

Aging Well with Disabilities: Strategies for Brain Health Throughout the Lifespan



Redwood Coast Regional Center



National Task Group
on Intellectual Disabilities
and Dementia Practices

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Presentation Objectives:

- Consider research, best practice and policies that can guide us in establishing healthy habits for brain health as individuals age with disabilities.
- What do we know about the trajectory of healthy brain aging for persons with IDD?
- What are some considerations about aging with a disability and with dementia including a review of the ***NTG-EDSD***.

According to the World Health Organization (WHO)

- Across the life course, people can improve their own health and well-being by learning about their health and well-being and making informed choices such as being more physically active, improving nutrition, avoiding tobacco, limiting alcohol and being aware of and claiming their rights...They can care for others and the environment and help promote health and well-being in their families, communities, places of education, work and leisure.
- Promoting health through the life course:

www.who.int/life-course WHO, 2019



The Good News...



- Although we do not have a cure for aging related cognitive decline, there is a great deal that we can do to reduce risk of that decline
- Many of the health conditions and lifestyle choices that put us most at risk for poor health and cognitive and functional decline as we age, are modifiable
- Healthy aging = cognitive health
- The same things we can do for persons without disability, we can do for persons with disabilities

Aging is a Lifelong Process

- Aging begins at birth...
- The quality of older adulthood for individuals with disabilities will be influenced by the quality of their childhood, early and middle adulthood
- Begin healthy lifestyle choices as early as possible
- Regular and routine healthcare
- Attention to exercise, nutrition, stress level, relationships, meaningful activity
- Attention to chronic medical conditions which will impact the overall health of the older adults with disabilities

Factors that can affect Brain Health

- Genetic make-up
- Certain medicines, smoking or excessive alcohol intake
- Diabetes and heart disease
- Depression
- Brain injury
- Poor diet, insufficient sleep, lack of physical activity, lack of social and mental stimulation

Modifying Risk Factors

- Treating co-morbidities
- Lifestyle choices



Life Expectancy for People with Intellectual Disability

- ✓ Improved access to and treatment of associated physical conditions (e.g. heart defects, epilepsy and status epilepticus).
- ✓ Use of antibiotics (recurrent infections).
- ✓ Development of proactive, holistic and individualized care philosophies within community settings, and decline in large scale institutionalized generic care.
- ✓ Encouragement and supports that provide the opportunity to age in place within the family home.

Aging and Disability

- Older people with intellectual and developmental disabilities have the same needs as other older people
- The increasing life expectancy of people with intellectual disability is now an established fact
- Older people with intellectual disabilities are subject to compound stigmatization for being both **older** and **disabled**
- Many adults with intellectual and other developmental disabilities remain at home with their families

Expected Physical Changes of Aging

- Age-related bone loss
- Progressive loss of muscle mass
- The lens of the eye becomes stiffer and less flexible – affecting the ability to focus on close objects (accommodation)
- Age related change in the ability to detect higher pitches – more noticeable in those age 50+
- Changes in the sense of taste 60+
- Olfaction (i.e. the sense of smell), decrements become more noticeable after age 70+
- Reduction in sensitivity to pain, touch, temperature, proprioception
- Reduction in balance and coordination
- Reduction in short term memory loss, attention, and, retrieval

Maintaining Health

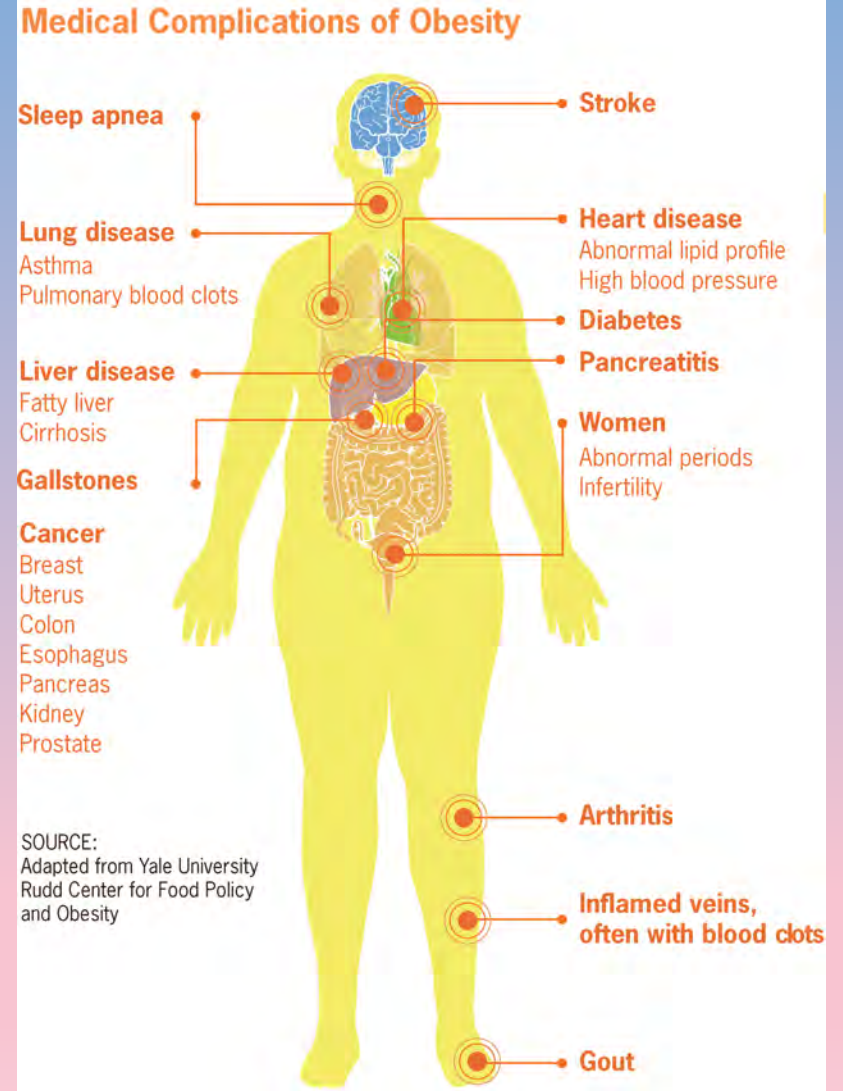


Diabetes

- **Preventing or controlling diabetes:** Type 2 diabetes (and possibly even prediabetes) increases the risk of cognitive decline and dementia, probably because it damages blood vessels, including those in the brain.
- Healthy eating, regular exercise and staying within normal weight range for your age and height all help in prevention of diabetes or better control of diabetes if someone is already diagnosed with this disease
- If blood sugar stays high, medication is needed in order to maintain good control

Obesity

- **Weight control:** Obesity, especially concentrating excess fat in the abdomen, has been linked to increased dementia risk.
- Obesity often goes along with other dementia risk factors—such as diabetes, hypertension, and physical inactivity

