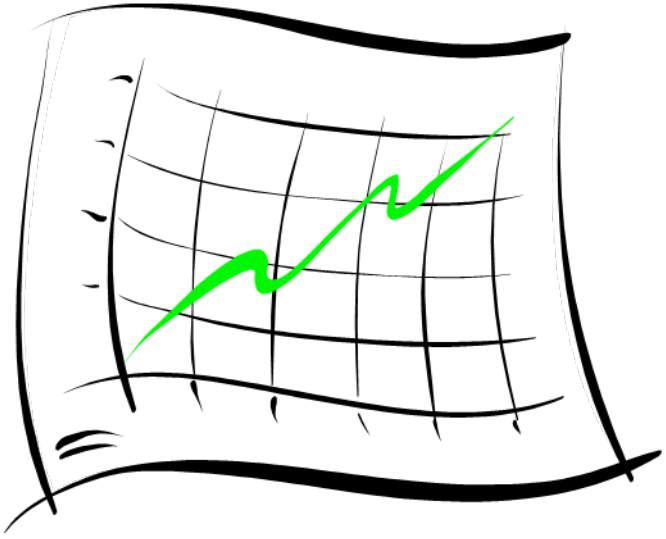
National Task Group on Intellectual Disabilities & Dementia Practices (NTG)

- Coalition of interested persons and organizations.
- Mission: Ensuring that the needs and interests of adults with intellectual and developmental disabilities who are affected by Alzheimer's disease and related dementias – as well as their families and friends – are taken into account as part of the National Alzheimer's Project Act (**NAPA).**
- **To access resources, visit** https://www.the-ntg.org/

Risk of Dementia in ID

Most adults with ID are typically at no more risk than the general population.



<u>Exception</u>: Adults with Down syndrome are at increased risk!

- Younger (40's and '50's)
- More rapid progression.

Dementia Prevalence: ID vs. DS

Intellectual Disability

Age	Percentage
40+	3%
60+	6%
80+	12%

Down Syndrome

Age	Percentage
40+	22%
60+	56%

Matthew P. Janicki and Arthur J. Dalton (2000) Prevalence of Dementia and Impact on Intellectual Disability Services. Mental Retardation: June 2000, Vol. 38, No. 3, pp. 276-288.

Dementia Prevalence: General Population

More than
5 million
Americans
are living with
Alzheimer's

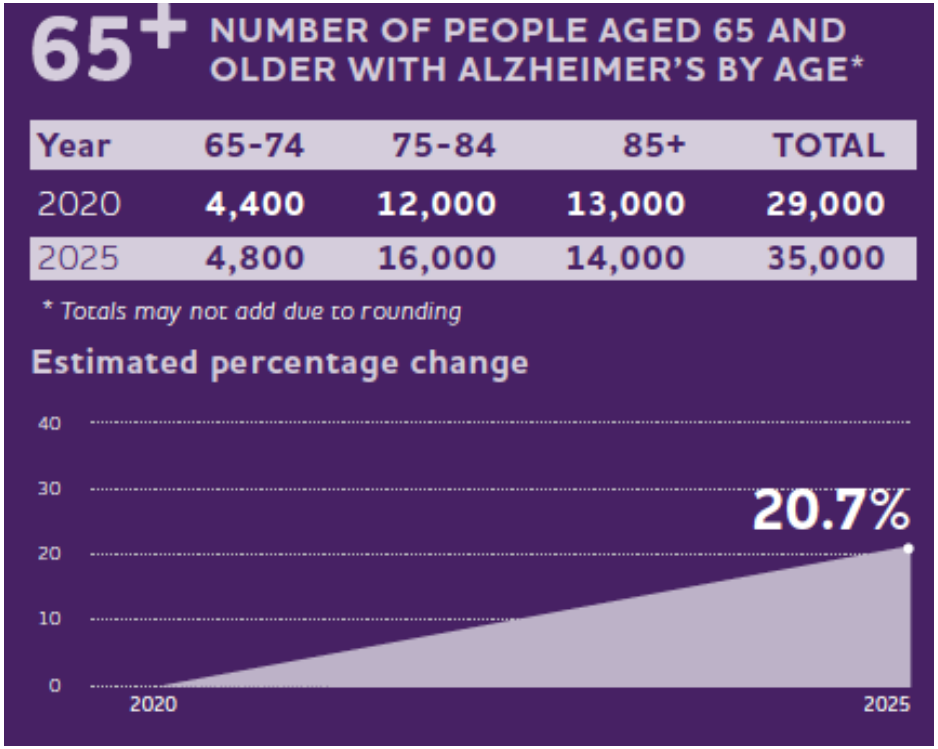
1 in 3
seniors
dies with
Alzheimer's
or another
dementia

It kills more
than breast
cancer and
prostate
cancer
combined

By 2050, the number of people age 65 and older with Alzheimer's dementia is projected to reach 13.8 million.

