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

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This training/workshop is being conducted by Ritabelle Fernandes, MD, who is an Affiliated Regional Trainer for the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) and is authorized to use copyrighted and branded NTG training materials.

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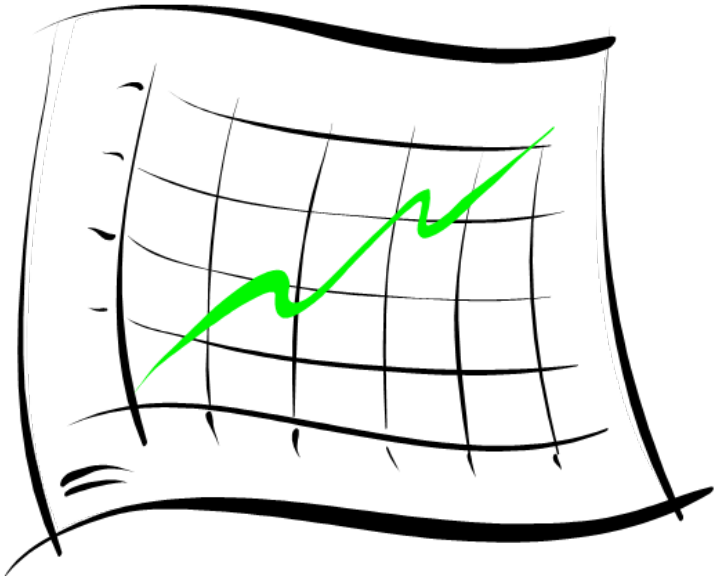
National Task Group on Intellectual Disabilities & Dementia Practices (NTG)

- 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.



Exception: 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

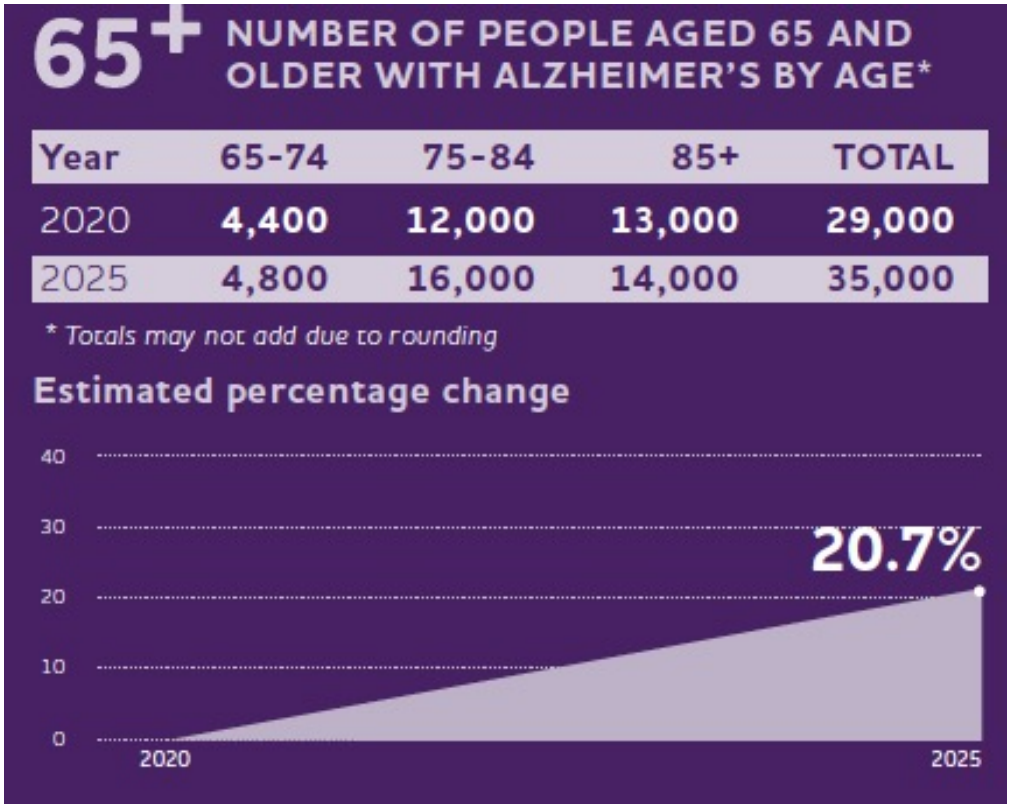
1 in 3 seniors dies with Alzheimer's or another dementia

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!

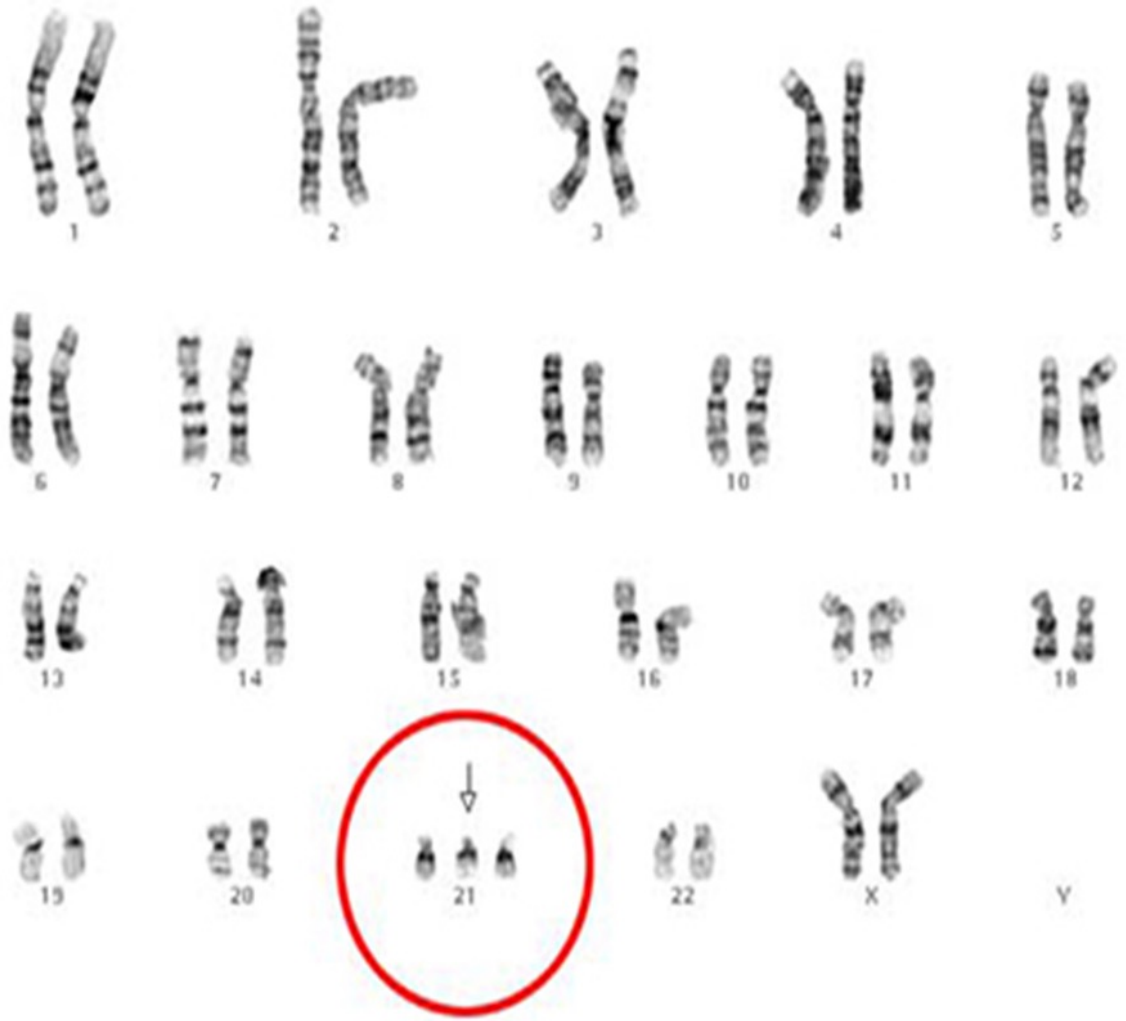
Hawaii figures do not include those who are undiagnosed