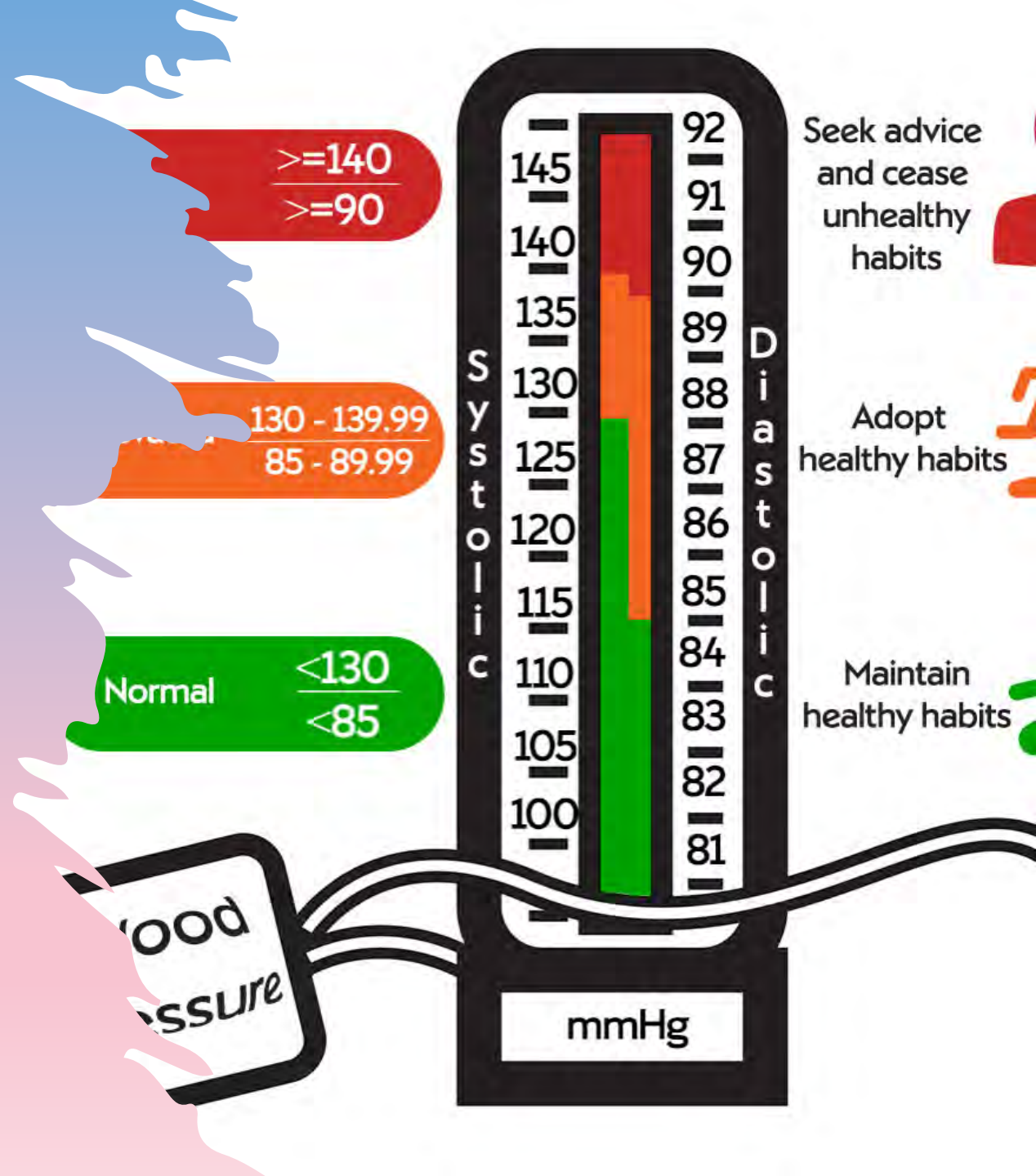


Controlling Blood Pressure

- Heart health is brain health
- Brain health is linked to the health of blood vessels that supply the brain. High blood pressure is the most important risk factor for brain blood vessel disease.
- High blood pressure has been associated with stroke, diffuse white matter disease and silent stroke on MRI brain images and brain examination at autopsy. These in turn have been linked to cognitive decline and dementia. For many reasons treating high blood pressure and keeping it under control is good for the brain!

Improve Blood Pressure

- High blood pressure in middle age increases the risk of cognitive decline as one ages
- There are ways to keep blood pressure low, including: keeping weight down, being physically active, limiting alcohol consumption to no more than two drinks per day, finding ways to reduce stress and following a low salt, low fat diet



Additional Risk Factors

- Tobacco
- Excessive alcohol consumption
 - Excessive drinking is a major risk factor for poor brain health. Drinking should be limited to no more than 2 a day/12 a week and possibly less for females
 - Alcohol affects the brain by slowing communication among brain cells



Depression and Aging with a Disability

- Older adults are at higher risk for depression. Depression is a treatable medical condition that often goes untreated because:
 - ✓ People think depression is a normal part of aging (it is not!)
 - ✓ Some people are ashamed to admit they are depressed because they see it as a sign of weakness or a character flaw
 - ✓ Older people report more physical symptoms of depression such as difficulty sleeping and loss of appetite than younger adults
 - ✓ When older adults lose their social supports and become isolated, they may be less likely to independently seek help

The 3D's: the importance of monitoring observed decline

- Several conditions, other than dementia, are associated with cognitive decline and may mimic dementia
- It is important, when possible, to rule out other sources of cognitive and functional decline and not assume that observed changes signal dementia
- We want to differentiate among the **3 D's: dementia, delirium and depression** (previously called "pseudodementia")
- Other conditions may alter mental status including psychiatric illness, sensory impairment, and exposure to extreme stressors
- **Spoiler alert!** More to say about this, later, when reviewing the **NTG-EDSD**

Delirium

- Delirium is a reversible, confusional state, or a mental disturbance characterized by acute onset, disturbed consciousness, impaired cognition; it is usually traceable to an identifiable underlying medical cause (i.e. medications, infections, sleep disturbance, electrolyte imbalance, etc.)
- Given the high co-occurrence of medical problems among people with disabilities, delirium can be a problem at any age
- Delirium is considered a medical emergency: the person who is delirious needs his/her underlying medical condition identified and treated
- Delirium is sometimes mistaken for dementia (which does not have an acute onset); when left untreated, delirium can lead to long-term changes in adaptive and cognitive functioning

Depression: “SIG-E-CAPS”

- □ **Sleep** disturbance (insomnia or hypersomnia)
- □ **Interests** (anhedonia or loss of interest in usually pleasurable activities)
- □ **Guilt** and/or low self-esteem
- □ **Energy** (loss of energy, low energy, or fatigue)
- **Concentration** (poor concentration, forgetfulness)
- □ **Appetite** changes (loss of appetite or increased appetite)
- **Psychomotor** changes (agitation or slowing/retardation)
- □ **Suicide** (morbid or suicidal ideation)

Prevent Falls

- Falls can cause a head injury, broken bones, or other harm that triggers gradual or sudden loss of function.
- To avoid falling, practice balance and strength exercises. Beware that drinking and drugs can affect balance. And be careful: watch for uneven walking surfaces and cords that can trip you. Wear shoes or slippers with good soles. Avoid going barefoot or walking in stocking feet. If you bike or ski, wear a helmet.

