Aging with Down Syndrome: Tips for Promoting Brain Health at Every Age

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What Do We Know About Aging and DS?

- Adults with Down syndrome are now reaching old age on a regular basis and are commonly living into their 50s, 60s and 70s.
- Adults with Down syndrome experience “accelerated aging”.
- The experience of accelerated aging can be seen medically, physically and functionally and therefore predicting and preparing for the aging process becomes more challenging.
- Persons with DS may have atypical presentation of disease-such as change in behavior of function

Healthy Aging Overview

Regular preventative healthcare-vaccines, flu shots, cancer screenings, oral health. Consider a Geriatrician or Down Syndrome specialist who specializes in Aging-and thinks about aging & DS issues.

Take advantage of Telehealth when possible if access is an issue

Treat hearing loss and sensory issues-RISK factor for dementia

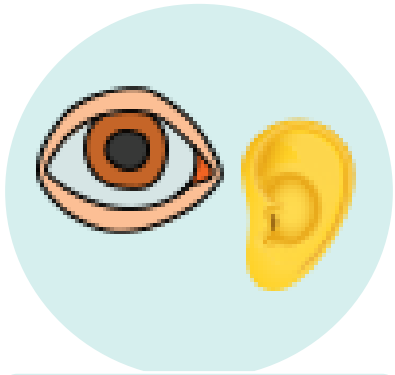
Keep moving and take care of mental health/socialization

MINIMIZE Medications-review every 3 months-helping or hurting

Hydration, Hydration, Hydration

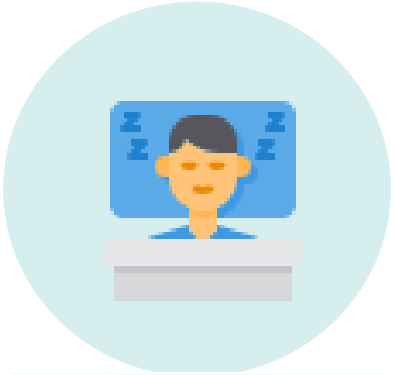
What is good for the HEART is good for the Brain-avoid too much alcohol, control weight, diet with whole grain, vegetables, nuts (Mediterranean)

Common Medical Conditions

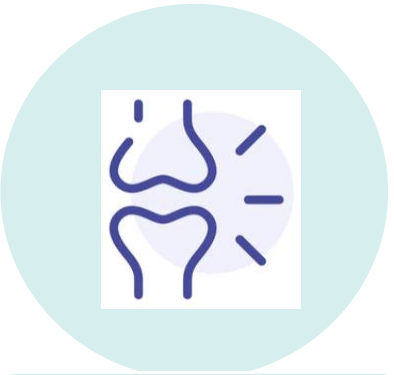


Sensory Loss

Hypothyroidism

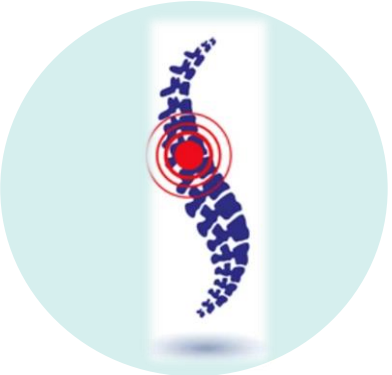


Sleep Apnea



Bone abnormalities

Celiac Disease

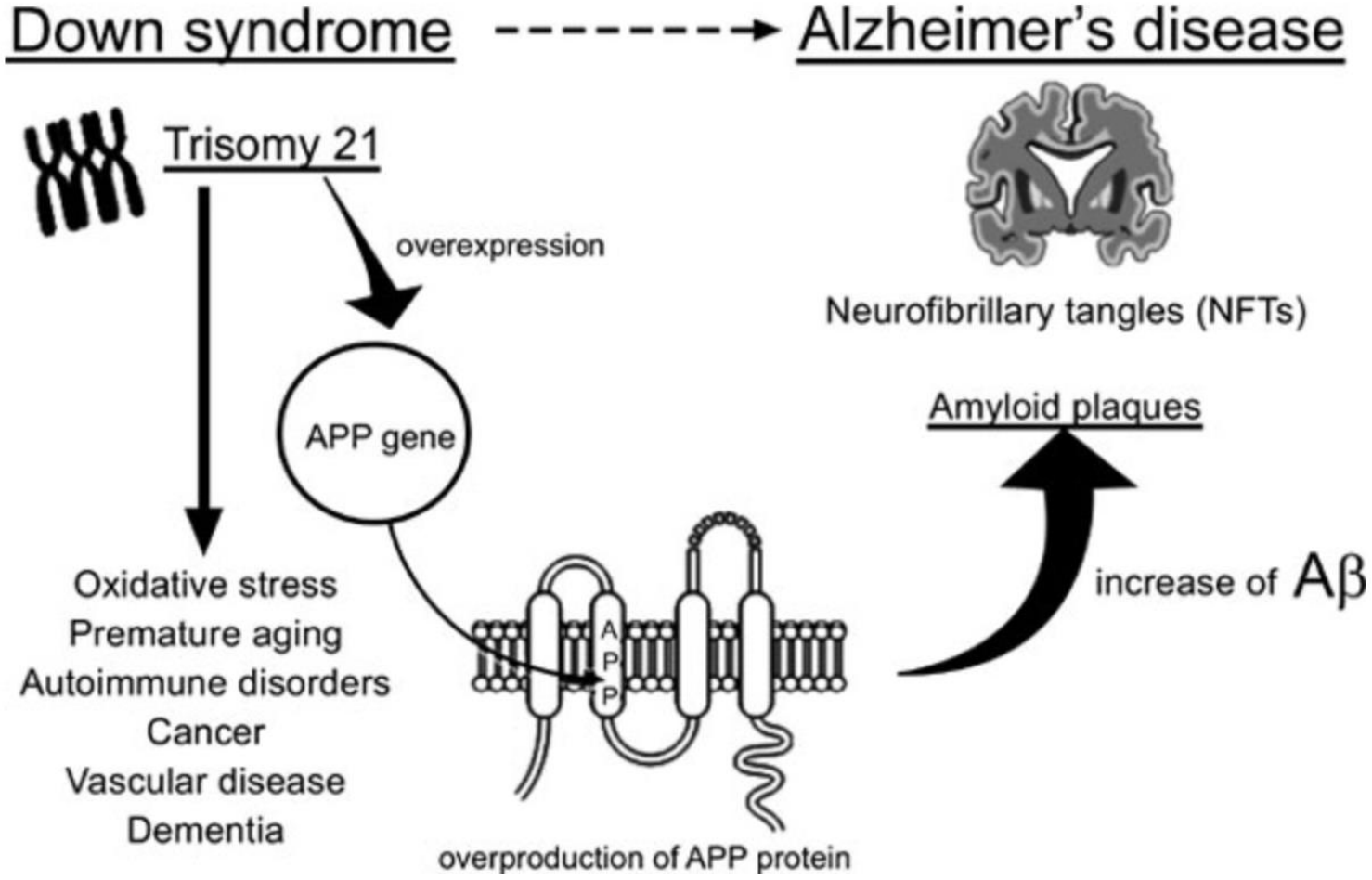


Cervical spine concerns

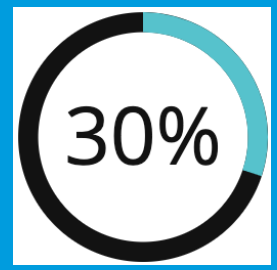
Alzheimer's Disease

Heart conditions

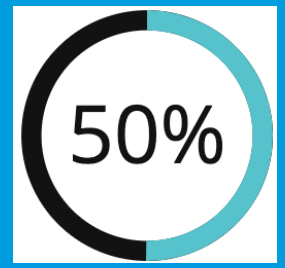
Connection between Down syndrome & Alzheimer's disease



Alzheimer's disease affects about



People with Down syndrome in their 50s



People with Down syndrome in their 60s

What is Dementia and Alzheimer's Disease?

