

Applying findings from a longitudinal study of dementia care group homes to the development of community dementia support services for adults with intellectual disability

Matthew P. Janicki, Ph.D. & Kathryn P. Service, RN, MS, FNP-BC, CDDN

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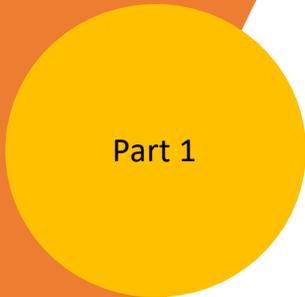
About us



Matthew P. Janicki, Ph.D. is co-president of the US National Task Group on Intellectual Disabilities and Dementia Practices, as well as an associate professor in the Department of Disability and Human Development at the University of Illinois at Chicago and a member of the federal Advisory Council on Alzheimer's Research, Care, and Services. Formerly, he was director for aging and special populations for the New York State Office for People with Developmental Disabilities.



Kathryn Service, RN, MS, FNP-BC, CDDN had worked as an RN/NP for close to 40 years with the Massachusetts Department of Developmental Services. In addition to 'hands-on' clinical support, she has worked together with and presented to people with ID and their families and direct support professionals and now still consults independently on matters on dementia, aging and end-of-life care. She is an officer of the National Task Group on Dementia and Intellectual Disabilities.



Part 1

Some Background on Dementia and Using a Group Home Model

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Why something to think about?

- Dementia is the result of a brain disease or injury, such as Alzheimer's disease, Lewy body disease, or a brain injury or trauma
- With progression an adult with dementia is increasingly less able to take care of him or herself ... and requires supervision and someone to help him or her with basic necessities
- Main dementia care options for most agencies are to support the person in place (whether at home or in their residential accommodation), refer to a long-term care facility, or admit to a specialty dementia-capable group home
- Dealing with dementia calls upon agencies to make some critical decisions about dementia care and developing support resources

Things to know about dementia

Alzheimer's disease is the name of a neuropathic or brain disease – that leads to general dysfunction

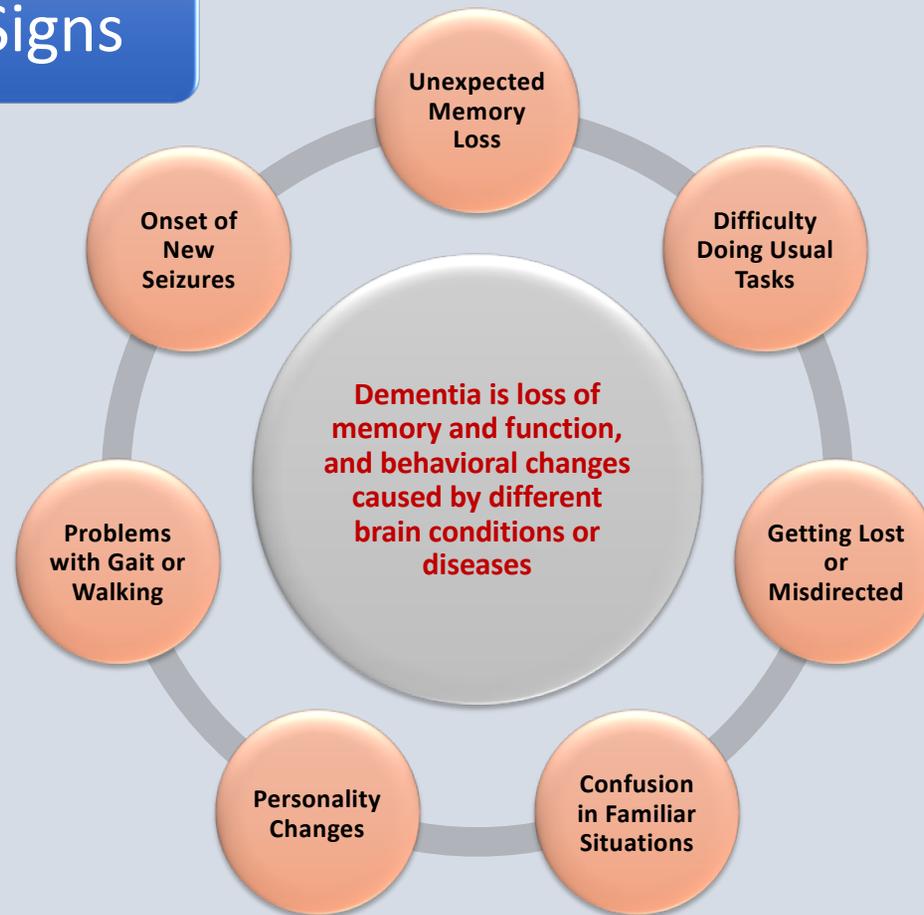
Dementia is the behavioral expression of the brain disease – usually via memory loss and behavioral dysfunction