Easy Home Modifications TO PREVENT FALLS



Install Handrails
along indoor and outdoor staircases, hallways, and anywhere you feel you need a little extra support.

Use nonslip mats and treads
to help improve traction on bathroom floors, shower, bathtub, outside decks, and outside steps.

Install grab bars
near showers, bathtubs, and toilets. Avoid grab bars that "stick on" to shower tiles with suction, which are less reliable than metal grab bars attached to wall studs.

Repair steps and flooring.
Repair crumbling outdoor steps, loose wall-to-wall carpeting, and uneven floorboards. Call a handyman to repair stairs or floorboards, or a carpet store to come and tighten wall-to-wall carpeting.

Inexpensive fixes.
Remove all floor clutter. Rearrange furniture so that it works well with the flow of traffic. Use double-sided tape to secure the edges of area rugs to the floor, and remove small throw rugs.

Improve lighting.
Make sure you have adequate lighting in hallways, stairways, and outdoor walkways, and areas in which you're likely to walk in the middle of the night.

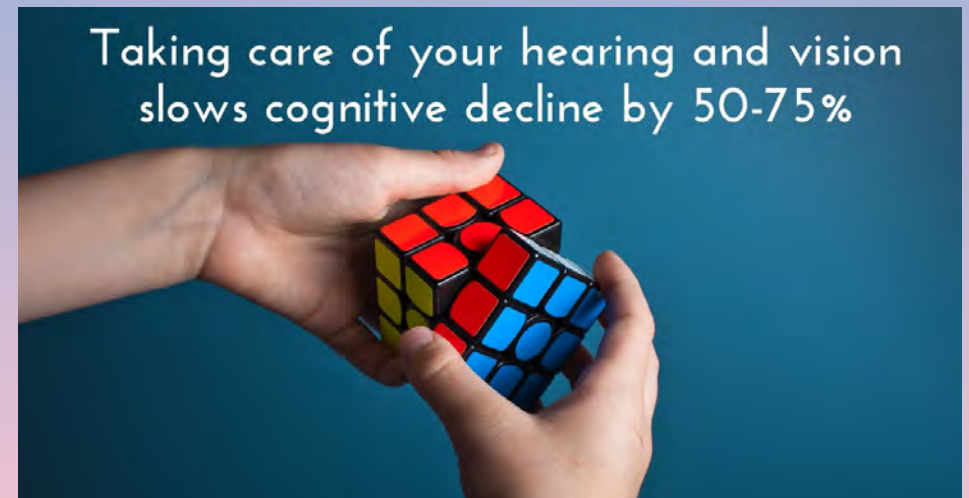
Falls are the leading cause of injuries among older adults, sending more than two million people to the emergency department each year.

Many of the fall hazards are right in our own homes, and a few inexpensive changes could lower your fall-risk.

For other strategies and tips to avoid falls, check out "**Preventing Falls,**" the online guide from Harvard Medical School.
www.health.harvard.edu/fall

Sensory input

- **Maintaining good hearing and vision**, by correcting or treating losses when possible. Poor hearing or vision reduces older adults' ability to participate in stimulating activities and can lead to social isolation





- Communication between people with disabilities and primary care providers is essential to maintaining good health
- See a primary care physician regularly

Work with your PCP

Ask Questions



- Know about medications or alternative treatments
- Review and act on health check-ups and health screenings
- Monitor existing and/or new symptoms
- Speak up about any concerns or doubts

Health Maintenance

- Wellness check-up
- Immunizations
- Age and gender relevant health screenings:
 - ❖ diabetes
 - ❖ cholesterol,
 - ❖ Cervical and breast cancer screening for females; prostate exams for males
 - ❖ Colorectal cancer
 - ❖ osteoporosis
 - ❖ depression and suicide risk
 - ❖ cognitive screening for adults 50+

Ten Health Risks That Impact Wellness

- Tobacco usage
- High Blood Pressure
- Stressful living
- Lack of physical activity
- Overweight/obesity
- Poor diet
- Home safety
- Lack of personal care
- Speeding
- Not wearing a seat belt or personal safety gear

Ten “Healthy” Habits

1. Stop tobacco usage
2. Reduce blood pressure
3. Manage stress
4. Exercise in moderation
5. Maintain a healthy weight
6. Eat a well-balanced diet
7. Check smoke detectors
8. Participate in cancer self-exams and age appropriate screenings
9. Drive within 5 miles per hour of the speed limit
10. Wear a seat belts in cars and helmets on bicycles/motorbikes

Exercise and Physical Activity

- Research has consistently found that staying physically active is a key to preserving brain function. Aerobic exercise seems especially beneficial, and some studies suggest that strength training can also help.



Physical Activity

- <https://www.hhs.gov/fitness/be-active/physical-activity-guidelines-for-americans/index.html>
- Preschool-aged children (3-5) should be physically active throughout the day
- Children and adolescents (6-17) should do 60 minutes or more of moderate-to-vigorous physical activity, daily including aerobic, muscle strengthening and bone-strengthening activity as part of that 1 hour at least 3 times a week
- Adults should move more than sit throughout the day; 2 ½ to 5 hours a week of moderate intensity activity including muscle strengthening

Physical Activity ***(cont'd)***

- When older adults cannot be active for 2 ½ hours a week of moderate-intensity aerobic activity because of chronic conditions, they should be as physically active as their abilities and condition allow
- Adults with chronic conditions or disabilities should do muscle-strengthening
- When adults with chronic conditions or disabilities are not able to engage in regular exercise, they should engage in physical activity according to their abilities and should avoid inactivity



Never Too Late to Start Exercising!