Alzheimer's Association Facts and Figures Report, 2020

#s in U.S. vs. Hawaii



Alzheimer's Association Facts and Figures Report, 2020

Tip of the Iceberg!

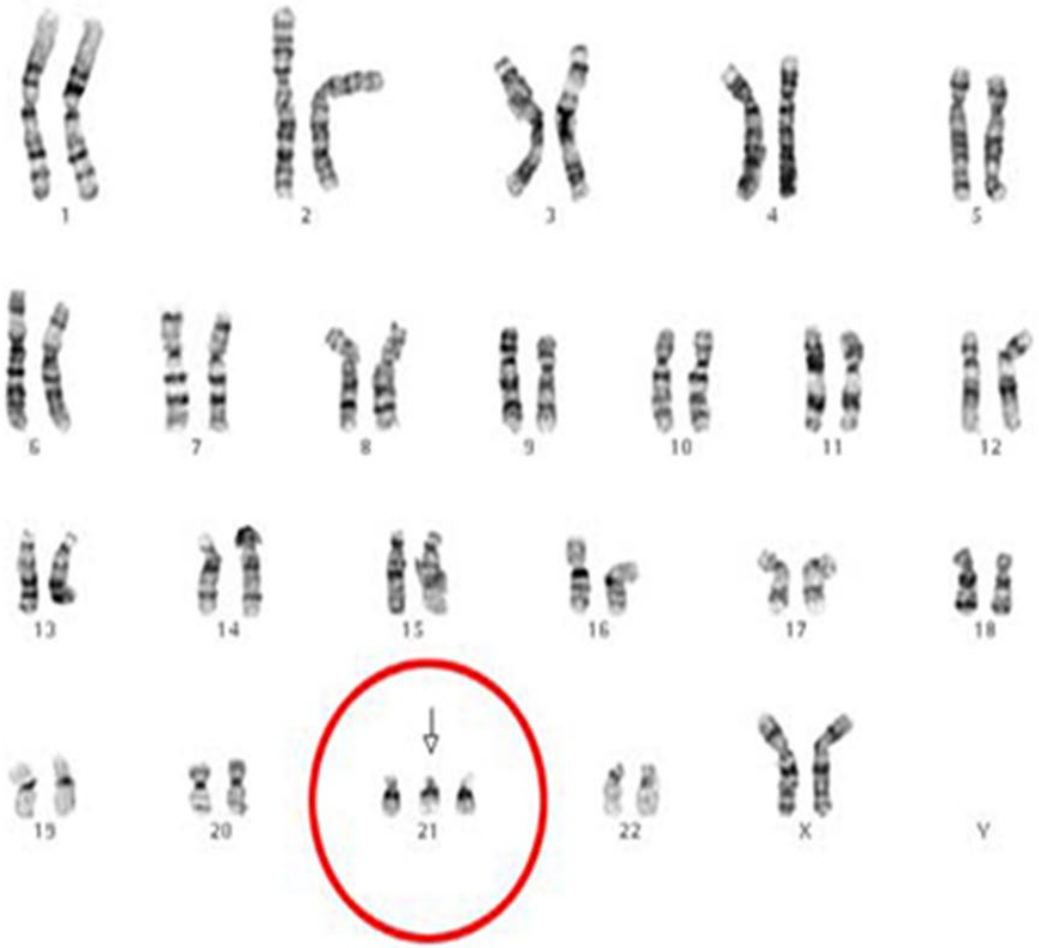
Hawaii figures do not include those who are undiagnosed

It's estimated that approximately 60-80% go undiagnosed!

What is Down Syndrome (DS)?