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

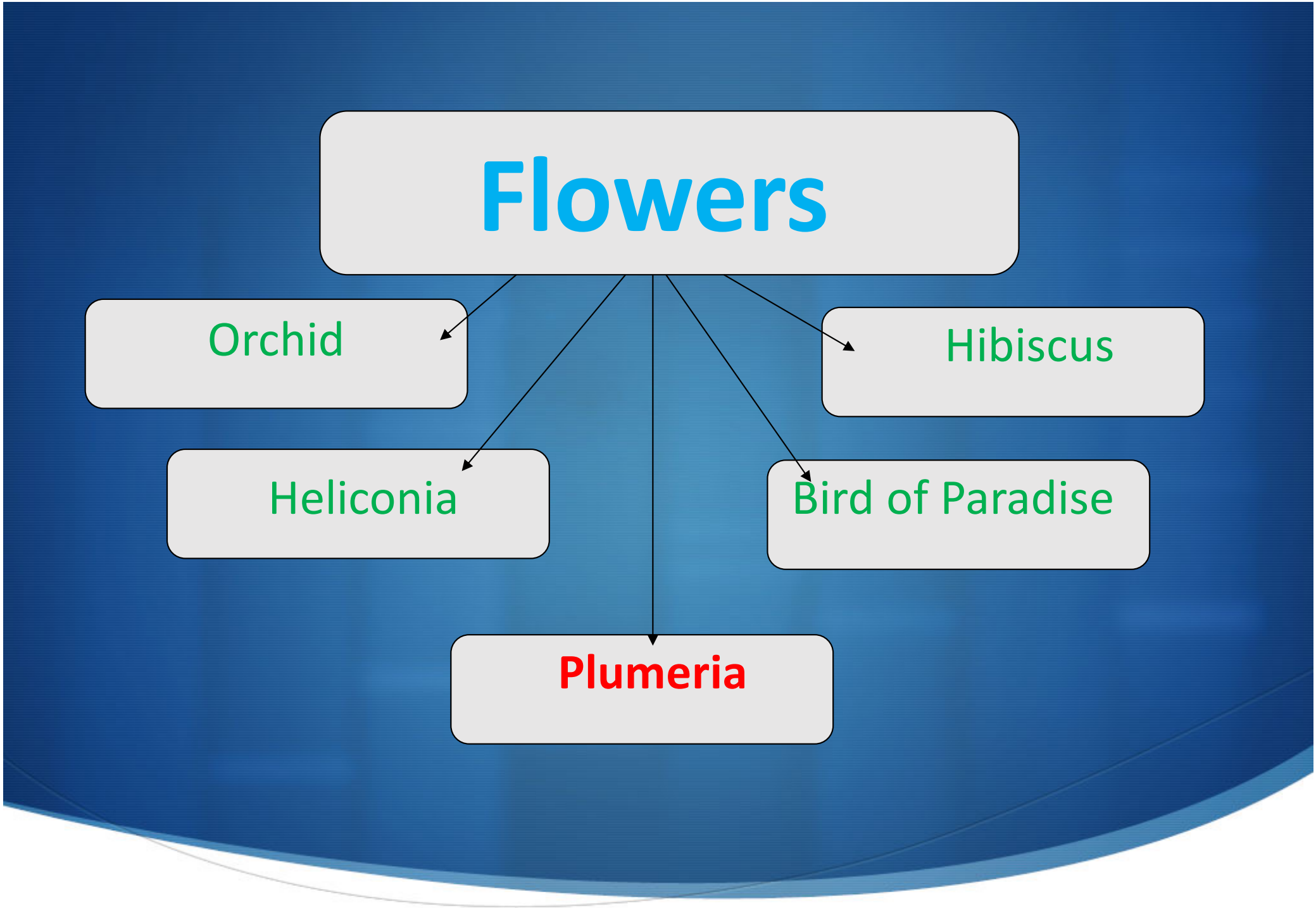
Down Syndrome



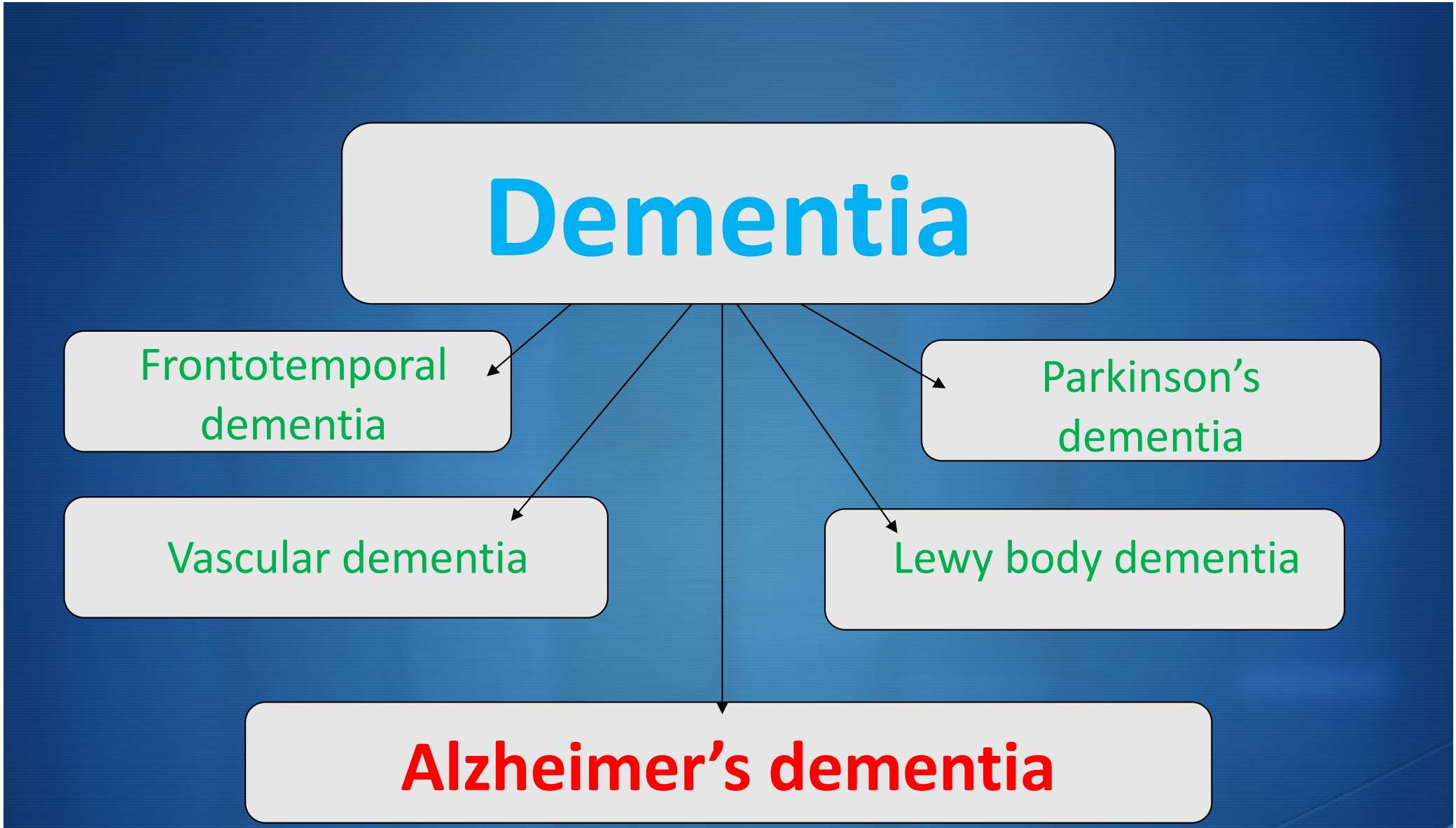
https://www.drbeen.com/blog/chromosome-abnormality-down-syndrome/