... losses occur in memory, language, orientation, ADLs [activities of daily living] and changes in personality and functioning

- **Dementia an umbrella term** for a range of changes in behavior and function affecting aging adults and usually linked to brain disease (e.g., Alzheimer's) or injury (e.g., stroke)
 - Alzheimer's is a **disease of the brain** – dementia describes the resulting behavior
 - Most adults with Down syndrome (DS) are at **risk of Alzheimer's disease** and consequently dementia; same risk as general population for adults with other ID
 - **Average age of 'onset'** in Down syndrome is about **52** and +60s/-70s for ID; Alzheimer's begins some 20 years before 'onset'
 - **Changes in memory** often signal dementia in ID; changes in personality often signal dementia in DS
 - After diagnosis **progressive decline in DS** can last for from 1 to 7+ years; up to 20 years in other ID
 - Care after the early stage can become more challenging as memory, self-care, communication, and walking become more difficult... eventually leads to advanced dementia

Dementia Warning Signs

These problems must be notable and usually occur in a cluster



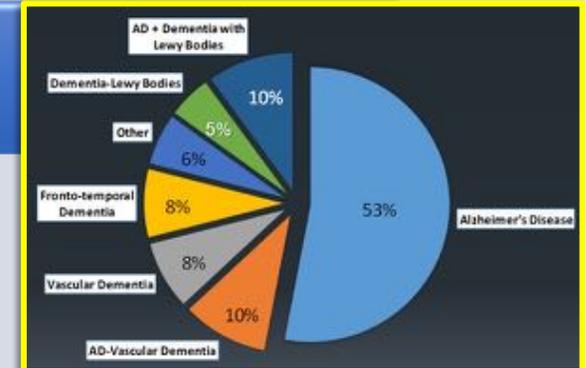
In ID similar signs but of varying presentation depending on level of ID

Type of dementia can influence tx

- Persons with intellectual disability (varying etiologies) may have a variety of dementias due to various causes
- Most adults with Down syndrome will have dementia caused by Alzheimer's disease

Generally,

- **Alzheimer's type dementia** is linear and leads to a slow, progressive decline of function and loss of cognitive abilities
- **vascular dementia** is sporadic, will affect specific parts of the brain damaged by a vascular accident, and will cause a 'stepped' diminution of function
- **fronto-temporal dementia** will first affect behavior and personality and then eventually all function



Why is it useful to know type?

- To determine 'course of treatment' and expectations of staging and rate of decline
- To help with determining best ways to handle 'challenging behaviors'
- To help with organizing care staffing patterns and clinical supports

Impact and changes... ID and dementia

Rate of occurrence ^{1,3,5,8,14}	<ul style="list-style-type: none"> ➤ Age-cohort % for adults with intellectual disability (ID) is like general population (~5-6% over 60) ➤ Much higher prevalence (60% >age 60) and neuropathology indicative of AD in most adults with Down syndrome (DS)
Dementia type ^{2,9}	<ul style="list-style-type: none"> ➤ Generally, dementia of the Alzheimer's type is prevalent <i>in DS</i> ➤ Similar range of dementias found in other ID as in other people
Risk ¹⁵	<ul style="list-style-type: none"> ➤ DS & head trauma are significant risk factors in ID; social deprivation also a factor
Onset ^{1,2,3,10}	<ul style="list-style-type: none"> ➤ Average onset age in early 50s <i>for DS</i> – late 60s for others ➤ Most DAT diagnosed within 3 years of “onset” in adults <i>with DS</i>
Behavioral changes ^{2,3,6,11,12,13}	<ul style="list-style-type: none"> ➤ <i>In DS</i> - early change in personality more evident ➤ In other ID - initial memory loss more evident ➤ Notable changes in behavior: aggressiveness, agitation, apathy, incontinence, irritability, sleep disturbance, uncooperativeness
Neurological signs ^{1,2,4,7,16,17,18,19}	<ul style="list-style-type: none"> ➤ Late onset seizures in 24%-53% of adults w/DS ➤ Late onset seizures in DS - indicator of life expectancy of less than 2 years ➤ Seizures more common at end-stage (84%) versus at mid-stage (39%) AD
Duration ^{2, 17}	<ul style="list-style-type: none"> ➤ Aggressive AD <i>in DS</i> can lead to death <2 years of onset ➤ 2-7+ years mean duration <i>in DS</i>; probable death within 3-5 years of onset ➤ Same duration expected among other ID as in other people with dementia