- First accurate description of a person with DS was published in 1866 by an English physician - John Langdon Down.
- DS is a developmental disability – intellectual impairment and physical abnormalities.
- DS occurs 1 in 750 live births.
- DS is caused by a genetic abnormality – an extra full or partial copy of chromosome 21 (Trisomy 21).
- Extra copy of genetic material alters the course of development and causes the characteristics associated with Down syndrome.
- common physical traits of Down syndrome are:
  - low muscle tone, small stature,
  - an upward slant to the eyes,
  - and a single deep crease across the center of the palm
  - each person with Down syndrome is a unique individual and may possess these characteristics to different degrees, or not at all

Down Syndrome



https://www.drbeen.com/blog/chromosome-abnormality-down-syndrome/

Premature Aging in Down Syndrome

- Life expectancy has continued to increase for people with Down syndrome.
- Aging increases risk for physical and cognitive changes for people with DS.
- Many individuals with DS age prematurely (age in their 50s).
- Adults with DS are at risk for diseases and changes about 20 years earlier than the general population.

Why focus on Alzheimer's Disease?

Alzheimer's often presents differently in people with Down Syndrome.

- Abrupt onset of seizure activity when there had been none in the past.
- Incontinence when an individual has always been independent in toileting.
- Short- term memory loss may depend upon the previous level of memory demands and reliance on memory in everyday life.
- Sleep/wake cycle disruptions.

**Just as in the general population, the course and symptom presentation is unpredictable and unique to the individual.*

Dementia Affects All Aspects of Functional Ability

- Memory
- Language skills
- Ability to focus and pay attention
- Reasoning & judgment
- Sensory perception
- Ability to sequence tasks

Traditional Screening Tools Not Useful

Traditional screening instruments for detecting dementia in the general population are designed for people with average baseline intelligence and are not useful for detecting cognitive impairment in adults with DS.

Example:

- Mini-Mental Status Exam (MMSE)

Alternative:

- NTG – EDSD

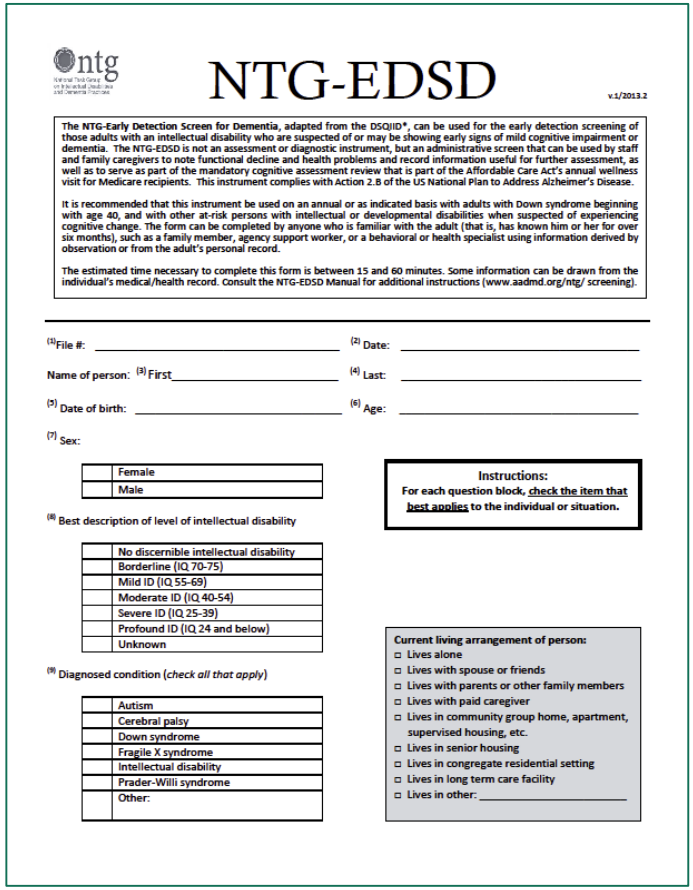
NTG Early Detection Screen for Dementia (EDSD)

Adapted from:

- Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (Deb et al., 2007), and
- Dementia Screening Tool (adapted by Philadelphia Coordinated Health Care Group from the DSQIID, 2010)

Down Syndrome begin age 40 then annually.

Non-DS begin at age 50.



ntg

NTG-EDSD

v.1/2013.2

The NTG-Early Detection Screen for Dementia, adapted from the DSQIID*, can be used for the early detection screening of those adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff and family caregivers to note functional decline and health problems and record information useful for further assessment, as well as to serve as part of the mandatory cognitive assessment review that is part of the Affordable Care Act's annual wellness visit for Medicare recipients. This instrument complies with Action 2.B of the US National Plan to Address Alzheimer's Disease.