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.



Adapted slide courtesy Dr. Terry & Michelle Barclay, Minnesota ACT on Alzheimer's and The Barclay Group, LLC.



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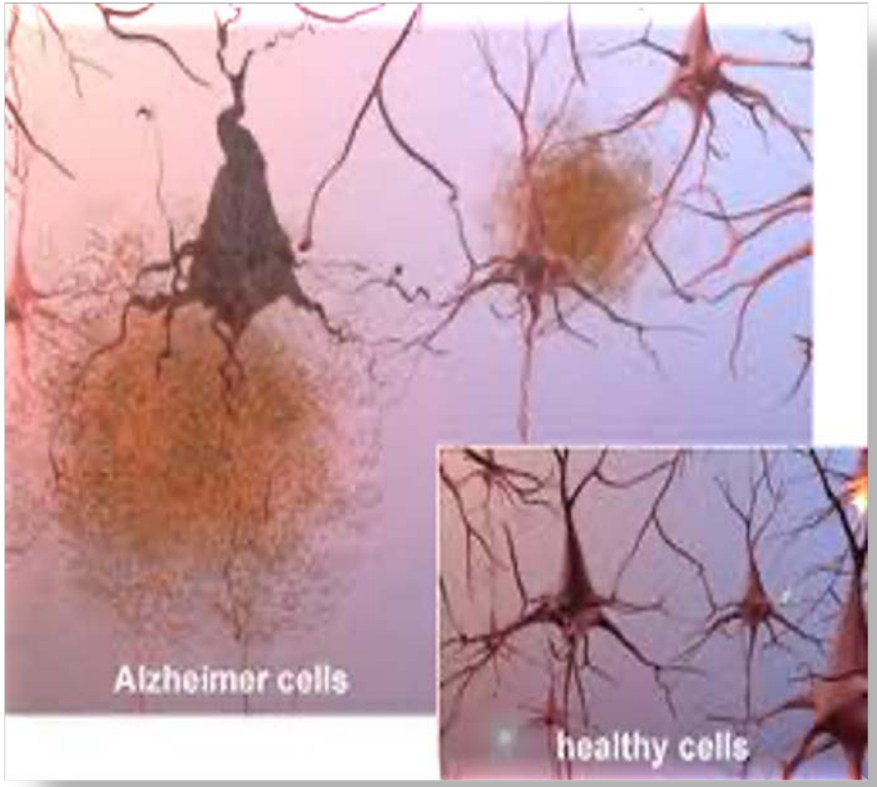
Alzheimer's Disease



- Most common form of dementia.
- Gradual onset.
- Short term memory.
- Generalized brain atrophy.
  - Shrinks by 30% by time of death.
- Amyloid plaques and neurofibrillary tangles.

Why a Focus on Alzheimer's?

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

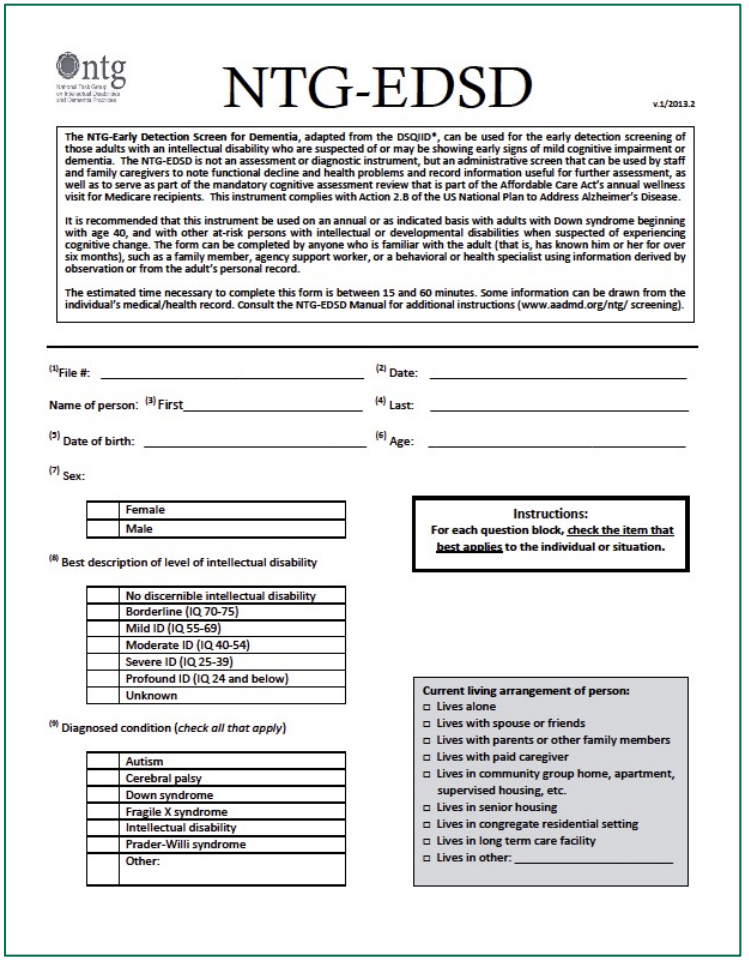
NTG Early Detection Screen for Dementia (EDSD)

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.