Sources: "Hollis, M. P. & Bithell, A. J. (2005). Prevalence of dementia and impact on intellectual disability services. Mental Retardation, 33, 373-389." "Lynch, M. P. & Bithell, A. J. (2008). Dementia, aging and intellectual disability: A handbook. Philadelphia: Brunner-Mazel." "Nash, A., & Bock, N. (2006). Risk factors for dementia and Down syndrome. JAMA, 295, 28-31." "Mendenhall, M. (2001). Down syndrome, Alzheimer's disease and autism. Birth Development, 27(5), 261-272." "Eggen, W. A., Chahuf, S., Swanson, D., et al. (2006). Incidence and prevalence of dementia in elderly adults with ID without DS. JAMA, 295, 232-241." "Wol, S.L., Wolford, A.A., Hill, L., Huggan, J.L., Trappner, S., Wilson, M., et al. (2005). Personality and behavior changes in the early stages of Alzheimer's disease in adults with Down's syndrome: findings from a prospective population-based study. International Journal of Geriatric Psychiatry, 20(6), 592-601." "Carpel, A., Giacino, P., Calkins, P., Gellera, P., Gellera, P. (2007). Brain structural changes of dementia: Two cases in Down's syndrome with dementia and the onset of epilepsy. Epilepsy Research, 77, 265-268." "Sommers, M. (2007). The etiology of dementia in aging people with intellectual disability. JAMA, 297, 1412-1419." "Simpson, A., Langston, G., King, M., & Reynolds, A. (2007). Prevalence of dementia in ID using different diagnostic criteria. J. Psychiatry, 191, 128-137." "Kopelman, M. S., (2002). Memory impairment in Down syndrome. Psychological review of the Department of Psychology, University of York, York, UK." "Carpel, A. (2011). Research on memory in Down syndrome. Psychological review of the Department of Psychology, University of York, York, UK." "Morgan, J. (2007). Symptoms of dementia among adults with Down's syndrome - a qualitative study. Journal of Intellectual Disability Research, 12(5), 728-739." "Carpel, A. (2005). A population-based study of memory impairment in Down syndrome: A qualitative study. Journal of Intellectual Disability Research, 10(5), 412-421." "Tay, L.B., Dool, R. (2007). Aging and mental health problems in people with intellectual disability. Current Opinion in Psychiatry, 20(5), 467-471." "Harris, J.A., Bell, M., & Kohn, L.M., Singh, R.K., & Jansini, M. P. (2011). The National Task Group on Intellectual Disability and Dementia: Practice consensus recommendations for the evaluation and management of dementia in adults with intellectual disabilities. May: Child Psychiatry, 48(5), 831-840." "Litherton, A.J. (2010). Health conditions associated with aging and end of life of adults with Down syndrome. Int Rev Res Ment Retard, 36(2), 187-198." "Parker, J.P. & Corbett, A. (2006). Short lifespan as a poor indicator of longevity in people with Down syndrome and dementia. International Journal of Geriatric Psychiatry, 21(1), 98-103." "Katherine, Hinton, Leonard, & Brown. (2001). Prevalence of epilepsy among people with intellectual disability: A systematic review. JAMA, 285, 48-52." "McCormick, M., Gilliam, M., McClellan, A., Murphy, C. (2005). Health in individuals in aging persons with Down syndrome and Alzheimer's dementia. J Intellectual Disability Res, 10, 100-108."