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record. Consult the NTG-EDSD Manual for additional instructions (www.aadmd.org/ntg/ screening).

(1) File #: _____ (2) Date: _____

Name of person: (3) First _____ (4) Last: _____

(5) Date of birth: _____ (6) Age: _____

(7) Sex:

	Female
	Male

Instructions:
For each question block, check the item that best applies to the individual or situation.

(8) Best description of level of intellectual disability

	No discernible intellectual disability
	Borderline (IQ 70-75)
	Mild ID (IQ 55-69)
	Moderate ID (IQ 40-54)
	Severe ID (IQ 25-39)
	Profound ID (IQ 24 and below)
	Unknown

(9) Diagnosed condition (*check all that apply*)

	Autism
	Cerebral palsy
	Down syndrome
	Fragile X syndrome
	Intellectual disability
	Prader-Willi syndrome
	Other:

Current living arrangement of person:
- ☐ Lives alone
- ☐ Lives with spouse or friends
- ☐ Lives with parents or other family members
- ☐ Lives with paid caregiver
- ☐ Lives in community group home, apartment, supervised housing, etc.
- ☐ Lives in senior housing
- ☐ Lives in congregate residential setting
- ☐ Lives in long term care facility
- ☐ Lives in other: _____

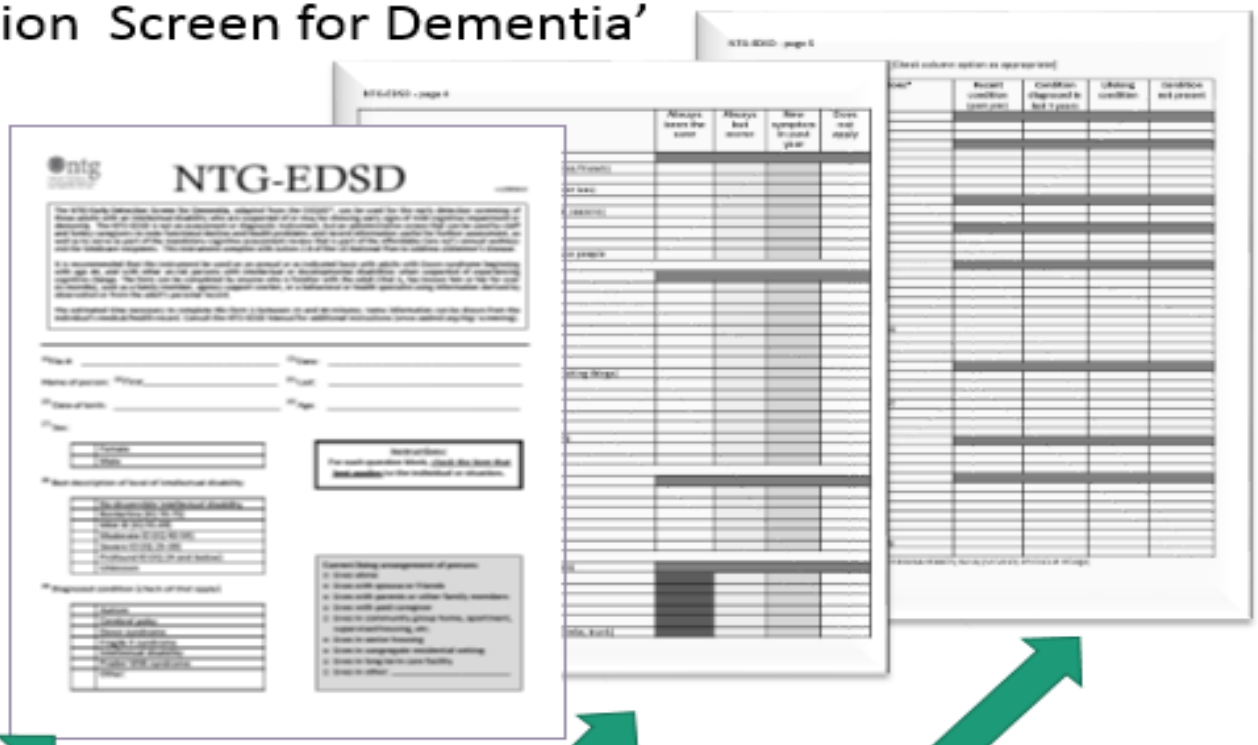
Tool & manual available online in multiple languages: https://www.the-ntg.org/ntg-edsd