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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: _____

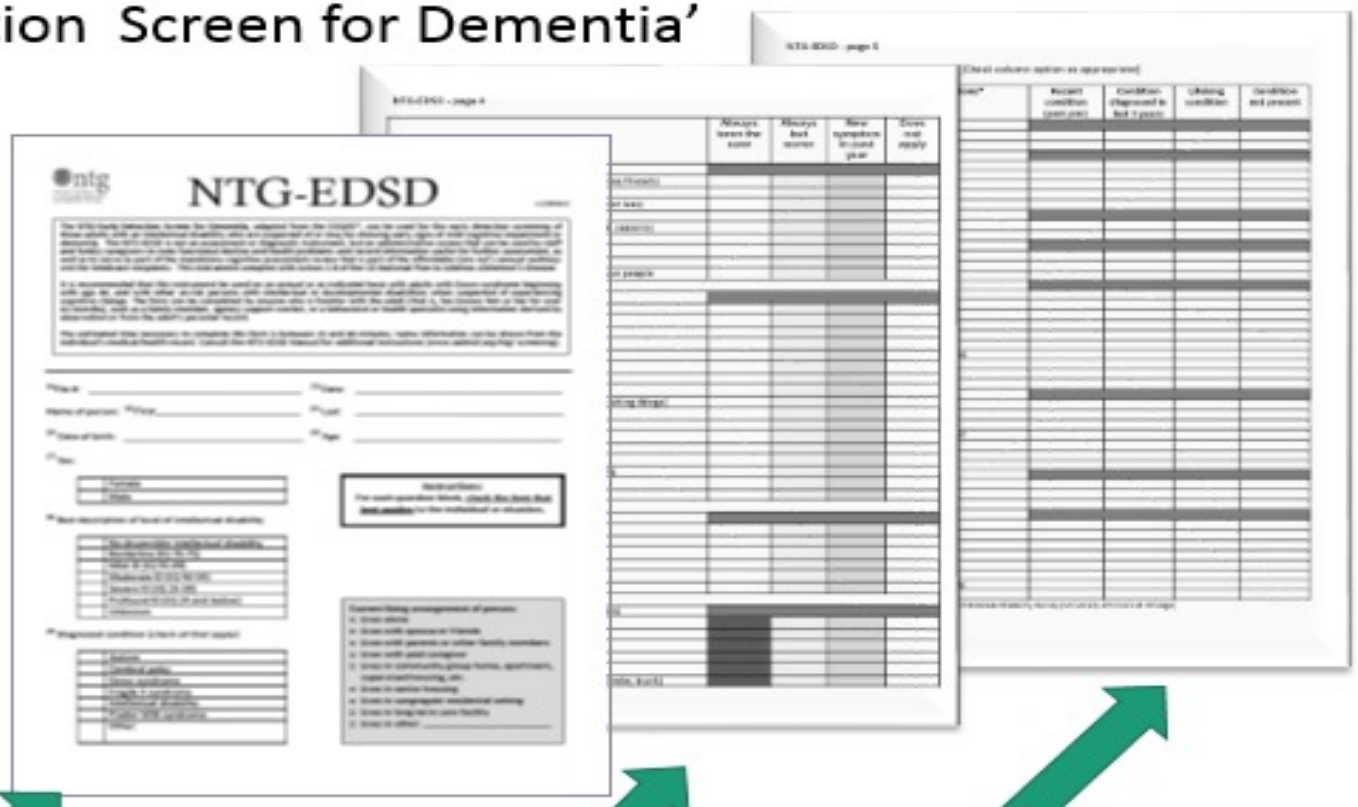
Tool & manual available online in multiple languages: https://www.the-ntg.org/ntg-edsd

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

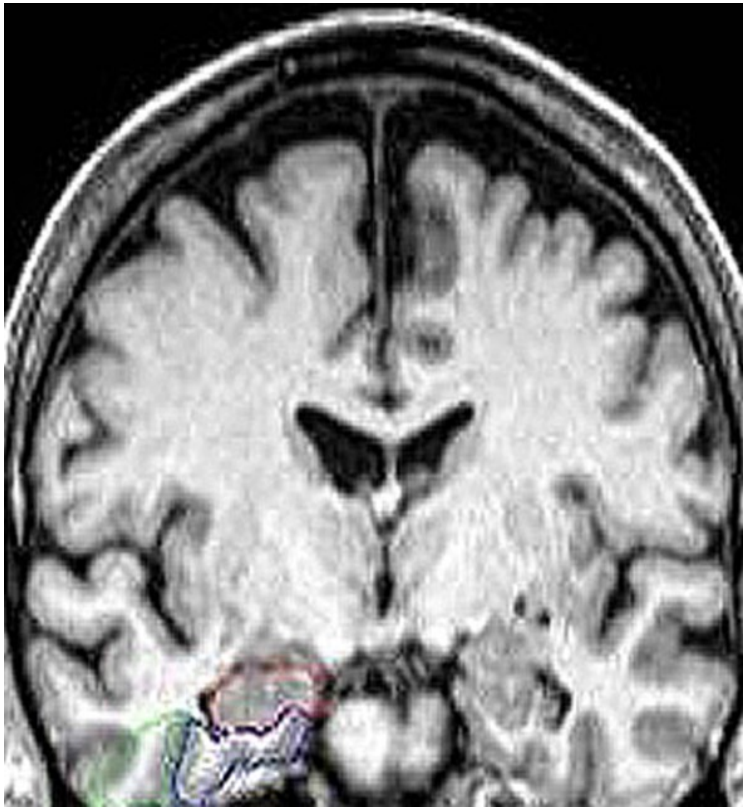
Delirium

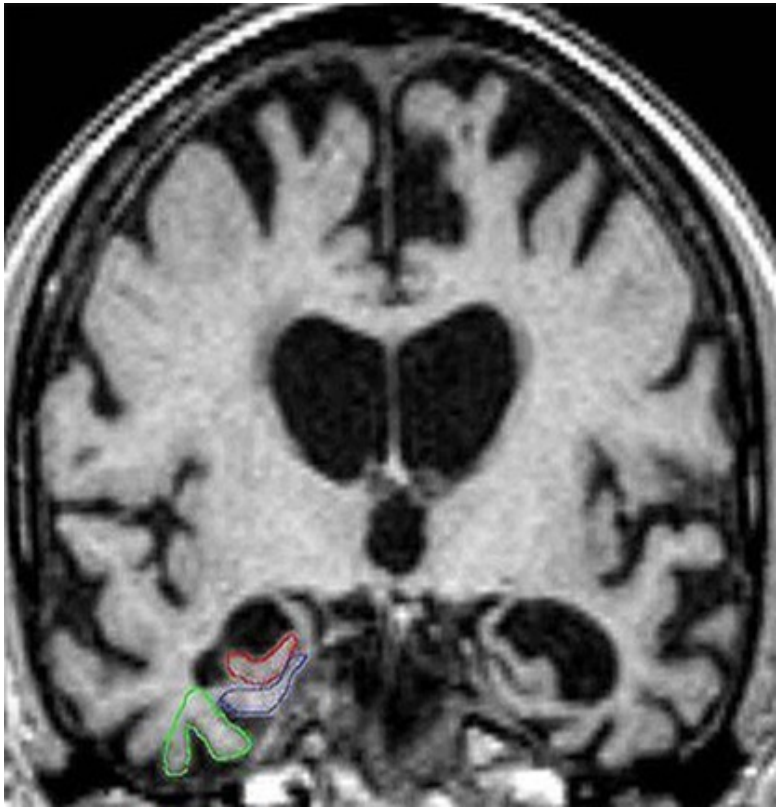
Sudden onset, hours to days

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.