- Dementia is a broad umbrella term for progressive cognitive impairment that (at this time) is not reversible and occurs slowly over months to years with impairments of memory, thinking, language, and functioning.

- Alzheimer's disease is one of the most common forms of dementia but there are others such as Vascular, Mixed, Lewy Body, Frontotemporal and others. AD is the most common dementia seen in DS. Is can ONLY be diagnosed by ruling out other possibilities (many that are reversible) SO A full work-up, thorough medical exam and correct diagnosis is important.

Dementia Diagnostic Criteria Updates

2013 DSM-5 Updates

DSM 5:

~~Dementia~~ = Major Neurocognitive Disorder

Criteria –

One or more acquired significant impairments (independence lost) in cognitive domains such as:

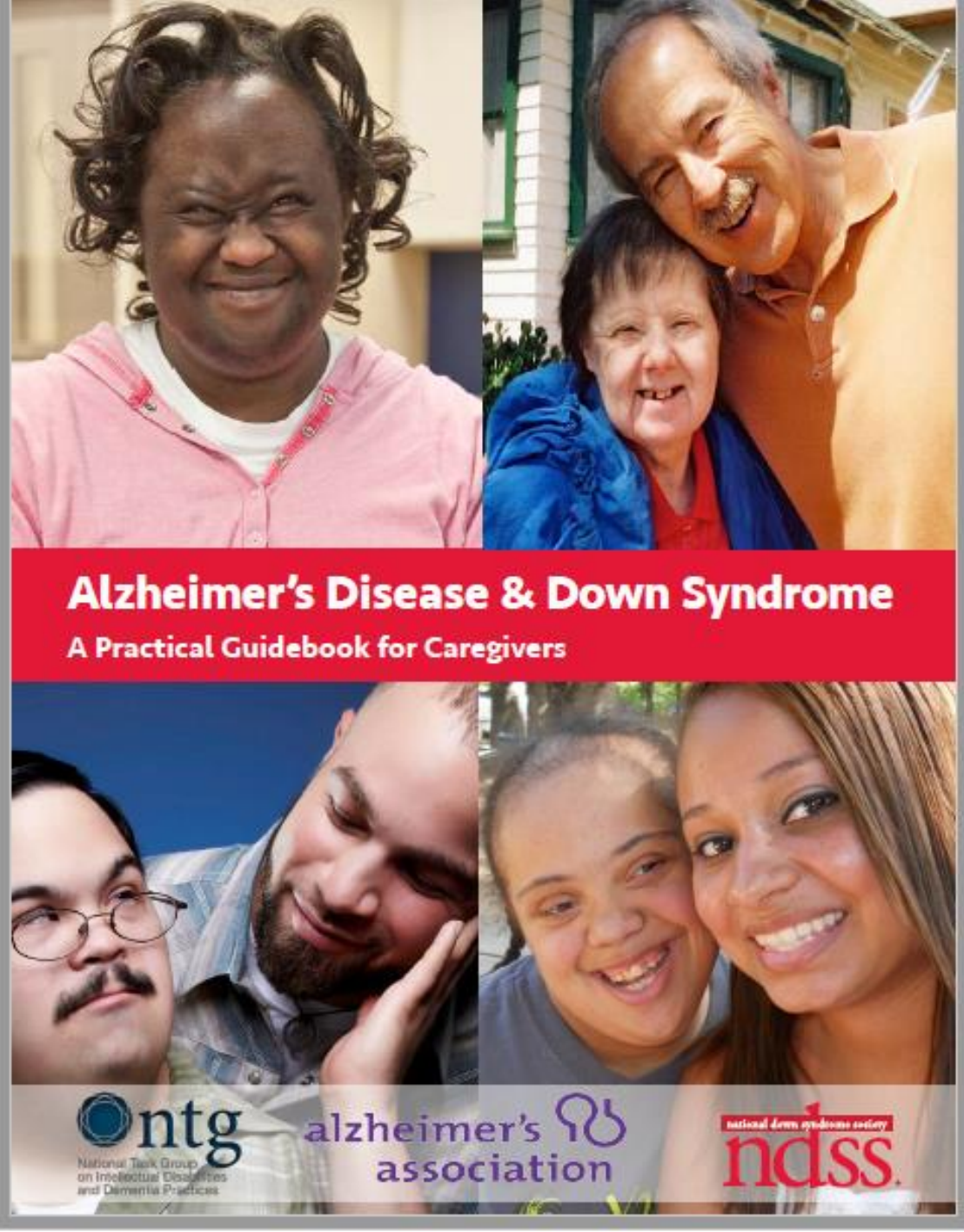
- Memory (amnesia)
- Language (aphasia)
- Execution of purposeful movement (apraxia)
- Recognition/familiarity (agnosia)
- Visuospatial function (topographical disorientation)
- Self control/management (executive functions impairment)
- Other examples:
  - Mathematics (dyscalculia)
  - Emotional expression/comprehension (dysprosody)
  - Writing (agraphia)

DSM 5's intent:

- Avoid "dementia's" negative connotation
- Better distinguish between disorders that have cognitive impairment as their primary feature and those that don't
- More accurately reflect the diagnostic process

2011 NIH and ADRD Workgroup
(first update in 27 years)

- In addition to AD added
- MCI
- & Pre-clinical disease
- Also updated guidelines for reporting, autopsy & biomarkers.



ndss manual of Alzheimer's
https://www.ndss.org/resources/?_paged=3

- Nice overview of dementia and ADRD
- Gives a chart to compare previous cognitive and functional abilities with how they are NOW
- Makes it clear that even though there is a connection with dementia and Down Syndrome it is NOT inevitable
- Overview of stages of dementia and assessment
- Caregiver support
- Communication
- ALL behavior has meaning-AVOID medicating for behavior –understand behavior as an unmet need

BASELINE ABILITIES AND CHARACTERISTICS

Describe the individual's abilities that are/were typical of what he/she can/could do throughout adulthood. Be as descriptive as possible!

FUNCTION	How independent was the individual in performing self-care tasks throughout lifetime – i.e.; bathing, dressing, toileting, grooming, eating, and walking?
SKILLS	What academic skills were achieved? What chores or responsibilities could the individual perform around the house? What jobs has he/she held? What activities would he/she typically do at day program? Any other talents or abilities throughout lifetime? Hobbies, sports, other favorite activities?
MEMORY	Could the individual learn and recall names of familiar people? Keep track of the day of the week and daily or weekly schedule? Know his/her way around familiar areas? Reliably remember short term or newly-learned information? Could he/she reliably recall recent past events? Any particular memory talents or skills?
BEHAVIOR	What behaviors have been present throughout adulthood? Self-injurious behaviors? Aggression towards others, either verbal or physical? Self-talk or imaginary friends? Any other quirks or rituals? Has the individual required a behavior plan? If so, what strategies have been helpful? Any other typical pattern or triggers to behaviors over lifetime?
LANGUAGE	Could the individual express him/herself verbally to let his/her basic needs be known? Speak in full sentences? Hold a conversation? If he/she was never verbal, how were needs expressed? Could the individual understand verbal language and answer questions appropriately or follow a verbal instruction?
PERSONALITY	Did the individual seek out peer relationships? Was he/she social? Well-liked by others? Did he or she show preference for routine and structure? How else would you describe his or her personality?
MOOD	What was the individual's mood like most days? Were there mood swings? Any mood/psychiatric issues that recurred or persisted throughout adulthood? Did he/she receive psychiatrist or therapist? Any past psychiatric hospitalizations?