Signs & Symptoms - Staging in AD

Early Stage	Middle Stage	Late Stage
Confusion and memory loss	Difficulties with ADLs [“activities of daily living”]	Loss of speech
Disorientation in space	Anxiety, paranoia, agitation and other compromising behaviors	Loss of appetite, weight loss
Problems with routine tasks	Sleep difficulties	Loss of bladder and bowel control
Changes in personality and judgment	Sleep difficulties	Loss of mobility
	Difficulty recognizing familiar people	Total dependence on others
		~Death

Key Aspects of Dementia Presence to Consider When Planning Housing



Onset

When change is first noticed

For DS: $\bar{X} = 52$

For ID: $\bar{X} =$ late 60s - early 70s

Prevalence (DS \nearrow 66%+

ID \rightleftharpoons 5 - 6%)



Progression

Patterns of change and decline

For DS: Some quick losses, other more normative (changes in personality before memory)

For ID: Varied trajectories; leading to progressive decline



Duration

Length of time persons are affected

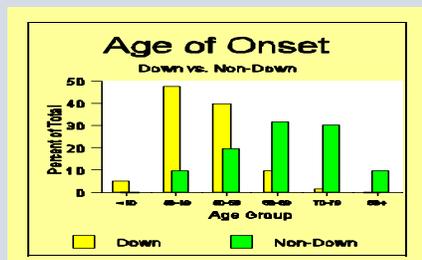
For DS: Compressed duration

For ID: Similar to general pop

Factors to consider in dementia housing and care planning

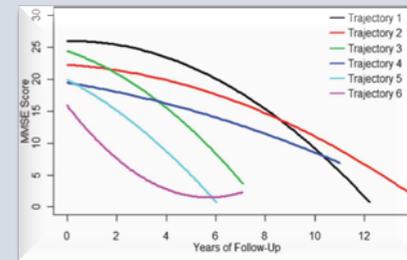
Onset

- *Onset is speculative . . .*
 - the best we can do is identify that point when significant change or impairment has become noticeable
 - early 50s for Down syndrome & late 60s for other ID



Trajectory

- Be aware of the expected trajectory of progressive dysfunction
- Influenced by
 - Duration (remaining life years)
 - Type of dementia
 - Health status/co-incidence conditions



Why is 'onset' of importance?

- Knowing expected onset gives a head's-up for surveillance
 - Look for changes
 - Introduce periodic screening
 - Alert staff/caregivers to be watchful
 - Provides for an 'index of suspicion'
- Helps us to reformulate services and care practices
 - Creating safer environments
 - Signaling changes in demands for daily efforts
 - Planning ahead for eventualities
 - Setting goals for terms of service – adapting personal program plans



EXPECTATION OF CHANGE AND FACTORS IN ID AND DEMENTIA UNDERLYING HOUSING AND CARE PRACTICES

Expectations of change

- Cognitive skills will decline
- Support needs will increase
- Increase risks of falls, injuries
- Swallowing dysfunction, clots, pneumonia, bladder infections, nutritional deficiencies, seizures

Care factors

- Watch for signs of abuse and neglect (including self-neglect)
- Watch for signs of caregiver burn-out and stress at home ... affected on adult's behavior
- Watch for advanced dementia and needs for end-of-life care (palliative care and hospice)

ID associated issues that extenuate these factors:

- Co-incident conditions that may affect gait, sensory faculties, and cognition
- Co-morbidities or diseases that may affect physiological functions
- Previously identified 'mental health' issue
- Late-onset seizures
- Precocious (early) aging effects
- Expressive language difficulties
- Nutritional deficiencies & diet inadequacies
- Presence of polypharmacy

Options for dementia care

Staying

Staying at home

- Continued care by family members until eventual advanced dementia and end-of-life
- *Considerations:* home adaptation, close supervision for safety and avoiding self-harm or neglect 24/7, possible wheelchair use, palliative and/or hospice aid

Agency focus
Outreach and
community supports
(HCBS)
Helping support family
caregivers

Leaving

Leaving home

- Admission to a nursing facility after non-ambulatory care is necessary
 - *Consideration:* SNF capability & understanding of DS?
- Looking for an agency run specialty dementia care group home
- Other options – perhaps memory care centers, assisted living programs?