Medications for cognitive decline in people with Down syndrome – Cochrane Review 2015

- **Reviewed 9 randomized clinical control trials to study:**
  - **donepezil**, a medicine used to treat Alzheimer's disease (four studies)
  - **memantine**, a medicine used to treat Alzheimer's disease (two studies)
  - **simvastatin**, a (statin) medicine used to prevent heart disease (one study)
  - **a mixture of antioxidants**, including forms of vitamins C and E, and alpha-lipoic acid (one study)
  - **acetyl-L-carnitine**, a dietary supplement that has previously been used to treat dementia (one study)

- **Generally, those who received the medicine did no better than those who received the placebo in any of the areas assessed in the studies.** The areas assessed included general functioning (including memory and thinking, speech, mood and behavior); cognitive functioning (including memory, following what's going on around you); adaptive behaviors (being able to do day-to-day tasks); or behavior problems (such as being irritable or aggressive).

- Overall, the **quality of the evidence for effectiveness is low**.

Livingstone N, Hanratty J, McShane R, Macdonald G. Pharmacological interventions for cognitive decline in people with Down syndrome. Cochrane Database of Systematic Reviews 2015, Issue 10. Art. No.: CD011546. DOI: 10.1002/14651858.CD011546.pub2

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

Four steps of health advocacy

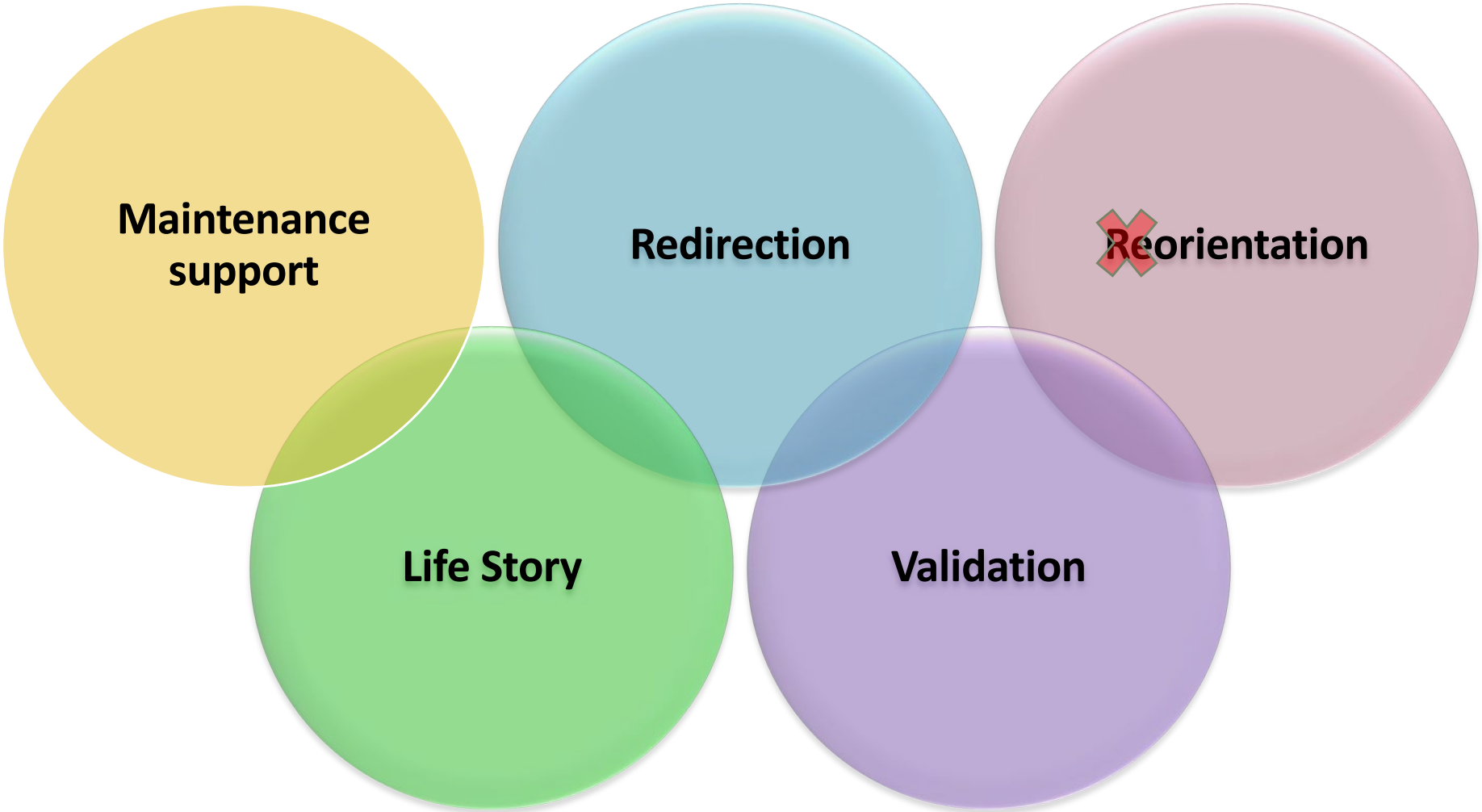
Why is Dementia Health Care Advocacy Needed?

- Helping to speak for an adult with dementia when his or her cognitive impairment becomes a barrier to self-advocacy.
- *Ageism* (prejudice or discrimination on the basis of a person's age) by health care providers.
- Assumption of automatic loss and decline as part of aging.
  - Untrue but commonly believed.
- Assumption that all changes are due to dementia.
  - Especially in persons with Down syndrome.
- "G*iving voice*" on behalf of those who cannot.

Caring for Someone with Dementia Requires a Shift in Thinking.

*Habilitation is the term used by dementia professionals to describe the non-medical interventions considered best practices in day-to-day care, in creating good environments for ADRD patients, and within all their relationships and activities.

Key Concepts in Dementia Care



Adapted from *Habilitation Therapy in Dementia Care*. Paul Raia, PhD. 2011.

Key Concept in Dementia Care #1

Maintenance Support

- Generally accepted as the **best practice** in dementia care.
- **Proactive** approach
  - A few minutes of pro-action can eliminate hours of reaction.
- Focus is on **support of remaining abilities**.
  - Respect changing needs of the person
  - Provide meaningful, failure-free activity.
  - Allow the person to do as much as they can for themselves but…be aware that as the disease progresses the need for assistance will increase.
- Can **reduce or eliminate difficult behaviors** at all stages by reducing frustration, boredom, anxiety, fear, etc.
- Can be done in **all settings by all staff**.