Continued

'NTG-Early Detection Screen for Dementia' (NTG-EDSD)

Usable by support staff and caregivers to note presence of key behaviors associated with dementia

- ✓ Picks up on health status, ADLs, behavior and function, memory, self-reported problems
- ✓ Available in several languages



Pages ①②: Basic information

Pages ③④: Information about function and indicators of problem areas associated with dementia

Page ⑤: Coincident conditions

Page ⑥ Medications & Comments

NTG-EDSD: 4 Key Sections

Demographics

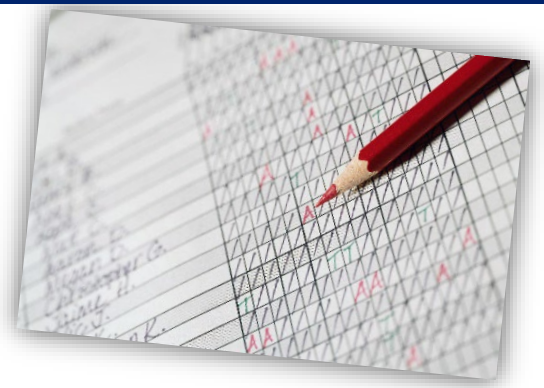
Ratings of health, mental health and life stressors

Review of multiple domains including

- Activities of Daily Living
- Language & Communication
- Sleep – Wake Patterns
- Ambulation
- Memory
- Behavior & Affect

Chronic Health Conditions

Who Can Complete the NTG-EDSD?



- Any caregiver, either family or staff who is familiar with the person can complete the NTG-EDSD if they:
  - Have known person for a minimum of 6 months
  - Have access to information in the person's record

How to best complete the form?

- Combine perceptions of function offered by several staff or family members.
- Use best judgment when responding to questions asking for impressions (e.g., health, function).
- Be truthful – don't 'hide' problems to make a good impression

Sources of Information

- Speak with:
  - family members
  - other staff who know the person
- Look through available medical records.
- Look through program plans and personal files.
- Get consensus among care team members on behaviors and other performance factors.
- Ask the person who is being screened.
- Ask friends or other close persons.

A short digital video of the person performing certain tasks can also be helpful.

I've completed the EDSD… now what?

- **Review** the form and see if there are any changes noted that are potentially of concern.
- **Talk it over** with the individual's key workers to ensure agreement with the findings.
- **Discuss** findings with the team and supervisor.
- If there are concerns, **make an appointment** to have the person further assessed.
  - Collate all of the information into useful packet
  - Assemble a list of medications being taken
  - Bring any digital video evidence of function or functional problems

Essentials of a Diagnostic Workup

- Rule out delirium – sudden confusion, inattention, medical emergency
  - UTI, impaction, pneumonia, medications
- Rule out depression/anxiety – has there been a recent significant life event?
- Medication review – new meds, changes, interactions, anticholinergics*
- History and physical (including psychiatric, personal, past medical and family histories and mental state assessment)
- Lab tests

  Evidence supports the following tests:
  - Complete blood cell count
  - Serum electrolytes
  - Glucose
  - BUN/creatinine
  - Serum B12 levels
  - Thyroid function tests
  - Liver function tests
  - Celiac screening if DS (tTG-IgA test)
- MRI and/or CT scan (possibly)