CURRENT ABILITIES AND CHARACTERISTICS

Now describe the individual's current abilities - highlighting, when applicable, the areas in which changes are noted compared to what was described above in the baseline section.

FUNCTION	Lately, how independent is the individual in performing self-care tasks? Bathing, dressing, toileting, grooming, eating, and walking? Have changes been observed in functional abilities compared to baseline? Describe.
SKILLS	Compared to what was outlined at baseline, how have typical daily skills and abilities changed? Is the individual still participating in baseline abilities, routine tasks, and household chores? Has job performance or participation in day program activities changed?
MEMORY	What concerns are there about memory skills? Increased forgetfulness, confusion, disorientation, poor concentration? Repeated stories or repeated questions? Forgetting names, mixing up days of the week, etc? What has changed compared to baseline?
BEHAVIOR	How have behaviors been lately? Are new behaviors emerging? Has there been a change in the frequency or intensity of typical behavior patterns? Any other new triggers for behaviors noted? What tends to make behaviors better?
LANGUAGE	Have language abilities changed lately? Is the individual able to let his or her needs known per usual? Has vocabulary gotten smaller or verbal output declined overall? Difficulty finding words? Difficulty hearing and answering questions, or difficulty following verbal instructions?
PERSONALITY	Any recent shifts in personality? Increased irritability, stubbornness, intolerance to change, withdrawal? Any other observed changes compared to baseline?
MOOD	Have there been observed changes in typical mood? Increased mood swings, tearfulness, sadness, withdrawal? Hearing voices? Seeing or hearing things that are not there?

The Mini-Cog © Form

Mini-Cog©

Instructions for Administration & Scoring

ID: _____ Date: _____

Step 1: Three Word Registration

Look directly at person and say, "Please listen carefully. I am going to say three words that I want you to repeat back to me now and try to remember. The words are [select a list of words from the versions below]. Please say them for me now." If the person is unable to repeat the words after three attempts, move on to Step 2 (clock drawing).

The following and other word lists have been used in one or more clinical studies.[1-3] For repeated administrations, use of an alternative word list is recommended.

Version 1	Version 2	Version 3	Version 4	Version 5	Version 6
Banana	Leader	Village	River	Captain	Daughter
Sunrise	Season	Kitchen	Nation	Garden	Heaven
Chair	Table	Baby	Finger	Picture	Mountain

Step 2: Clock Drawing

Say: "Next, I want you to draw a clock for me. First, put in all of the numbers where they go." When that is completed, say: "Now, set the hands to 10 past 11."

Use preprinted circle (see next page) for this exercise. Repeat instructions as needed as this is not a memory test. Move to Step 3 if the clock is not complete within three minutes.

Step 3: Three Word Recall

Ask the person to recall the three words you stated in Step 1. Say: "What were the three words I asked you to remember?" Record the word list version number and the person's answers below.

Word List Version: _____ Person's Answers: _____ _____ _____

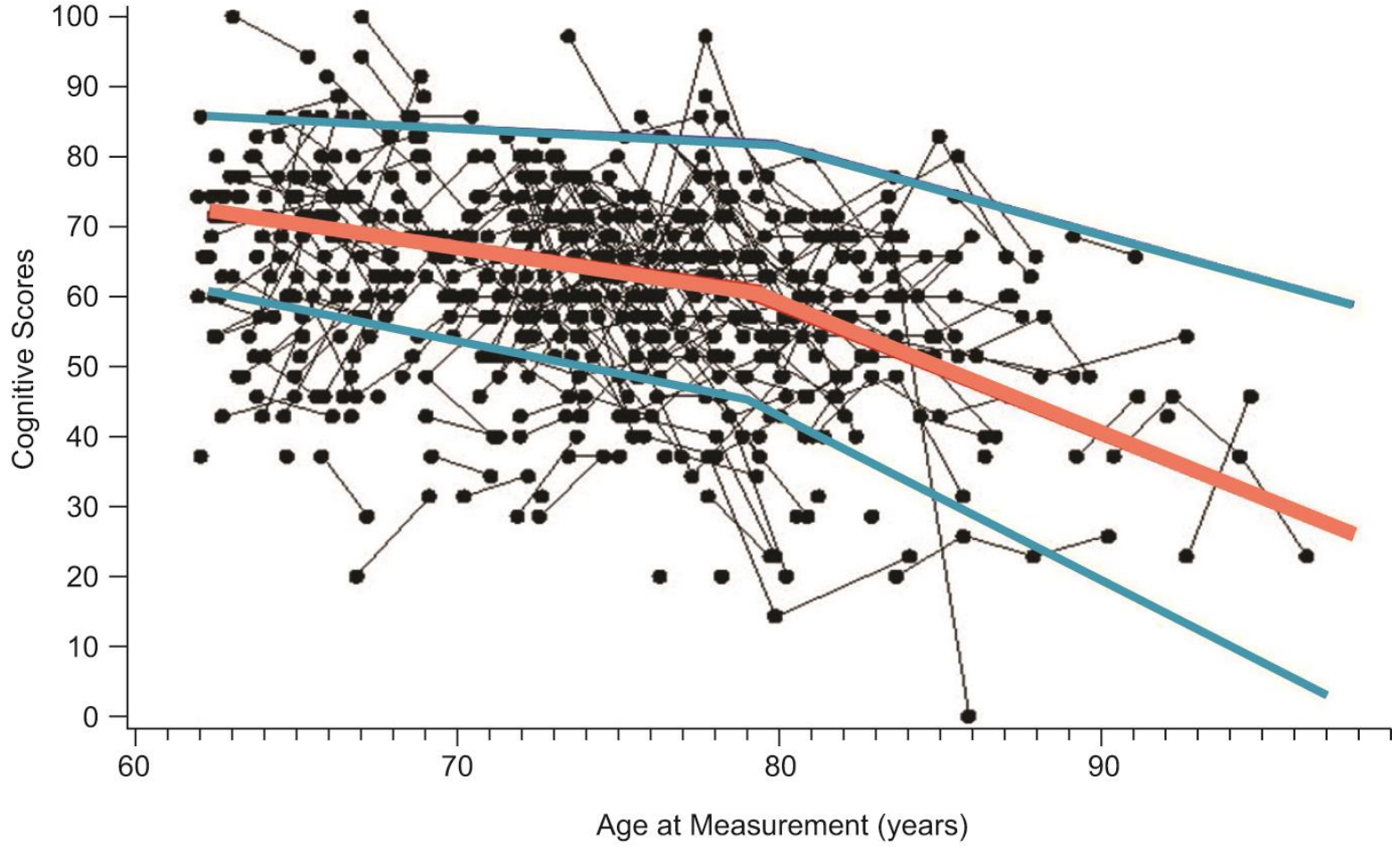
Scoring

Word Recall: _____ (0-3 points)	1 point for each word spontaneously recalled without cueing.
Clock Draw: _____ (0 or 2 points)	Normal clock = 2 points. A normal clock has all numbers placed in the correct sequence and approximately correct position (e.g., 12, 3, 6 and 9 are in anchor positions) with no missing or duplicate numbers. Hands are pointing to the 11 and 2 (11:10). Hand length is not scored. Inability or refusal to draw a clock (abnormal) = 0 points.
Total Score: _____ (0-5 points)	Total score = Word Recall score + Clock Draw score. A cut point of <3 on the Mini-Cog™ has been validated for dementia screening, but many individuals with clinically meaningful cognitive impairment will score higher. When greater sensitivity is desired, a cut point of <4 is recommended as it may indicate a need for further evaluation of cognitive status.