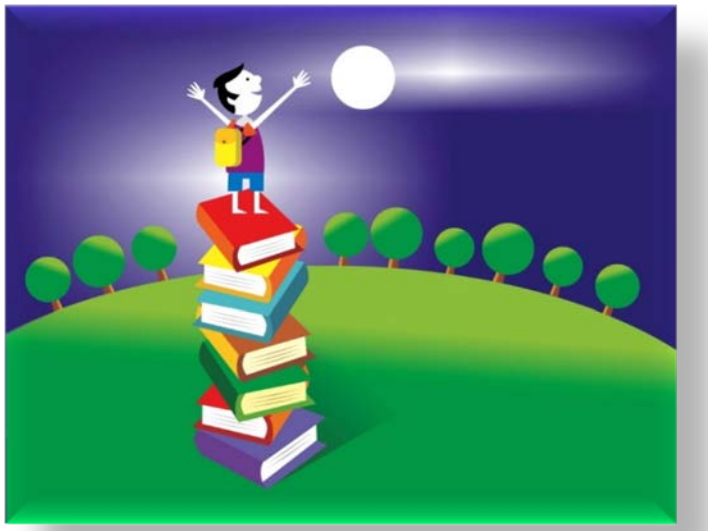
Focus on remaining abilities…
not the losses.

Key Concept in Dementia Care #2

Life Stories

Everyone has a life story that needs to be honored and respected.

- The story is the *essence* of each person and should be documented over the lifespan.
- When a person can no longer tell their own story, activities related to storytelling can still be used to inform caregiving and plan activities.



Key Concept in Dementia Care #3

Validation Approach

- Focuses on **empathy and understanding**.
- Based on the general principle of ***validation***…the acceptance of the reality and personal truth of a person's experience… no matter how confused.
- Can **reduce stress, agitation, and need for medication** to manage behavioral challenges.
- Forcing a person with dementia to accept aspects of reality that he or she cannot comprehend is cruel.
- Emotions have more validity then the logic that leads to them.

Example of Validation

John (agitated):
Someone stole my book.

You: "I'd be upset too, if that happened to me. I'll help you look for it."

Key Concept in Dementia Care #4

To Reorient or Not Reorient

- Best practice in dementia care: Do not correct or try to "reorient" the person.
- Requires staff to shift their care philosophy…

Example:

"What time is my mother coming?" (You know Ken's mother died 20 years ago.)

Which response is better:

a. *"Your mother is dead, Ken. Your sister will pick you up at 4:00."*

b. *"She'll be here in a little while. Let's get a dish of ice cream while we wait."*

Key Concept in Dementia Care #5
REDIRECTION

Distract AND Divert

- Distract and redirect to minimize or avoid outbursts and challenging behaviors.
    - Redirected with gentle distraction or by suggesting a desired activity.
        - Providing food, drink, or rest can be a redirection.
- Smile, use a reassuring tone.

Example: Distract & Divert

It's 4 am and raining. Harry wakes up and wants to go outside for a walk.

What should you do? Divert and Distract!

Your response:

"Sure, lets go for a walk. But before we go I need to have a snack. My favorite snack is ice cream. What's yours?"

- By refocusing their attention you can often redirect behavior.
- The goal is to distract the person long enough that their faulty memory will work to your advantage.

Behavior is Communication

Behaviors are often triggered by:

Caregiver Interaction

- Did I argue?
- Did I display frustration or impatience with the person?
- Did I order the person to do something, or not do something?

Pain

- Does the person have known medical conditions that can cause pain?
- PRN orders for pain medication = "**P**ain **R**elief **N**ever"
- Think broadly…kidney stones, gallbladder, heartburn, migraine, arthritis, fx from osteoporosis, earache, sinus infection

Frustration: Task Too Difficult

- Am I expecting the person to be able to do more than they can??
- Will be able to do fewer and fewer steps of a task as disease progresses
- Do I need to increase my level of support and supervision? Do I need to "set-up" the task or activity?
- Am I forgetting to only ask the person to do ONE step at a time?

Environment

- Is it too noisy? TV or radio on? People talking. Background noise?
- Is there too much visual motion? People moving, etc.
- Are there shadows or glare or reflections that could be misinterpreted?
- Does the behavior always occur in the same room, same time of day, etc.?

Dementia Communication 101

- Speak slowly and clearly.
- Use short familiar words and phrases.
- Give adequate time to respond.
- Ask one question or give one direction at a time.
- Break down complex tasks into simple tasks.
- Avoid arguing or correcting.
- When approaching a person come from the front and maintain good eye contact.
- Join – Validate – Distract.

Routine and Consistency

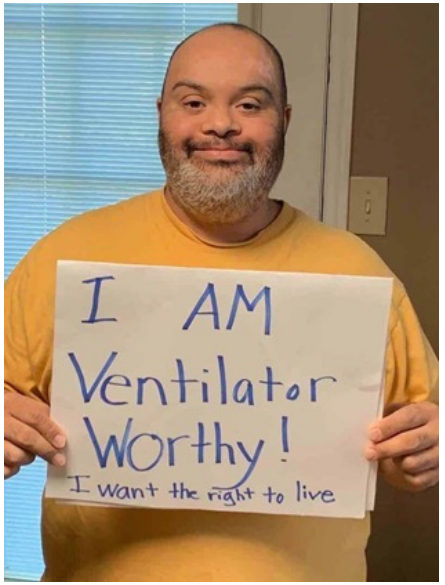
Established, consistent routines can be calming and reassuring, for both the person with dementia and those around them.

Structure the day

- Dining same time, same place, same setting as much as possible
- Community outings may become too challenging and need to be eliminated on any given day or time
- Plan activities ahead so everything is right there when needed
- Create quiet corners within residential and program areas with objects that are comforting and meaningful to the individual
- Provide fluids & healthy snacks in areas as behaviors may be the result of hunger and thirst

COVID-19

- Change of routine and habits
- Challenges of physical distancing, PPE
- Increased fear and confusion
- Visitation limitation – nursing homes, hospitals
- Testing issues
- Ethical dilemmas
- Grief and Loss



Adapt activities so they are "failure free."