Exercise is a great way to improve health, physical functioning and well-being. Among the reported benefits:

- improved strength and mobility
- improved balance which can help prevent falls
- improved mood, decreased fatigue, lowered blood pressure and cholesterol
- improved self-esteem
- increased clarity of thinking
- Physical Activity can improve sleep, prevent weight gain and improve bowel and bladder function

Sleep



Sleep

- Children vary in their sleep needs according to age
- Adult should have 7-9 hours of sleep per night
- Sleep is a vital indicator of overall health and well-being. We spend up to one-third of our lives asleep, and the overall state of our "sleep health" remains an essential question throughout our lifespan.
- <https://www.sleepfoundation.org/>

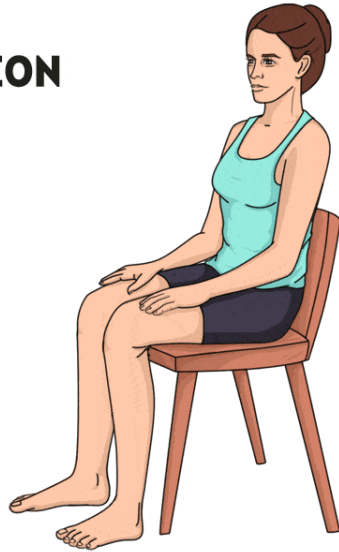


Sleep

- Sleep changes occur naturally after age 60. Shifts in hormone and melatonin levels may cause us to take longer to fall asleep, sleep more lightly, and wake up more often during the night
- Lack of sleep is not to be taken lightly: It depresses our immune systems, affects our daily activities, increases confusion, affects our mood and concentration, and may lead to falls. It's vital to good health as good nutrition, regular exercise, and a positive attitude. So if someone is not sleeping soundly, that person should consult his/her doctor.
- Develop a more consistent sleep routine:
 - Go to bed at the same time every night; awake at the same time every morning
 - Fall asleep in the same position
 - Have a cup of warm milk or herbal tea before bedtime
 - Try a warm soak in the tub
- Address snoring issues

ZZZs (cont'd)

PROGRESSIVE MUSCLE RELAXATION



Top10
Home Remedies

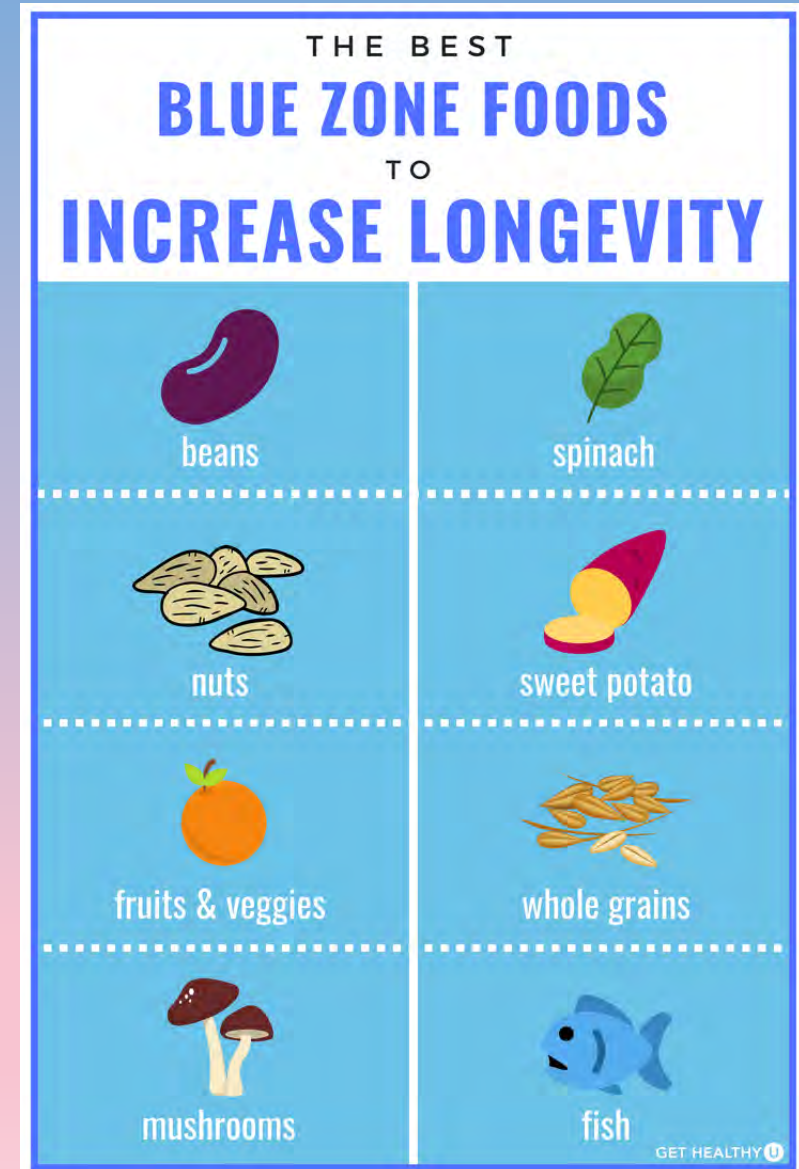
- If snoring is serious it may mean that breathing is interrupted; consider whether sleep apnea might be the cause of sleep problems and talk with a doctor. A C-Pap machine may change the client's life for the better.
- Try to avoid late night stimulating activities such as eating (especially spicy foods), watching TV, or lively debates with family or friends. Some quiet music or a little reading are better bedtime choices. Try progressive muscle relaxation—systematically tensing and then relaxing all the muscle groups of your body. It's been known to help with insomnia..
- Skip afternoon naps

Common Denominators within the “Blue Zone” (places known for healthy brain aging)

- Move naturally, such as walking, gardening
- Purpose for waking up each day
- Routines to deal with stress
- Stop eating when 80% full and eat smallest meal at end of day
- Diet includes beans (fava, black, soy and lentil)
- Drink wine moderately
- Belong to a faith-based community
- Put families first
- Belong to social circles that support healthy behaviors

Food Eaten in the “Blue Zones”

- Follow the 95:5 rule—eat mostly plants
- Eat small portions of meat
- Moderate fish because of pesticides
- Avoid cow’s milk
- Eat a cup of beans daily
- Limit sugar; use honey
- Eat a handful of nuts daily
- Eat only 100% whole-grain breads
- Eat whole foods or ones with fewer than five ingredients
- Drink mostly water