Cognitive aging is not the same as Alzheimer's disease.

ALZHEIMER'S DISEASE	COGNITIVE AGING
Chronic neurodegenerative disease	Part of aging
Extensive neuron loss	Neuron number remains relatively stable, but neuronal function may decline
Affects approximately 10 percent of older Americans	Occurs in everyone, but the extent and nature of changes varies widely
Declines are often severe and progressive	Changes are variable and gradual

Intra-individual changes in cognition scores over time (random sample of ~500 adults, ages 60 and older)



SOURCE: McArdle, J. 2011. Longitudinal dynamic analyses of cognition in the health and retirement study panel. Advances in Statistical Analysis 95(4):453-480.

Key Messages

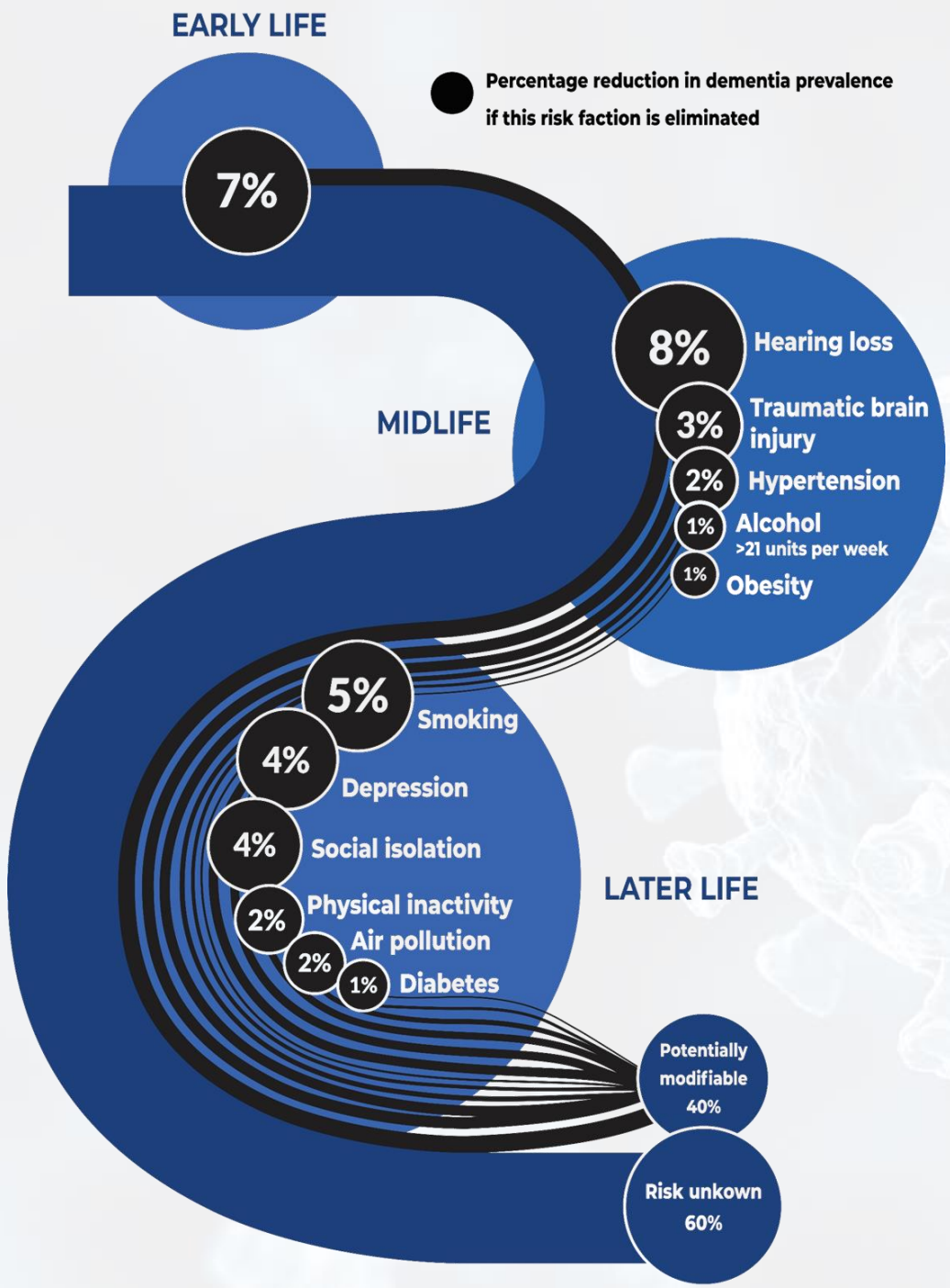
- Aging affects all organs, including the brain
- Occurs in everyone as they age
- Highly dynamic process with variability within and between individuals
- Only beginning to be understood biologically and clearly involves structural and functional brain changes
- Alzheimer's Disease is NOT inevitable in Down Syndrome, cognition may not change, may decline, or may actually improve with aging
- Actions can be taken to help maintain cognitive health.
- Taking care of the PHYSICAL health is important for BRAIN health-What is good for the HEART is good for the brain

What Can We Do? (LOTS!)

Dementia and Cognitive Decline are NOT inevitable in Down Syndrome

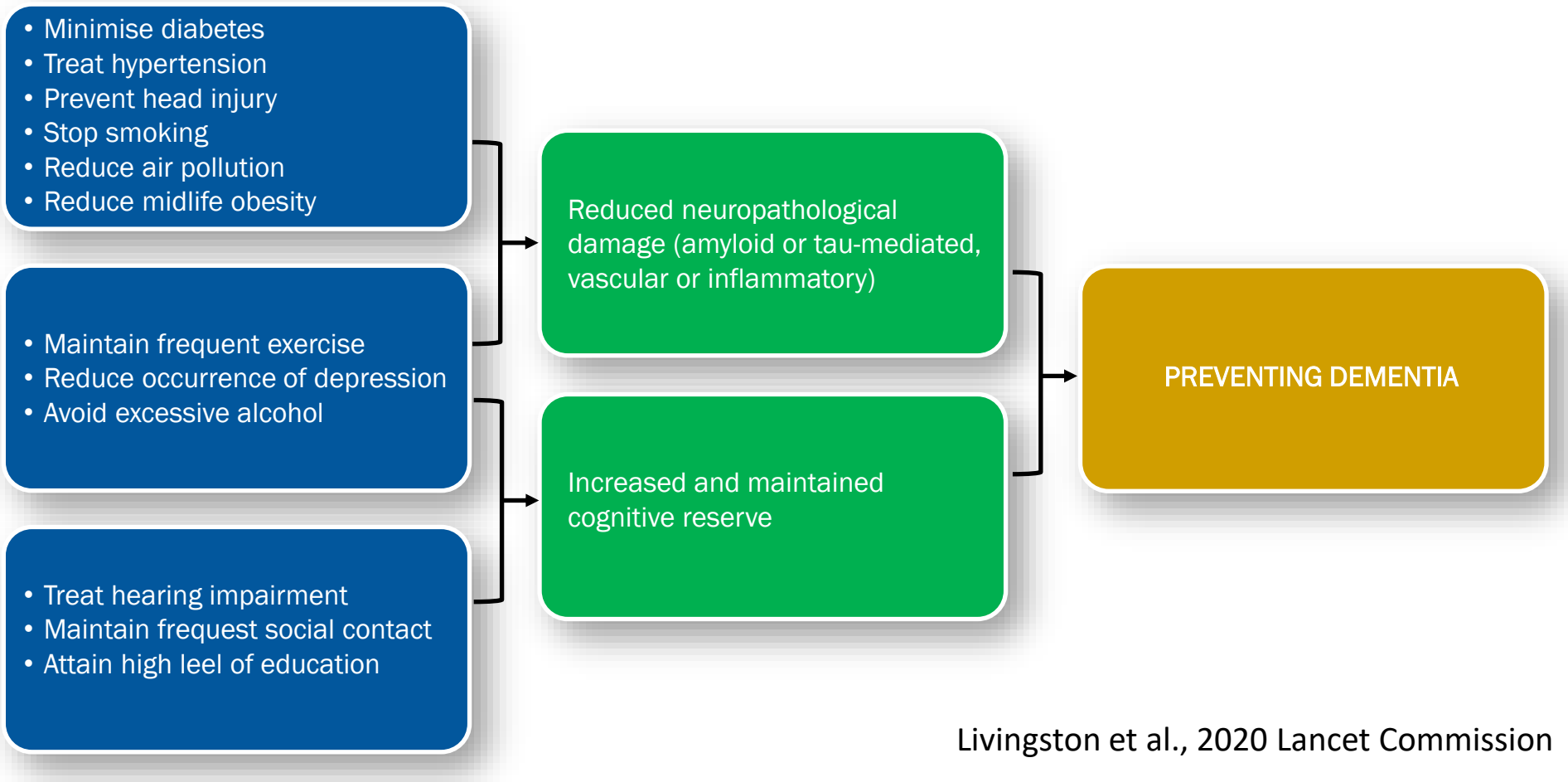
Most of the known risk factors for dementia are modifiable