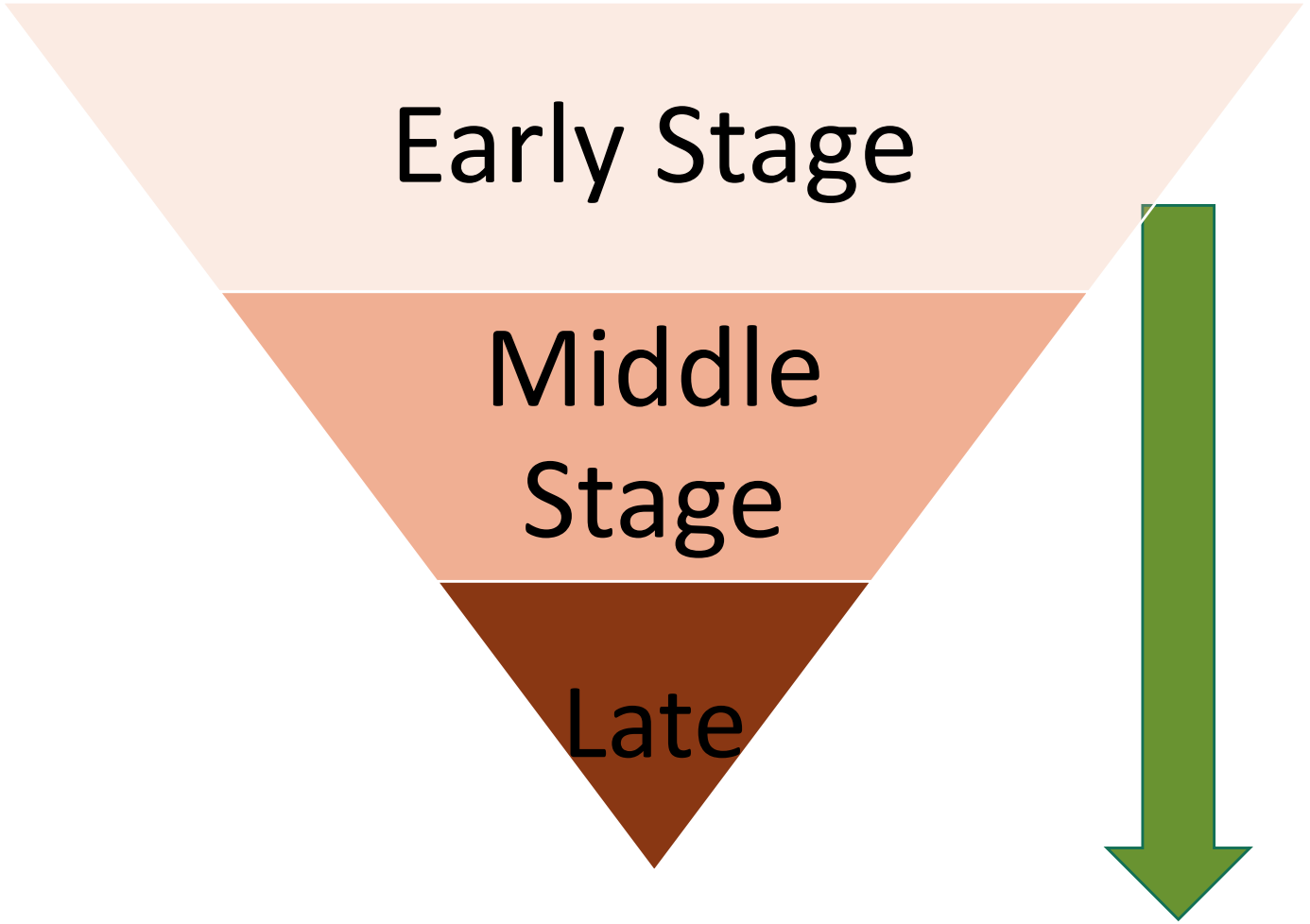
Adapt activities to suit the needs and capacity of the person.

Focus on simple activities which reinforce self-esteem while relieving boredom and frustration.

Emphasis is on remaining abilities, not losses.

Task

- Complex
- Simple steps
- Modified for increased impairment



Environment

- New or unfamiliar setting, change in routine
- Change in staff
- Noise
  - TV, radio, overhead paging system, people talking
- Lighting
  - People with dementia need 30% more light than we do.
  - Glare, shadows
- Large number of people
  - Over stimulating
- No orienting cues for way finding.
  - Bedroom, bathroom

Dementia, Environment, & Safety

Remove obstacles in pathways to prevent falls.

Create an environment supportive for the caregiver as well as the adult with ID and dementia.

Lock or disguise hazardous objects, areas.

Disguise doors for safe wandering.

Maximizing Location & Function

Environmental cues:

Ex. Pictures on door

Familiar textures for matching.

Ex. On the seat for meals.

Lighting.

Contrasting colors.

Reduce unnecessary stimuli.

Wandering: What can you do?

- Promote as exercise. Do not prevent the movement.
- Keeping the landmarks the same as much as possible.
- Create safe wandering spaces with opportunities for sitting, drinking water and juices, snacks.
- Disguise doors, locks, knobs of doors, use signaling devices when door is opened,
- Add meaningful activity within the wandering as much as possible:
  - Music
  - Dance
  - Rhythm

Wandering: What can you do?

- Alzheimer's Association Safe Return Program

www.medicalert.org/alz

Disrupted Sleep Wake Cycle

- Rule out pain, physical discomfort, medications, or other unmet need as cause.
- *Try*: Bright light therapy, short naps during day, keep room dark and quiet, use red or amber bulbs in night lights.

Dementia & Vision

Factors that may be affected by AD:

- Visual field reduced about 3 feet from the floor
- Depth perception
- Color contrasts
- Acuity
- Motion versus stationary objects
- Object identification
- Delayed recall to visual stimulation
- Figure-ground differentiation
- Size and shape
- Visual memory

Suggestions for Modifications

Reduce visual clutter.

Organize visual clutter into specific appropriate places.

Clearly identified walking paths.

Reduce glare.

- Use matted and low gloss surfaces.
- Floors with texture and not shiny surfaces.
- No-gloss waxes and cleaning products.

Hearing Challenges

- Hair cells in the ear receive the auditory stimuli, transmitted to the neurons of the brain, etc.
- Increased incidence of hearing loss with dementia.
  - One study reported 83% of people with early to mid-stage dementia.
- Continual noise pollution in our environments.
- Impairment in reception and response to stimuli.
- Impairment in comprehension (underlying cause?).
- May need examination to assess for ear wax.

Suggestions for Hearing Impairment

Reduce background noises (fans, radios, TVs, appliances).

Add soft materials such as carpeting whenever possible.

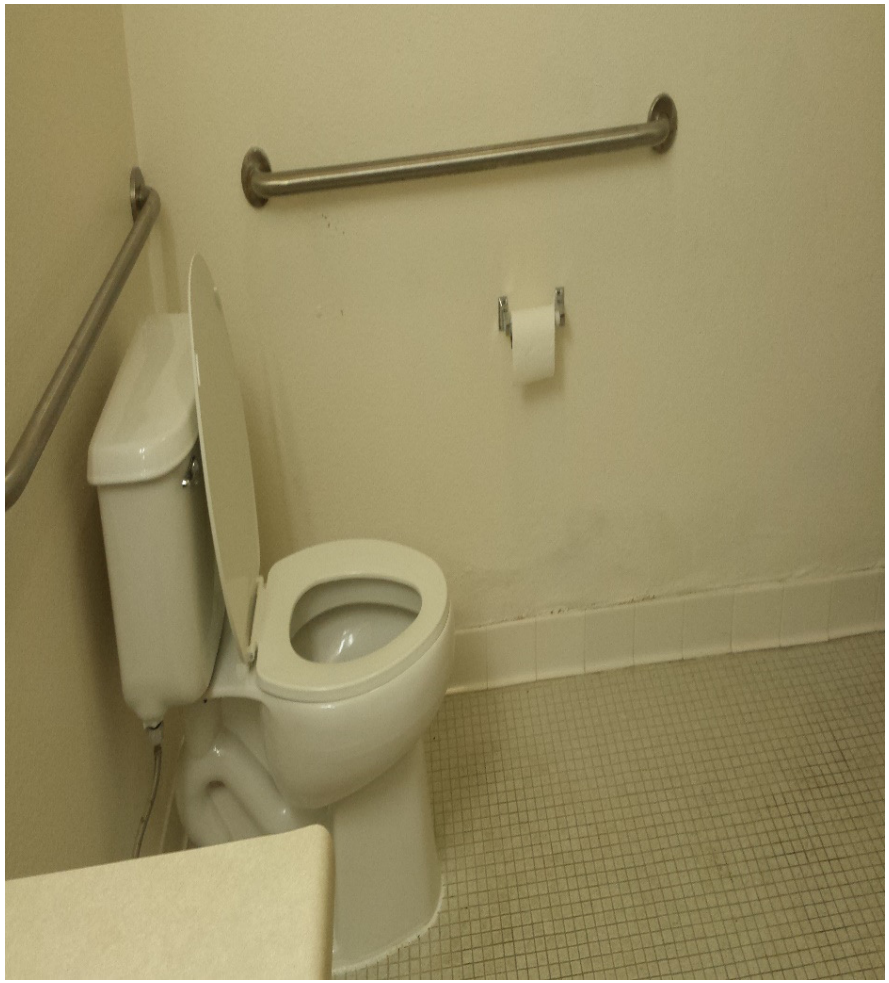
Visual and/or physical cueing along with auditory information.