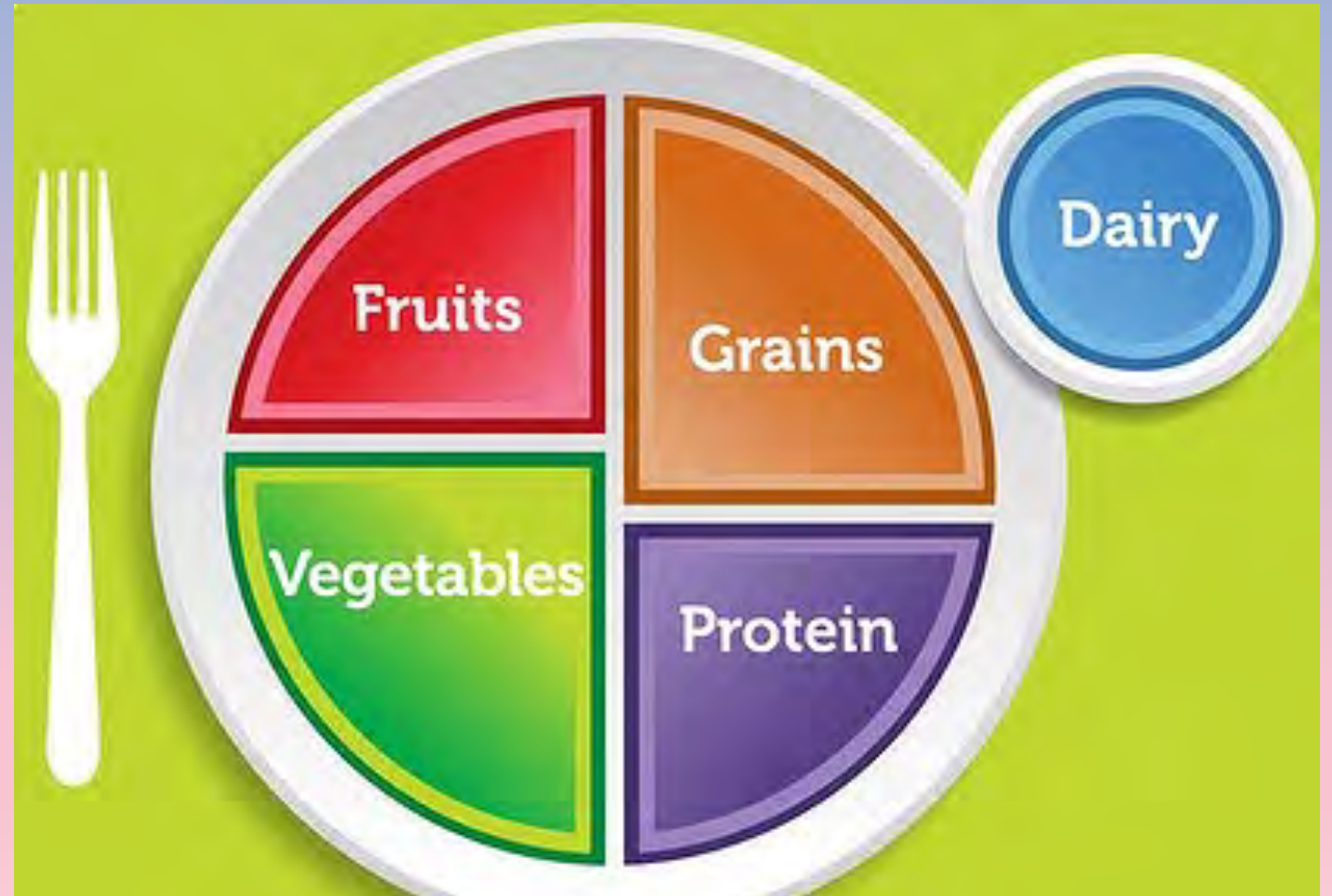


MIND- Mediterranean Intervention for Neurodegenerative Delay (DASH)

- Dark chocolate (with at least 85% cocoa)
- Turmeric
- Kale
- Sweet potatoes
- Berries (blackberry, blueberry, cranberry, raspberry, strawberry)
- Garbanzo beans
- Walnuts
- Fish with omega-3 fatty acids (mackerel, lake trout, herring, wild salmon)
- Red wine
- Green tea

Overall Recommendations for Healthy Diet

- Eat more fruits and vegetables
- Choose whole grains
- Consume legumes and nuts
- Limit sodium, sugar and saturated fats
- Limit fast food
- Cook your own meals
- Learn to read ingredient labels on cans and packaging



Healthier Food and Beverage Choices

- *Shift* from whole milk to low-fat milk for your breakfast cereal
- *Shift* from soda with added sugars to water during lunch
- *Shift* from a cream-based pasta dish to one with a lighter sauce and more vegetables for dinner
- Healthy eating can prevent chronic diseases like obesity, heart disease, high blood pressure and Type 2 diabetes
- *You can make small changes to the way you eat with the result that you will have healthier outcomes*





Try Out these Shifts

- White Bread to Whole- Wheat
- Fatty cut of meat to Seafood or beans
- Ice Cream to homemade fruit smoothies
- Potato chips to unsalted nuts
- Butter to olive oil

[ChooseMyPlate.gov](https://www.choosemyplate.gov)

Mental Stimulation

- **Mental activity and lifelong learning.** Staying mentally active can enrich your life, reduce boredom, and confer a sense of purpose and accomplishment—all good for cognitive health.
- Mental stimulation does not have to be in a classroom/academic setting. You can learn a new hobby, do puzzles, watch an educational television show, learn to play an instrument, learn to sing a new song, learn how to cook a new recipe



Social Connection

- **Staying socially active.** Social activity, and the interpersonal exchanges can help counter depression and help people maintain cognitive abilities
- Connect with family, friends and communities



Learn ways of handling stress

- Hormones secreted when you're under stress have a stronger effect on older brains, challenging your ability to recover from emotional upset. So take change slowly and learn ways to cope with anxiety or tension.



Developing Healthy Habits

- It takes at least 6 weeks to develop a new habit
- Track your behavior and identify patterns (on-track and off-track with your goals)
- Visualize your future goals to offset the tendency for “delay discounting”
- Delay discounting= tendency to undervalue long-term benefits in favor of smaller, immediate rewards
- Have someone to whom you are accountable for change in habits
- Remember, motivation can vary so don't rely on it for habit change



**KEEP
CALM
AND
STAY
ON TRACK**

How Do We Develop and Maintain Healthy Habits?

- Look at your current patterns of behavior and what triggers unhealthy habits (**awareness**)
- Make a **plan** that includes small reasonable steps
- Make your healthy choices the **easy** choices
- Identify what you need to be **successful**
- Get **friends and loved ones** involved
- Plan for **obstacles** including when you are stressed, fatigued, lack motivation to continue healthy lifestyle choices or are tempted by old habits



Where to Start ?

Positively Impact Brain Health.

Start with one
small step in the
right direction:

Schedule a
health
screening or
physical exam

Review your
medicines with
your health
care provider

Add one daily
serving of
vegetables to
your diet

Start a food,
activity, or
health journal

Find your
community
center's activity
schedule

The 3D's

- Several conditions other than dementia are associated with cognitive decline; they may mimic dementia
- It is important , when possible, to rule out other sources of cognitive and functional decline
- In particular we want to differentiate among the **3 D's: dementia, delirium and depression** (previously called “pseudodementia”)
- Other conditions may alter mental status including psychiatric illness, sensory impairment, and exposure to stressors

Cognitive changes of Aging with Disabilities which deserve attention

- Memory problems that interfere with everyday functioning
- Problems in orientation to time, place or person (presuming that the person was previously oriented in these spheres)
- Slowing down in movement, thinking and processing information
- A coarsening of social behavior
- Increased impulsivity
- Difficulty with new learning
- Change in ability to communicate (impoverishment of communication)
- Problem pursuing well-learned routines and activities
- Confusion in familiar places

Dementia and IDD vs. dementia in the general population?