Many simple lifestyle changes can help



Livingston et al., 2020 Lancet Commission

Preventing dementia



Livingston et al., 2020 Lancet Commission

Recommendations to Individuals and Families

The top 3 actions you can take to help protect your cognitive health as you age

1. **Be physically active.** Staying physically active can promote cognitive health in middle-aged and older adults.

2. **Reduce your cardiovascular risk factors (including hypertension, diabetes, and smoking).** Maintaining cardiovascular health supports cognitive health.

3. **Manage your medications.** A number of medications can have a negative effect on cognitive function when used alone or in combination with other medications. The effects can be temporary or long-term. It's important to review all of your medications with a health care professional and learn about their effects on cognitive health.

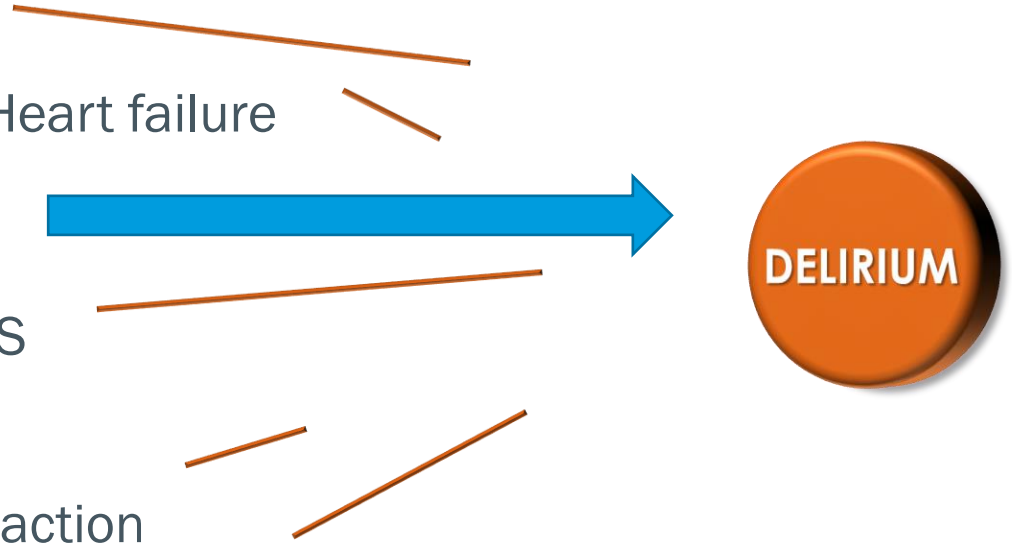
Other actions that may promote cognitive health

- Be socially and intellectually active, and continually seek opportunities to learn.
- Get adequate sleep and seek professional treatment for sleep disorders, if needed.
- Talk to your health care provider to learn more about preventing delirium (a decline in cognitive function that can be associated with some medications and hospitalization).

"THINK DELIRIUM"/Assess Delirium (Acute, reversible, preventable confusion)

ATYPICAL PRESENTATIONS in Persons with Disabilities

- Pneumonia
- MI/Congestive Heart failure
- **COVID-19**
- Infection/SEPSIS
- Depression
- Adverse Drug reaction
- Dehydration
- DELIRIUM MEASURES NIDUS
  https://deliriumnetwork.org/measurement/delirium-info-cards/



DO THIS TO PREVENT DELIRIUM

PREVENTION IS MORE EFFECTIVE THAN TREATMENT

Simple but effective

JAMA 2015 review 11/14 studies and 62% falls reduct.

AGS21 VIRTUAL ANNUAL SCIENTIFIC MEETING

Nonpharmacologic Approaches for Delirium Prevention and Support Using the 4Ms of Age-Friendly Care*

Orientation and cognitive stimulation activities	■ Provide lighting, signs, calendars, clocks ■ Reorient the patient to time, place, person ■ Use validation if they have dementia and consider use of an "All About Me Board" ■ Introduce cognitively stimulating activities (e.g., reminiscing, familiar phrases) ■ Assess and document "What Matters" ■ Facilitate regular visits from family, friends ■ Consider a video from familiar friends or family
Fluid repletion and nutrition	■ Encourage patients to drink; consider parenteral fluids if necessary and have an easy-to-hold drink container with markings so older adults can see their intake ■ Seek advice regarding fluid balance in patients with comorbidities (heart failure, renal disease)
Medications	■ Avoid inappropriate and central-nervous system medications that may cause or worsen delirium (see AGS Beers Criteria®) ■ Review the type and number of medications ■ Consider deprescribing (taper) if needed and offer non-drug or safer alternatives
Early mobilization	■ Encourage early mobilization (every older adult/everyday) ■ Keep walking aids (canes, walkers) nearby at all times ■ Ensure all older adults have a daily mobility goal
Vision and hearing/sensory enhancement	■ Resolve reversible cause of the impairment ■ Ensure working hearing and visual aids are available and used by patients

Medication Management

- A complete medication review (including over-the-counter and herbal remedies) should be performed frequently, and especially during care transitions, such as post-surgery or hospital discharge.
- Over-the-counter medications (such as antihistamines, sedatives, and other medications that have strong anticholinergic activity), may have significant cognitive side effects, so their use should be carefully assessed.