Staff awareness:

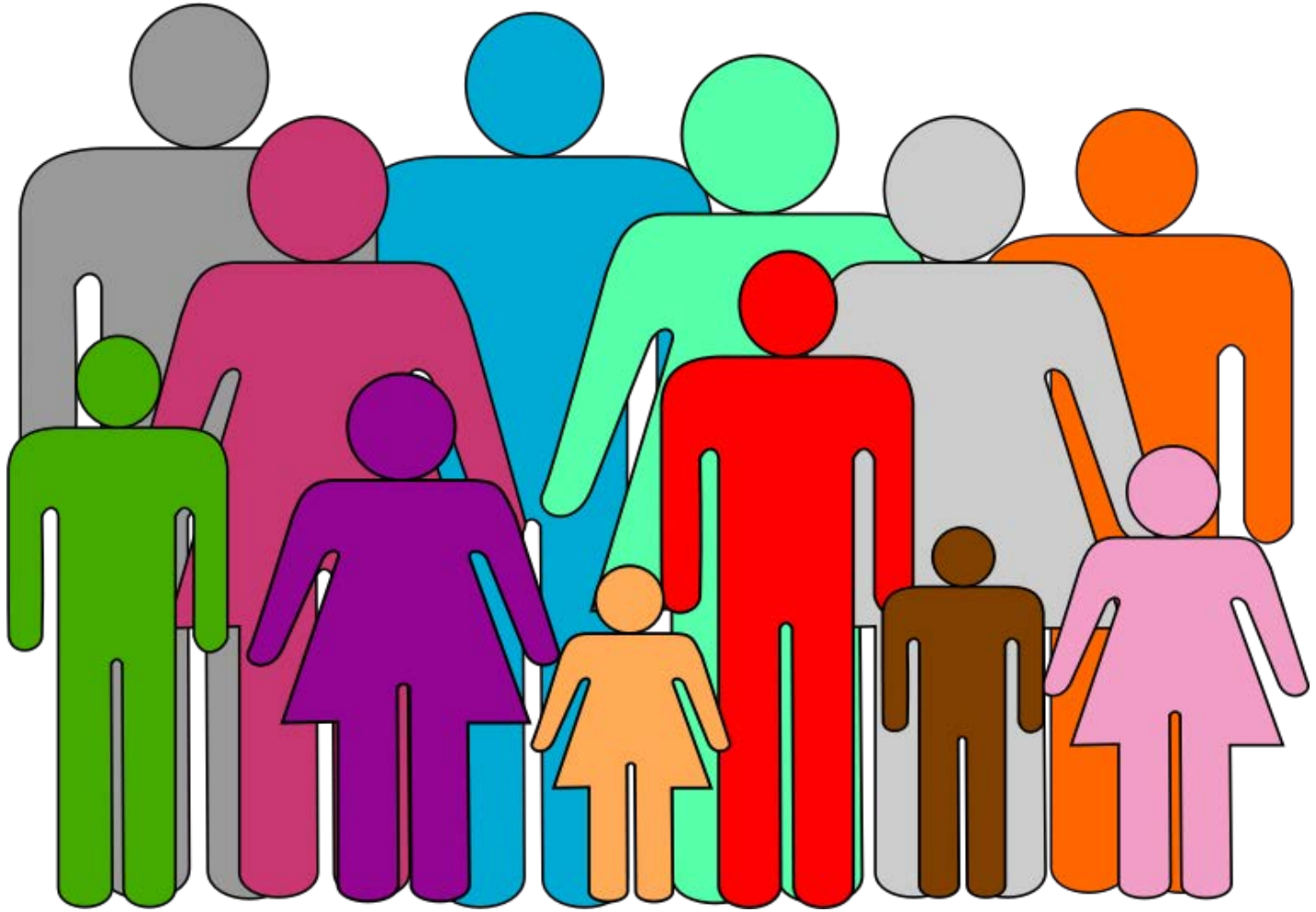
- Simple, short, one direction or piece of information at a time.
- Speak at eye level after gaining eye contact.
- Wait longer for the response than in the past.
- Hearing aid batteries are tiny and need to be replaced frequently.

Example of a Residence for Adults with ID

Lack of color contrasts, significant shadowing, and glare increase likelihood of difficulty functioning for the adult with ID and dementia.



Caregivers



Extent of Family Caregiving for People with ID (Braddock. 1999).

From the 1930s until the 1990s, the mean age at death for persons with ID rose from 18.5 years to 66.2 years.

- 75% live with a parent, spouse, or other family caregiver,
- 13% live alone, and
- Only 12% live in a residential facility.
- Approximately 25% of those caregivers are aged 60+ with 35% aged between 41 and 59.
- The projected population growth in the 65+ age group, due to the aging baby boomer generation, will significantly increase the number of aging caregivers in the years ahead.

Unique Challenges Caring for an Adult Child with ID (and Dementia)

General Population

Average period of time that a caregiver provides assistance to a spouse or older family member with a chronic illness:

4.5 years

Parents with Child with ID

Caregiving can last for 60 years or more.

For a vast majority of family caregivers…

lifelong career

(National Alliance for Caregiving & AARP, 1997).

ID & Dementia: A Special Risk

Aging caregivers for people with ID may be at special risk because of:

- age-related health and behavioral declines in the aging care recipient and caregiver,
- extensive duration of the caregiving role, and
- concerns about the long-term care of the care recipient
  - Who will care for their child if/when they die?
  - How will they pay for care?
  - Who will provide it?

Connect to Resources

- **Alzheimer's Association**
  - 24/7 Helpline | **800.272.3900** www.alz.org/hawaii

- **Hawaii Aging & Disability Resource Center (ADRC)**
- **643-ADRC (2372)** | TTY line: 643-0889
- www.hawaiiadrc.org

End-Of-Life Care

- Hospice Criteria

Advanced Dementia evidenced by functional decline, weight loss, infections

- Hospice Providers
https://kokuamau.org/hospice-providers/

- Resources

https://kokuamau.org/kokua-mau-resources/advanced-dementia-resources-and-issues/

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!

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