- Neurocognitive disorder is brain disease that affects all domains of functioning cognitive, social, behavioral and adaptive regardless of whether the person is classified as intellectually disabled or has been neurotypical:
- **Cognitive skills** like memory, attention, problem solving, perception and language
- **Social skills** such as understanding behavior and emotional and
- **Behavioral skills** such as self-control appropriate to setting and situation
- **Adaptive Skills** like the ability to walk, dress, toilet and feed oneself
- Individuals with pre-existing cognitive deficits (IDD) are more likely to display early onset dementia
- Individuals with Down Syndrome are at particular risk

Brain changes occur before signs of dementia

Brain changes are likely to precede functional signs of probable Alzheimer's dementia by more than a decade

- If dementia can be identified earlier, there is the potential to proactively address signs and symptoms.
- Interventions, services or supports may be more effective if offered prior to significant cognitive and/or functional change.

Early Identification

- Early identification of signs and symptoms of cognitive and functional decline associated with dementia is an important first step in managing the course of the disease and providing quality care
- Family and professional caregivers can work with the consumer's health care provider to share information about observed changes
- NTG promotes a rating tool the **National Task Group Early Detection Screen for Dementia (NTG-EDSD)** to substantiate changes in adaptive skills, behavior and cognition

Benefits of Early Identification of Change

- Identifying the cause of decline can lead to proper, targeted care and affords a greater chance of benefiting from existing treatments
- Early diagnosis can help ease the anxiety that may accompany unexplainable changes in behavior
- Educating persons with dementia and their caregivers gives them time for advanced care planning
- Quality of life for persons with dementia and their family can be maximized

I/DD may complicate early recognition

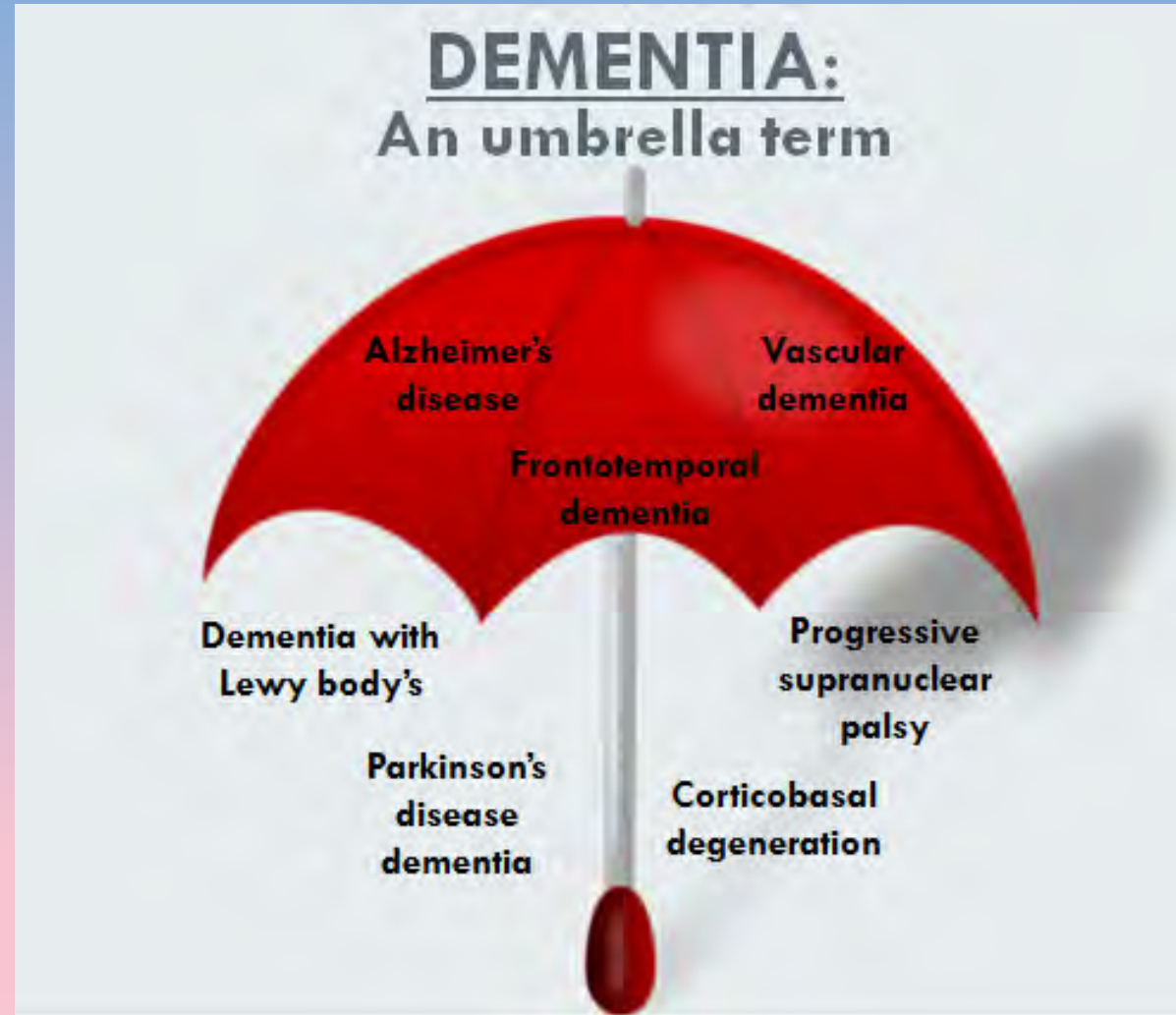
- Pre-existing cognitive impairment, behavioral disorders and poor emotional control may complicate recognizing the early signs of dementia
- Early cognitive and functional changes may be subtle or intermittent
- Pre-existing level of intellectual ability, sensory impairment, and health status may all impact upon cognitive and functional status

Things to Know about Dementia

- Dementia is not a diagnosis or disease, it is an umbrella term for changes (from characteristic baseline) in behavior, cognition, emotional control, and functioning
- Alzheimer's Disease is the most common form of dementia
- The average age of onset of dementia in a person with Down syndrome is about age 52; actual brain changes may begin as early as 20 years prior to "onset"
- Changes in personality and behavior often predate changes in memory among individuals with DS and dementia
- Progressive decline can last from 1-7+ years for persons with DS
- As the disease progresses, so do the care needs of the individual as memory, self-care, communication and walking become more difficult

Neurocognitive Disorders

- What will you observe?
- What will you do?
- How can you best advocate?





Know the Warning Signs of Dementia

- Unexpected memory problems
- Getting lost or misdirected in a familiar setting
- Problems with gait or walking
- New seizures
- Confusion in familiar situations or with customary tasks at home or at work
- Changes in personality
- Difficulty maintaining social connections with family and friends

Variety of Early Indicators

- Reduced work performance
- Difficulties with recent memory and new learning (e.g. *can't remember the names of new staff*)
- Changes in communication skills including impoverishment in expressive language compared with baseline (e.g. *a person who was talkative no longer says anything*)
- Emotional lability, heightened irritability, apathy, “coarsened” social behavior

First steps...