The Three D's

Dementia

Gradual over months to years

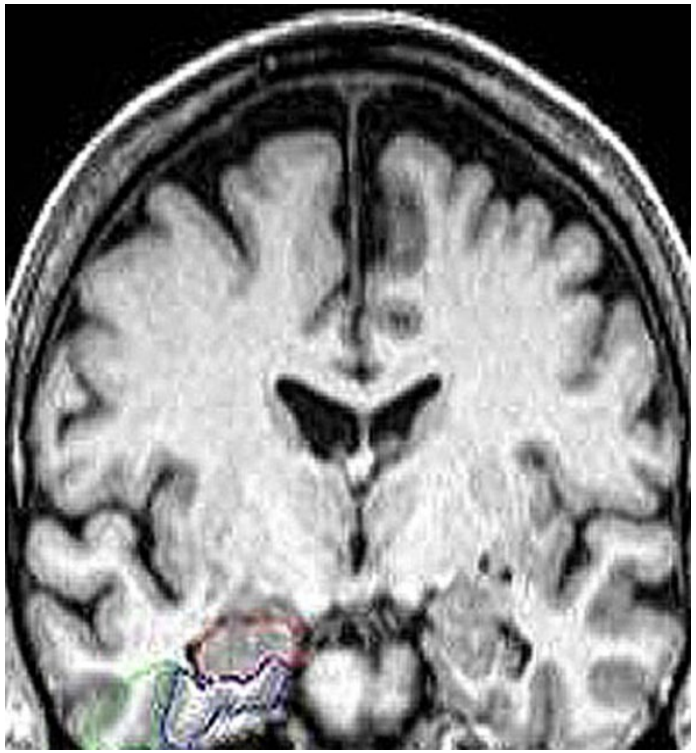
Delirium

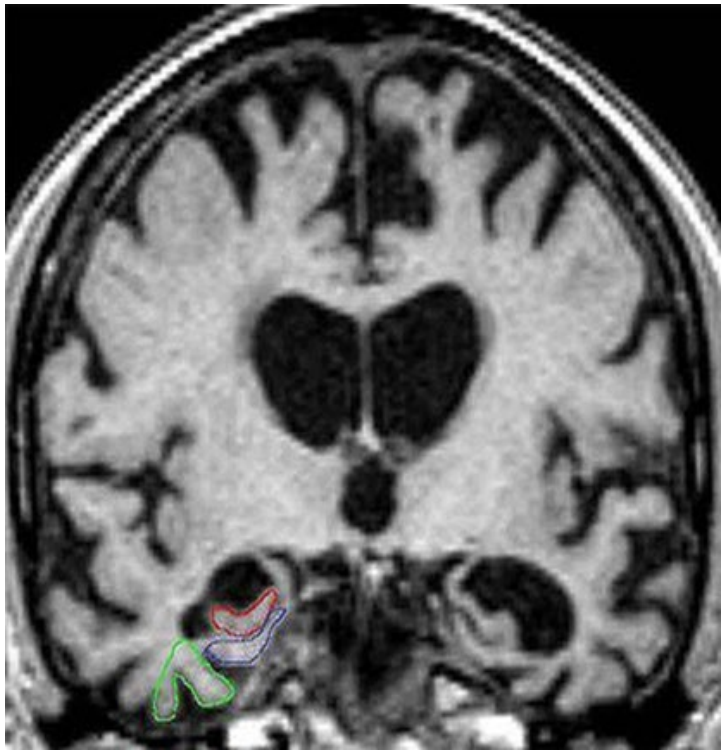
Sudden onset, hours to days

Depression

Recent unexplained change in mood that lasts for over 2 weeks

CT Scan Brain





https://www.radiologyinfo.org/en/info.cfm?pg=alzheimers

Medications for Alzheimer's

- **Aricept*** (Donepezil)
- **Namenda**** (Memantine)
- **Exelon*** (Rivastigmine)
- **Razadyne*** (Galantamine)

- Often used together for moderate to severe AD.
- Statistically significant improvement in cognition and global function for patients treated with NAMENDA XR 28 mg plus an AChEI compared to placebo plus an AChEI

- **Namzaric – NEW 2015**. Extended release.
  - Namenda + Aricept
  - Approved for the treatment of moderate to severe dementia of the Alzheimer's type
  - Capsule can be opened to sprinkle onto food

* Cholinesterase inhibitors are prescribed to treat symptoms related to memory, thinking, language, judgment and other thought processes in early to moderate AD. Delay worsening of symptoms for 6 to 12 months, on average, for about half the people who take them.

** Regulates the activity of glutamate, a different messenger chemical involved in learning and memory. Delays worsening of symptoms for some people temporarily.

YOU may be in a position to be a health advocate…

- You are given the responsibility to look after the welfare of the adults that are in your program
- You are a care manager
- You work along with health personnel
- You are a relative or family member
- You are a friend or mate
- You are involved in way that the health of adults you work with can be your concern
- You are engaged in some other capacity that gives you access to the health practitioners

Importance of Health Care Advocacy

There are often interventions that can make a difference in quality of life and health.

Staff and family are the experts about individuals with ID.

- To recognize current changes and symptoms knowing the person across the lifespan is the best resource.

Health care is an art, not a science!