Agency Focus
Securing housing with
dementia specialty
care
Clinical team supports
Training for staff

Prevalent models of group home-based dementia care

AGING-IN-PLACE

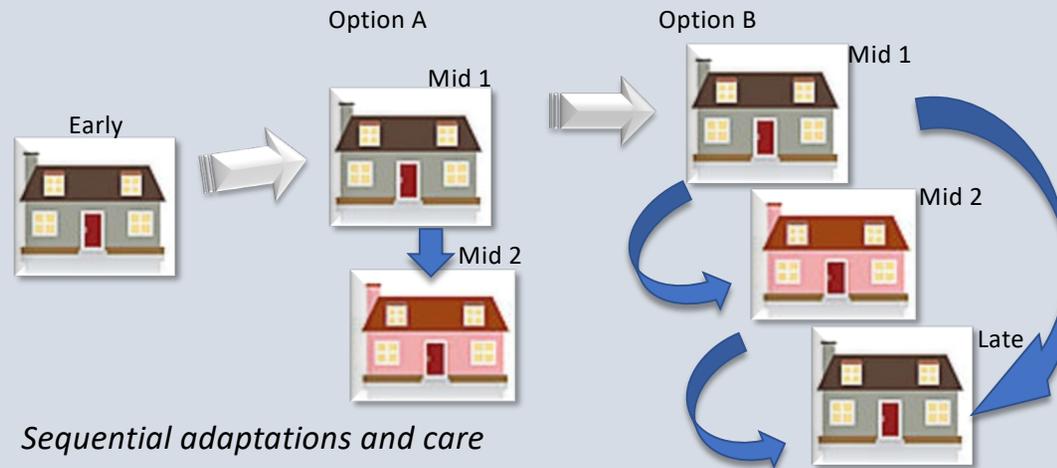
- single care home and stable stay



Linear adaptations and care

IN-PLACE-PROGRESSION

- multiple care homes & movement with progression



Mid = mid-level

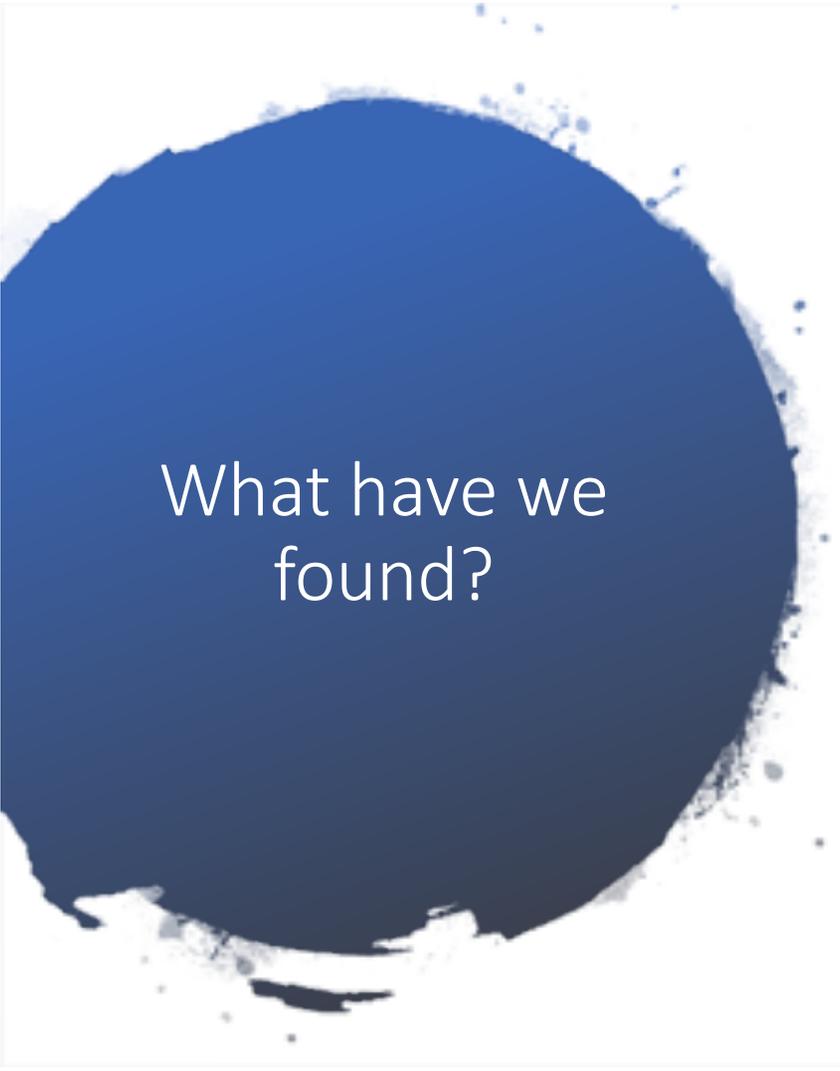
Source: JANICKI (2010)

Sequential adaptations and care

Study



- Since 2011, we have been following a cohort of 15 legacy adults with ID (w/15 replacements) who lived in **3 purpose-built, 5-resident, dementia-capable GHs**
 - along with 15 community-dwelling (non-dementia) adults with ID as age-matched controls
- Data collected include resident function, demographics, health, and other related information as well as staff/home administrative factors



What have we
found?