- When you observe a change in thinking, mood or behavior that is significantly different than what is typical and characteristic for the person whom you support:
 - ✓ Collect information for a period of 2 weeks
 - ✓ Make an appointment for the consumer to see his/her PCP
 - ✓ Advocate for assessment if the consumer demonstrates changes in behavior at work and within his/her residence/familiar setting

Rationale for development of the NTG-EDSD

- Need to equip family and professional caregivers with a tool to capture information about changes in cognition and function
- Provide caregivers with a format to share important information with the consumer's health care practitioner
- Tool trains caregivers to be better observers and reporters of relevant signs and symptoms of change

Need for an administrative tool

- Clinicians report that individuals are not brought to attention until well advanced in the dementing process
- Need for an administrative tool that will help link individuals who exhibit change to relevant health care options
- Cognitive and functional status are not usually included in annual health screenings
- For those eligible, the **NTG-EDSD** could be used as part of the Annual Wellness Visit

NTG -EDSD

Early Detection Screen for Dementia

- adapted from *the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities* (Deb et al., 2007) and *the Dementia Screening Tool* (adapted by Philadelphia Coordinated Health Care Group from the *DSQIID*, 2010)
- Down Syndrome: begin as early as age 35 but not later than age 40, then annually; non-DS: begin when changes noted or ≥ 50
- Piloted in 2012; now used internationally

ntg
National Task Group
on Dementia in Individuals
with Disabilities

NTG-EDSD

v.4/2013.2

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 2.8 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:

<input type="checkbox"/> Female
<input type="checkbox"/> Male

(8) Best description of level of intellectual disability

<input type="checkbox"/> No discernible intellectual disability
<input type="checkbox"/> Borderline (IQ 70-75)
<input type="checkbox"/> Mild ID (IQ 55-69)
<input type="checkbox"/> Moderate ID (IQ 40-54)
<input type="checkbox"/> Severe ID (IQ 25-39)
<input type="checkbox"/> Profound ID (IQ 24 and below)
<input type="checkbox"/> Unknown

(9) Diagnosed condition (check all that apply)

<input type="checkbox"/> Autism
<input type="checkbox"/> Cerebral palsy
<input type="checkbox"/> Down syndrome
<input type="checkbox"/> Fragile X syndrome
<input type="checkbox"/> Intellectual disability
<input type="checkbox"/> Prader-Willi syndrome
<input type="checkbox"/> Other: _____

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

Current living arrangement of person:

<input type="checkbox"/> Lives alone
<input type="checkbox"/> Lives with spouse or friends
<input type="checkbox"/> Lives with parents or other family members
<input type="checkbox"/> Lives with paid caregiver
<input type="checkbox"/> Lives in community group home, apartment, supervised housing, etc.
<input type="checkbox"/> Lives in senior housing
<input type="checkbox"/> Lives in congregate residential setting
<input type="checkbox"/> Lives in long term care facility
<input type="checkbox"/> Lives in other: _____

<http://aadmd.org/ntg/screening>

NTG-EDSD use considerations...

- This tool is not used for the diagnosis of dementia
- This is an administrative and not a clinical rating instrument
- The diagnosis of a neurocognitive disorder involves medical exam and direct cognitive and adaptive testing of the individuals in question
- If the consumer is already known to have a neurocognitive disorder, use the rating form to baseline observation
- Since this is an early screening tool, it is not necessary to continue using if the person has been formally diagnosed with neurocognitive disorder



Role of Families and Professional Caregivers

- Caregivers are raters for the **NTG-EDSD**
- Staff need to have worked with the individual for at least 6 months in order to serve as a rater on this instrument
- Families and Staff who are familiar with the person, are more likely to be aware of subtle changes in behavior and functioning that may signal important changes for the individual, constitute important information for health care providers



How to complete the form

- The **NTG-EDSD** should be completed by someone who is familiar with the consumer
- Gather medical and other chart materials in order to fill out some of the questions pertinent to medical and mental health status changes
- If the consumer attends day program, it may be helpful for the staff at day program to complete a separate record form or the day program's staff can be included in the completion of one rating instrument

Utilizing findings from EDSD

- Has the individual displayed new symptoms in at least 2 domains on the **EDSD**?
- Alternatively, is the individual rated as having gotten worse for symptoms already noted in 2 areas?
- Has delirium been ruled out?
- Has depression been ruled out?
- What is the healthcare provider suggesting with regard to medication, monitoring, non-pharmacological interventions?

How Does the EDSD help capture information about change?

- Domains correspond to areas in which you may see a decline in functioning (from baseline) related to dementia:
- *Behavior*
- *Personality*
- *Memory*
- *Activities of Daily Living*
- *Sleep*

How do you establish baseline?

- Baseline is what is characteristic and usual for the person
- Observation
- Data collection
- Self-report



What do you do with the Ratings from the EDSD?

- Look for patterns
- What are areas in which change has been noted?
- What is the extent of change?
- Is something being done to currently address issue?
- Bring to team to brainstorm an options
- Develop an Action Plan
- Share with everyone
- Evaluate the effectiveness of the plan



Sharing Findings with Members of the IDT

- Discuss observations captured through EDSD ratings
- Reconcile any discrepancies across settings
- Request additional information, if necessary
- Brainstorm possible approaches
- Operationalize a plan of action



Sharing findings from EDSD can advance important conversations

- Raise neurocognitive disorder or competing problems for exploration as possible explanation for change. In addition to dementia, the following can be contributing to observed changes:
- Depression
- Delirium
- Sensory loss
- Unaddressed pain



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Types of Decisions that May Follow from Use of the EDSD

Modification of residence

Change in residence

Changing staffing support

Changing programming

Developing a positive daily routine

Identifying items and activities for stimulation

Promote time-sensitive interventions and support

Findings:

- The consumer has declined in ADLs requiring additional support with personal care and other activities
- This may affect level of care supports, deployment of staff, staffing arrangements, physical or modifications to the setting in which the individual is supported



Share ratings from NTG-EDSD with the healthcare provider

- Use: to provide information to physician or diagnostician on the consumer's daily functioning
- Advance the conversation leading to possible assessment/diagnosis
- Get the most out of visits with the healthcare provider



Utilize to determine care and support needs of the individual

- What types of visual and verbal cuing, role modeling or other supports help the individual remain as independent as possible?
- What does the person need in order to be safe?
- What does the person need in order to be comfortable?
- What does the person need in order to have the best Quality of Life (QoL)



How might the use of the EDSD lead to a diagnosis of neurocognitive disorder?