How these can translate to our Children/Adults

Technology/online-exercise programs, dance, theatre (Penn State Harmony), art, music, SMART SPEAKERS

Best Buddies https://www.bestbuddies.org/

Campus Worklink College Programs https://www.pacer.org/transition/learning-center/postsecondary/college-options.asp

Home and Community-based services

Work and volunteer programs

Socialization with local Down Syndrome Society-Buddy Walk

Special Olympics https://www.specialolympics.org/

The New York Times

The Right Dose of Exercise for the Aging Brain

GETTY IMAGES

By GRETCHEN REYNOLDS
AUGUST 12, 2015

65

A small amount of exercise may improve

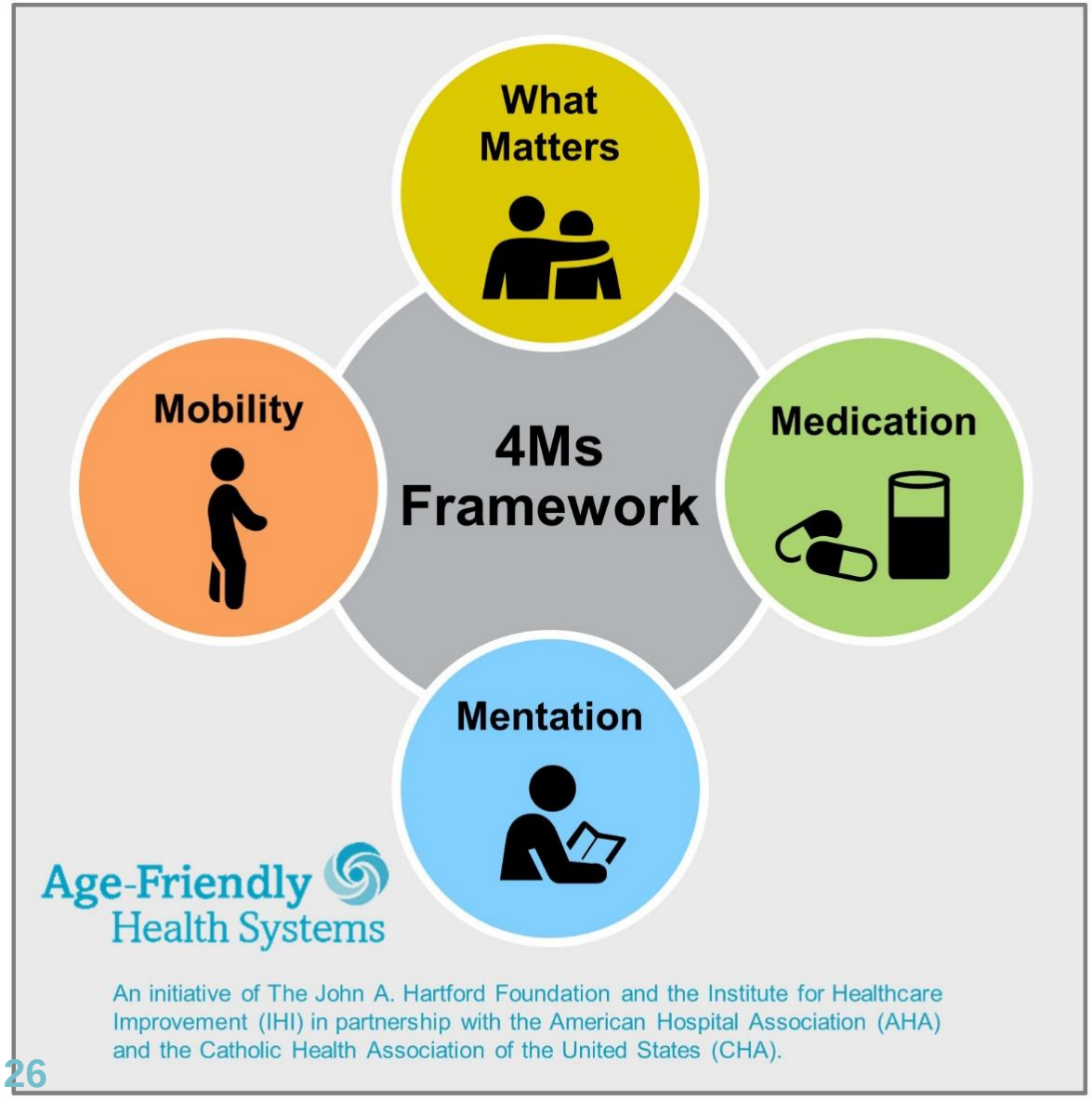
Adapted Exercise for Intellectual and Physical Disabilities

- DAILY activity goal is critical—movement, adapting is GOOD!
- Reach out to local YMCA, Colleges, AAA
- Exercises-walking, reclining stationary bike, three-wheel bikes, chair
- Dance, music, theatre
- FitLink Program https://happyvalleyfitlink.wixsite.com/happyvalleyfitlink

Work & Volunteer

Look for new challenges at work-new and novel tasks

The 4Ms Framework



What Matters

Know and align care with each older adult's specific health outcome goals and care preferences including, but not limited to, end-of-life care, and across settings of care.

Medication

If medication is necessary, use Age-Friendly medication that does not interfere with What Matters to the older adult, Mobility, or Mentation across settings of care.

Mentation

Prevent, identify, treat, and manage dementia, depression, and delirium across settings of care.

Mobility

Ensure that older adults move safely every day in order to maintain function and do What Matters.

4Ms worksheet For Home

My Life • My Health • My Goals
My 4Ms

Make a difference in how your health care works for you by using the **4Ms of Age-Friendly Care:** What Matters, Medications, Mind, & Mobility! The 4Ms are explained below – then flip the page and write your own 4Ms down on the other side. Put your 4Ms on your fridge, update them as needed, and take them with you to all your healthcare visits!

WHAT MATTERS

Receive the best care possible by telling your healthcare providers WHAT MATTERS to you. Think about what is most important to you in life; things you want your health care team to understand about you as an individual. Who are the most important people in your life? What do you view as essential to your quality of health and well-being?

If something were to happen to you, who would you turn to for help making healthcare decisions?

MEDICATION

Understanding your medications and what they do is important. Our bodies change with age in ways that can increase the chances of side effects from medications. One way to help prevent complications from medicine is to understand why you are taking them and to address any concerns about them with your healthcare provider.

MIND

Thinking, memory, and mood matter! Just like your body changes with age, so can your brain. Depression, delirium, and dementia may occur during older adulthood, but they are not a normal part of aging. If you're worried about your memory and thinking, or you are feeling sad a lot, tell your healthcare provider or call the National Helpline at 1-800-662-4357. Find ways to

My Life • My Health • My Goals
My 4Ms

Health is a team effort, and YOU are in the driver's seat! Complete the 4Ms below and take this sheet with you to your next healthcare visit. Look at your answers before each visit and see if they change over time.

PREFERRED NAME: _____

WHAT MATTERS

Take a moment and think about who you are and what you are facing right now, what is the most important thing for that comes to mind?

_____
_____
_____

MEDICATION

Are there any medications that you feel unsure about why you are taking them, or how to take them? List your concerns and questions.