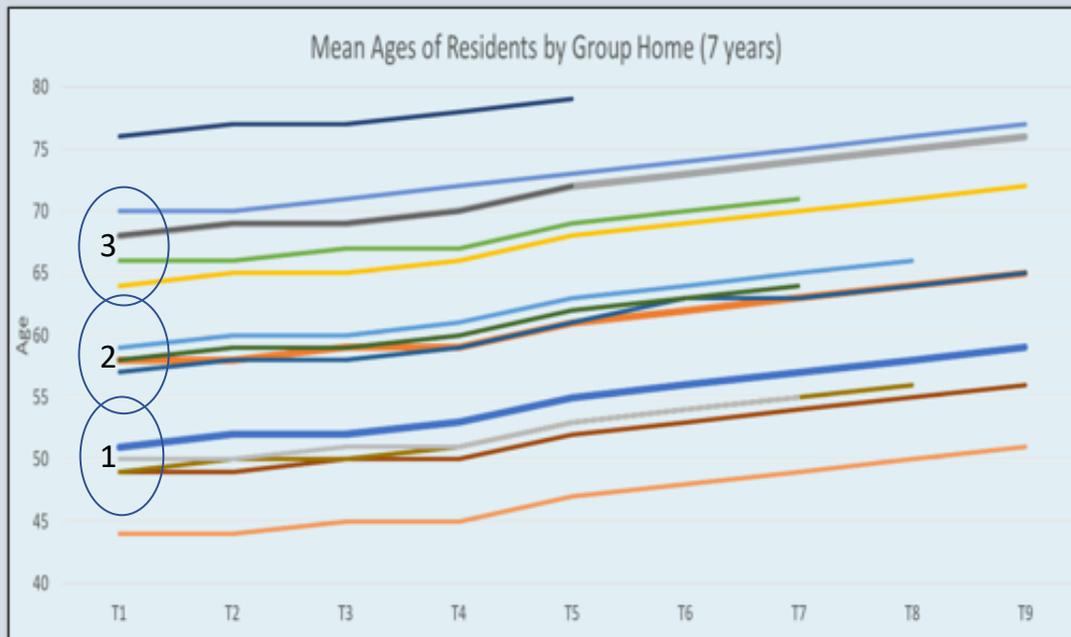
√ Admission trends

√ LOS

√ Mortality

√ Care patterns

√ Staffing



Admission age clusters

Admissions based on dementia and age showed a **tri-modal** pattern

- Admit Age Group #1 entry:
± age 50 [X=50.5] [range: 49-53]
– *generally DS*
- Admit Age Group #2 entry:
± age 57 [X=57.1] [range: 56-59]
– *some DS and ID*
- Admit Age Group #3 entry:
± age 67 [X=66.8] [range: 64-70]
– *generally ID*

Outliers were either

- much older [76, 79] or
- much younger [40, 44]



Length of stay patterns by home

Average LOS over 10 years for 3 group homes was 4.9 years (58.5 months)

includes transfers, deaths, and new admissions

Average LOS for 15 'legacy' residents over 10 years was 8.3 years (99.6 months)

Implication

home compositions may change over time

Lighter color = DS

Mortality

Original residents n=15

Survivor residents n=4 (27%)