By ruling out other factors, the health care provider may recommend further testing and evaluation

Although the **NTG-EDSD** is not a diagnostic tool, the review of the findings may result in a referral for further diagnostic work-up that can confirm/disconfirm the likelihood of dementia



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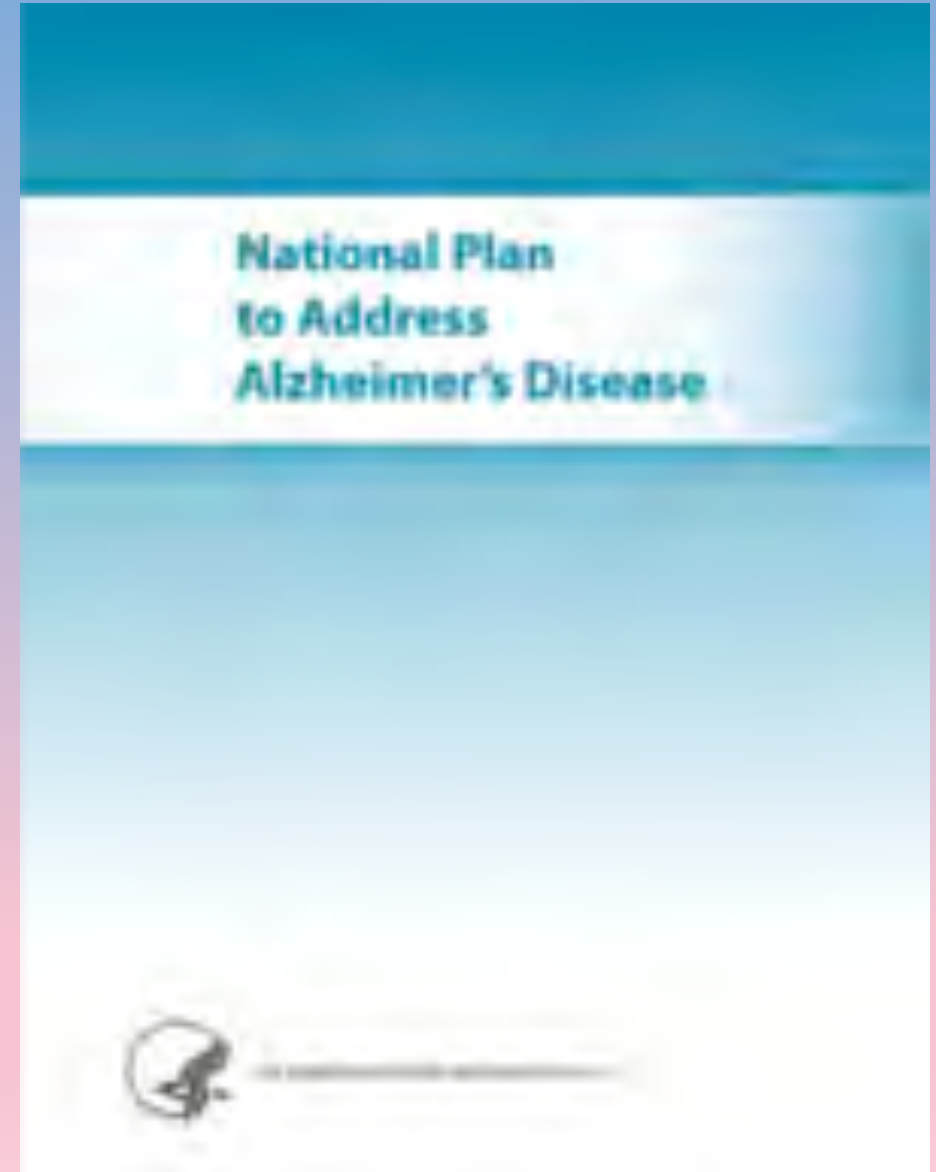


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National Plan to Address Alzheimer's Disease

- Five goals of The Plan required by the National Alzheimer's Project Act (2011) :
 1. Prevent and effectively treat Alzheimer's disease by 2025.
 2. Optimize care quality and efficiency.
 3. Expand supports for people with Alzheimer's disease and their families.
 4. Enhance public awareness and engagement.
 5. Track progress and drive improvement.



A Model System would...

- **Educate the public** about brain health. This would include information about the risk factors associated with developing dementia, first signs of cognitive problems, management of symptoms if individuals have dementia, support programs, and opportunities to participate in research.
- **Identify** people with possible dementia and recommend that they see a physician for a timely, accurate diagnosis and to rule out reversible causes of dementia or conditions that resemble it.
- **Ensure** that program eligibility and resource allocation include the impact of cognitive disabilities.
- **Ensure** that staff communicate effectively with people with dementia and their caregivers and provide services that: a) Are person- and family-centered b) Offer self-direction of services c) Are culturally appropriate
- **Educate workers** to identify possible dementia and understand the symptoms of dementia and appropriate services.
- **Implement** quality assurance systems that **measure** how effectively providers serve people with dementia and their caregivers.
- **Encourage** development of dementia-friendly communities, which include key parts of dementia-capability. Below

To Educate is to Empower

- <https://www.nia.nih.gov/health/alzheimers>
- adear@nia.nih.gov
- www.aadmd.org/ntg
- <https://www.cdc.gov/aging/healthybrain/index.htm>

References

- Edward GA III, Gamez N., Escobedo G Jr., Calderone O and Moreno-Gonzalez, I. (2019) Modifiable Risk Factors for Alzheimer's Disease. *Front.Aging Neurosci.* 11:146.
- Esralew L, Janicki MP, DiSipio M, et al, Members of the National Task Group Section on Early Detection and Screening. National task group early detection screen for dementia. *NADD Bull.* 2013;16:47–54.
- Olivari, B. S., Baumgart, M., Lock, S. L., Whiting, C. G., **Taylor, C. A.**, Iskander, J., . . . McGuire, L. C. (2018). CDC Grand Rounds: Promoting Well-Being and Independence in Older Adults. *MMWR. Morbidity and Mortality Weekly Report*, 67(37), 1036-1039. <http://dx.doi.org/10.15585/mmwr.mm6737a4>
- Olivari BS, French ME, McGuire LC. The Public Health Road Map to Respond to the Growing Dementia Crisis. [Innovation in Aging, Volume 4\(1\)](#)
- Snowden, M., Steinman, L., Carlson, W.L., Mochan, K.N., Abraido-Lanza, A.F., Bryant , L. ... & Anderson, L.A. (2015). Effect of Physical Activity, Social Support and Skills Training on Late-Life Emotional Health: A Systematic Literature Review and Implications for Public Health Research" *Frontiers in Public Health*.
- Zeilinger EL, Gärtner C, Janicki MP, et al. Practical applications of the NTG-EDSD for screening adults with intellectual disability for dementia: a German-language version feasibility study. *J Intellect Develop Disabil.* 2016;41:42–9.
- Zeilinger EL, Stichl K.A., Weber G.A. A systematic review on assessment instruments for dementia in persons with intellectual disabilities. *Res. Dev Disabil* 2013;34:3962-77.

Thank you for
attending this
presentation!

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