_____
_____
_____

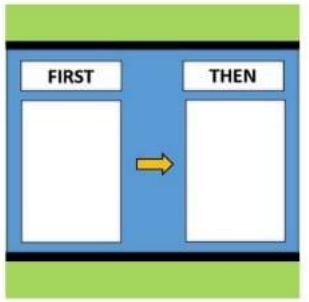
MIND

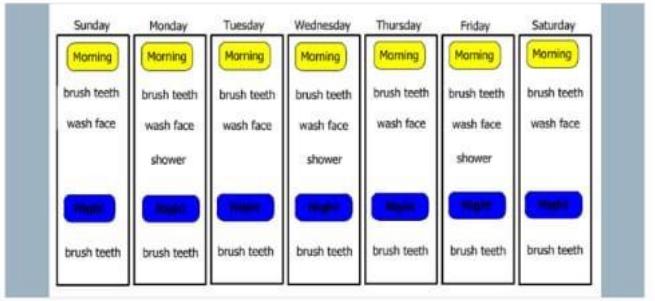
_____

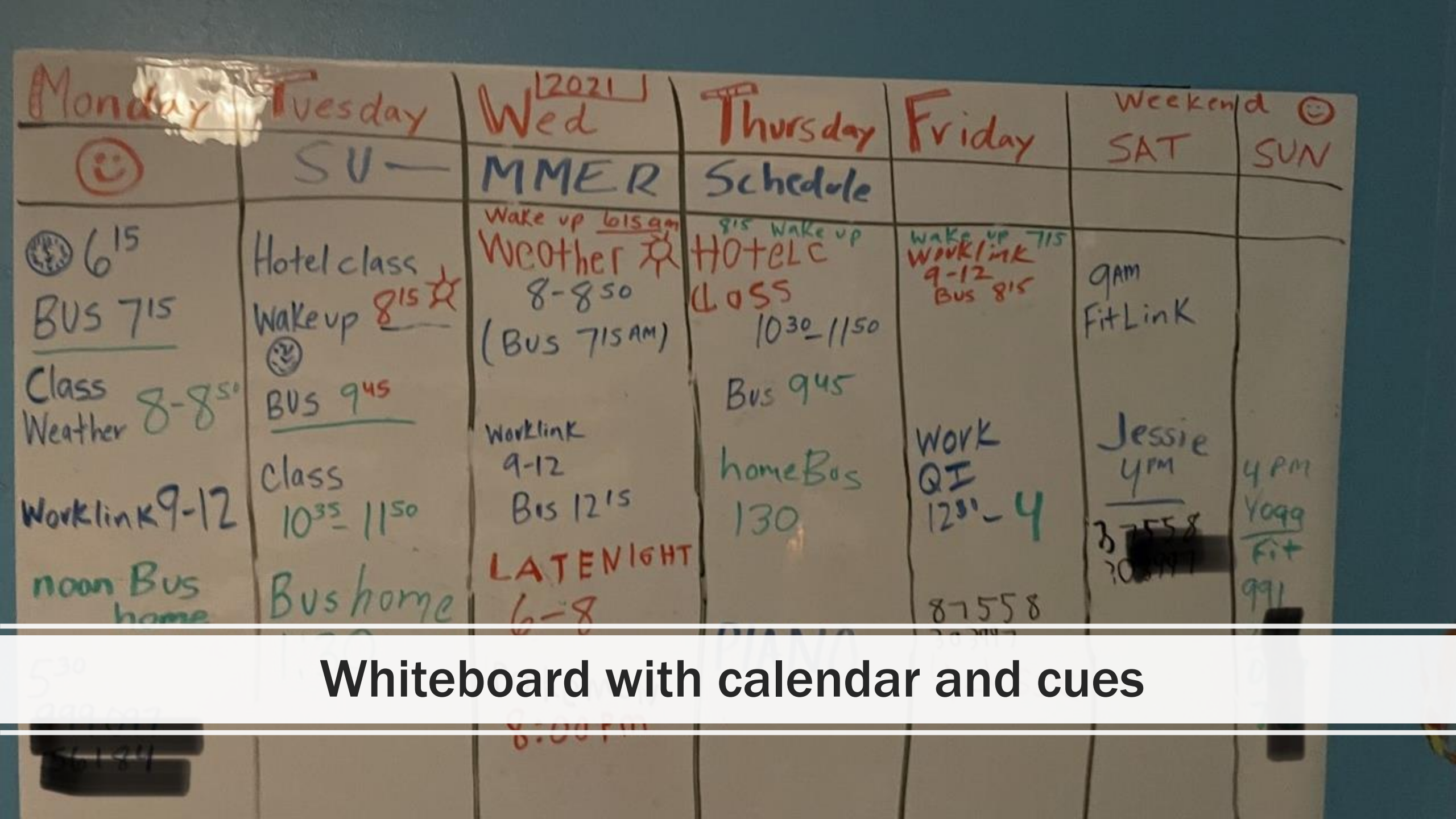
List two things you do that help you relax, stay calm

ndss resources

- Katie Frank, PhD, OTR/L
- https://www.ndss.org/katie_frank/
- Technology Supports-smart speakers, speechify, sensory adaptation
- White Boards
- Knowing them







Whiteboard with calendar and cues

KNOW YOUR RIGHTS IN THE HOSPITAL

Persons with disabilities **CAN** have a support person at the bedside during COVID-19

- The supporter is essential and a "reasonable accommodation" to help communicate, make decisions, feel safe, understand choices, help with personal care, safety and ADL's
- Be ready to tell the health system **WHY YOU/THEY NEED A SUPPORT PERSON** at the bedside-they are NOT visitors
- This is **YOUR RIGHT**
- Have a plan for how your supporter will be safe while in the hospital (masks, handwashing, testing if needed)

TABLE 1

Tips for Planning Safe Visitation in the Hospital or Nursing Home During a Pandemic

Be ready to advocate. The support person is essential and a "reasonable accommodation" to help the older adult communicate, make decisions, and understand choices, as well as provide help with personal care, safety, care preferences, and activities of daily living.
Be ready to explain. Tell the health system why a support person is necessary at the bedside. Stress they are not just visitors but essential partners in care. This human right is protected under the Americans With Disabilities Act (ADA) and Section 504 of the Rehabilitation Act—health systems must provide equal access. For questions or concerns, contact the Office for Civil Rights (access https://www.hhs.gov/ocr/index.html).
Be ready with a plan. Indicate how the support person will be safe while in the hospital or nursing home (e.g., will wear a mask, be vaccinated, wash hands, undergo COVID-19 testing if needed) to keep themselves, staff, and others safe and healthy.
Be ready to be available. Supplement in-person visits with virtual visits via tablet, phone, or other device.

CREATED BY MY DAUGHTER

JULY 18, 2020

All About Al

So you can know who I am on the inside....

I'm married!

I've been married to my wonderful and supportive wife for 61 years.
We met when we were both in college at Ohio State and we discovered we grew up near each other in Northwestern Ohio.

I have always been interested in helping youth and the volunteers that support them. I worked in Ag and Extension Education during my career at Michigan State, Oregon State and Penn State. I worked to get the 4-H program merged into the college of Ag and Extension Education so they could do research like other Big Ten Universities. I had a grant from Fox Chase Cancer Society in Philly while I was still working and was able to continue to work with smoking cessation after I retired too. I worked very hard to get Beaver Stadium a smoke-free environment!

What I enjoy!

Family means the most to me and I have three children, 11 grandchildren and eight great-grandchildren.

1

GOLF!

I'd still play golf every day if I could! I helped start a Junior Golf Program too!

2

ICE CREAM!

I enjoy desserts (ice cream, pie, cake & cookies) but other favorites are chicken, rueben sandwiches, burgers, lasagna, French toast, waffles, orange juice and fruit

3

PEOPLE!

I have always enjoyed helping people and working on projects!

My goals:

- To be able to walk on my own!
- To go home!
- Continue to feed myself
- Use the restroom by myself
- To dress myself

My challenges:

- I have had severe cognitive decline - especially this year. I used to be able to communicate what I liked and didn't like much better than I can now.
- I recognize my family, but processing things takes me time and needs to be said in multiple ways. I may say I understand what to do, but I don't act quickly and usually respond best if someone shows me what to do and encourages me.
- I do not respond to being shouted at to do things. Encouragement goes much better for me.
- I don't like to drink fluids! Flavored sparking water seems to go down best for me. Orange juice is good too. I used to drink coffee with sweetener, but have not liked it recently.
- Evenings are tough for me and I get fidgety and pick at my skin (head, ears, arms, etc.). My skin is very dry! My confusion is always worse in the evenings.

Who knows me best?

- I go by 'Al'.
- My wife – I still know her and am comforted by her voice. I respond to her best.
- My youngest daughter – she lives in State College - she is a power of attorney like my wife and can answer any questions and loves to help any way she can.
- My son – he lives in Phoenix, AZ but we are close and enjoy(ed) playing golf together!
- My oldest daughter – she lives in Idaho. We talk on the phone - and I saw her in February in AZ.

What Remains—COVID-19 has exposed cracks in our system-disabilities, aging…

- Ableism
- Ageism
- Intersection of Ageism, Ableism, and Racism
- Health inequities
- Persons with disabilities disproportionately impacted and still do not have the **GREEN LIGHT** to work or socialize or receive medical care-many are still sheltered in their home
- We can be active in our own communities for practical short-terms solutions and longer term needs for changes, advocacy, & policy

Hyper Links for resources

Paper - Cognitive Vital Sign of Delirium/Tips	https://www.healio.com/nursing/journals/jgn/2018-8-44-8/%7b69a01f5e-c46f-4d49-b906-cc37a572b080%7d/the-critical-vital-sign-of-cognitive-health-and-delirium-whose-responsibility-is-it#x00989134-20180713-03-bibr7
Office of Civil Rights Case Caregivers Essential at Bedside	https://www.hhs.gov/about/news/2020/06/09/ocr-resolves-complaints-after-state-connecticut-private-hospital-safeguard-rights-persons.html
LINK to UB-CAM & other delirium tools & 4Ms worksheet	https://deliriumnetwork.org/measurement/adult-delirium-info-cards/ https://www.agefriendlycare.psu.edu/older-adults-and-their-caregivers

- Informing patients with a condition that meets the key exclusion criteria (see Table 1) that aducanumab was studied only in generally healthy people with mild cognitive impairment or mild dementia due to Alzheimer's disease. The studies did not include people with the types of health issues they may have (e.g., atrial fibrillation and on a blood thinner). There are no safety or efficacy data from the aducanumab studies for someone with these conditions.
- Informing people living with Alzheimer's disease and their loved ones about how aducanumab was studied and the basis of the FDA approval. Specifically, and importantly, it is not yet known whether treatments like aducanumab that remove amyloid from the brain produce clinically important slowing of cognitive or functional decline in Alzheimer's disease.

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Aducanumab: What Clinicians Should Know

AGS Geriatrics Healthcare Professionals

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- Establishing, using validated staging tools, that the patient has mild cognitive impairment or mild dementia due to Alzheimer's disease. An example of a validated staging tool is the Clinical Dementia Rating (CDR) scale[1] which is used to assess dementia severity.
- Confirming that the patient has evidence of Alzheimer's disease, defined by a validated test to establish the presence of amyloid pathology. In the trials, a positive amyloid Positron Emission Tomograph (PET scan) was re
- Informing patients about the (Biogen has indicated that th of aducanumab will start at $ there are additional costs rel drug is administered (by infu monitoring of the brain via c and MRI, and any additional (including hospitalization) tha to deal with complications of treatment. Coverage may differ by payer, and this i an evolving landscape given that Medicare, Medicaid, and third-party insurers have not yet issued decisions as to what will be covered.
- Alerting patients that monthly infusions (approximately one hour in length) will be needed for 12 to 24 months or longer; and telling them where they will receive treatment (e.g., in the physician's office, at a health care center, or at another location).
- Alerting patients that they will need to obtain a baseline MRI (within one year prior to commencing treatment) and MRIs prior to the 7th and the 12th infusions.
- Having a plan in place for closely monitoring abnormalities (ARIA). In the trials, if ARIA was found, treatment was suspended until it was the lack of information on the matter, decisions about whether and when to discontinue the drug would be based on clinical judgment.

Guidance/Resources for Aducanumab

EDITORIAL

Aducanumab and the Medicalization (Still) of Alzheimer's Disease: A Challenge to Measure and Act On What Matters

As a doctoral student in the 1990s at the University of California San Francisco (UCSF), I listened intently in class as my interdisciplinary instructors warned of the over-medicalization of Alzheimer's disease and related dementias (ADRD). Patrick Fox, former co-director of the UCSF Institute for Health & Aging, and others warned of the medicalization of ADRD where the biomedical lens dominated all oth-ers. "'We accepted the disease frame,' says Fox. 'People with memory loss became poor, lost souls who need a cure' (Schwartz, 2011, para. 3). Fox in the voices of persons with dementia (PWD) to show the positive aspects knowledge could turn into a negative and stigmatized view of dementia and involve a steady stream of physician visits and over-medicalization.

on dementia from oxybutynin. Her delirium was missed, and she was brought to the emergency department where she was further sedated. After her discharge, Anita accepted home care management and supports who understood her delirium risk factors, behavior expressions, dementia, and her expressed desire to live at home for as long as she could. She was tapered off several medications that had worsened her cogni-tion and function, was provided reg-ular meals and aide help, and stayed home for 1 year after that episode. Anita was able to reconnect with her days, two things that mattered to her and brought her joy.

ve are ed for a drug (aducanumab) was approved by the U.S. Food and Drug Administration (FDA) for Alzheimer's disease in June 2021 without showing any clini-

patient annually, was tested only in persons with mild cognitive impairment, has serious side effects of brain swelling and microhemorrhages, and most certainly will require PWD to sit in an infusion center for a drug that has not shown a clear benefit (Drugs.com, 2021). The cost of the drug will likely take away funds and resources from families and the health care system that are needed to help persons live well with the disease. The drug is already being highly marketed as a "breakthrough" for families des-perate for care.

Where do we go from here? We and must educate consumers and frontline clinicians on the approval process and potential harms (direct and indirect) of aducanumab and help them make informed decisions about the use of this medication and other treatments. We must advertise and promote this information in the same glossy and eye-catching manner as Biogen® and other pharmaceutical companies. Consumers should understand the trial results, the costs of treatment, how the diagnosis was made in the trial, the length and time-

Resources

• Alzheimer's Disease & Down Syndrome A Practical Guidebook for Caregivers
www.ndss.org /about-down-syndrome/publications/

• NTG & NDSS Caregiver News
www.the-ntg.org/caregiver-newsletter-archive

• The Guide to Good Health for Teens & Adults with Down syndrome, Brian Chicoine, M.D., Dennis McGuire, Ph.D.
https://books.google.com/books/about/The_Guide_to_Good_Health_for_Teens_Adult.html?id=v6eQSQAACAAJ&source=kp_book_description

• Alzheimer's Disease in People with Down Syndrome from NIA
https://www.nia.nih.gov/health/alzheimers-disease-people-down-syndrome

Alzheimer's Association Resources

- Education Materials for your clinic
- Caregiver Support
- **24/7 Helpline: 800.272.3900 with Master's level consultants & TDD: 866.403.3073**
- Caregiver education and support groups in local communities

Education Content For Caregivers

(adapted from Marie Boltz, Evidence-based Geriatric Nursing Protocols for Best Practice, 2020, page 338)

- Communicating with the person with dementia
- Maintaining function and reviewing disease & progression
- Advance planning-advance healthcare directives & finances
- Tips to modify the environment as needed for SAFETY
- Caregiver self-care and tips-especially sleep and activity
- Building a caregiver support network
- Managing behavior problems with NON-DRUG approaches – ALL BEHAVIOR HAS MEANING. Listen to the behavior (avoid medications as they cover it up)

National Funding and Centers for Down Syndrome

National Institute of Health The Down Syndrome Consortium-https://downsyndrome.nih.gov/

National Institute of Child Health and Human Development (NICHD)-https://www.nichd.nih.gov/

INCLUDE PROJECT - https://www.nih.gov/include-project

Down syndrome research- https://www.nih.gov/news-events/news-releases/nih-launches-tool-advance-down-syndrome-research

https://www.ndss.org/wp-content/uploads/2020/05/2020-Issue-Brief-on-NIH-Research.pdf

NDSS Aging Initiative https://www.ndss.org/wp-content/uploads/2020/11/Alzheimers-Disease_v02.pdf

Intellectual and Developmental Disabilities Branch (IDDB)-
https://www.nichd.nih.gov/about/org/der/branches/iddb

Thank you & Take Time To Celebrate Down Syndrome & Disabilities Month Regardless of Age/Ability