11/15 (73.3%) died over 10 years

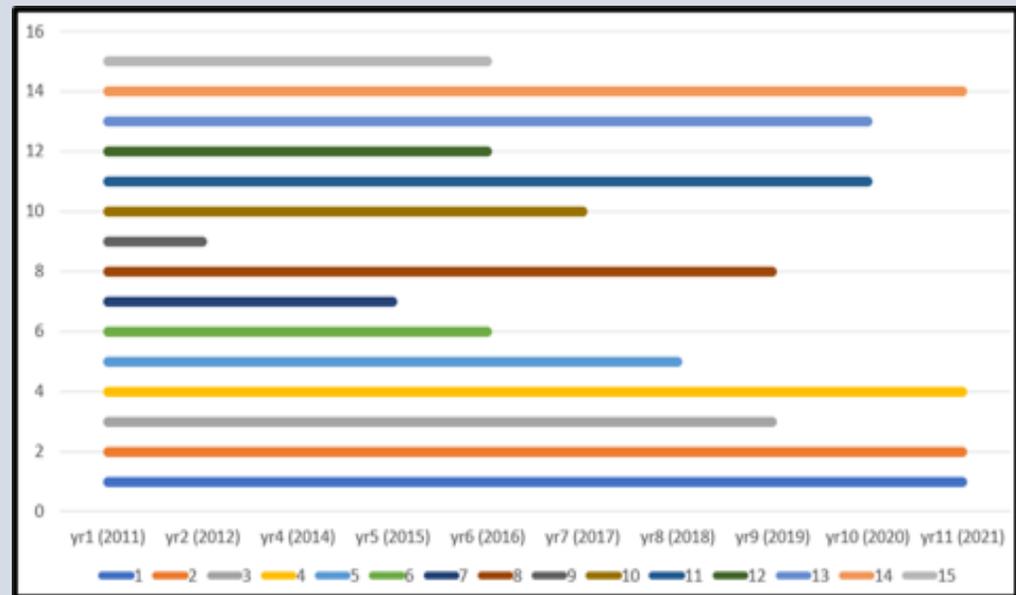
- Mean age at entry: 59.1
 - [ID: 66.2; DS: 53.5]
- Mean age at death = 67.5
 - [DS: 58.8; ID: 72.4]
 - Males = 66.3 yrs; Females = 69.5 yrs
- Mean years from entry to death: 5.4 yrs

Mean age at entry of original residents who

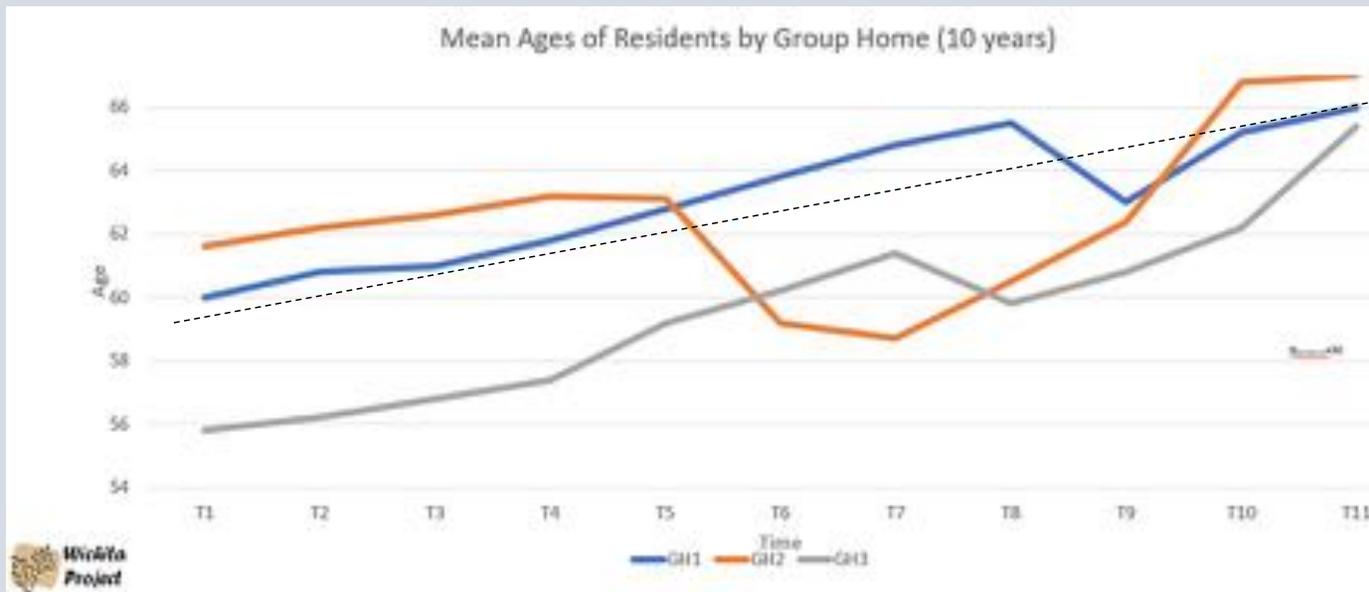
> died = 60.9

> are survivors = 54.4

- Deaths began 2 years following admission
- Average age of death for controls: 71.4 yrs
 - 5/15 (33%) deaths among controls



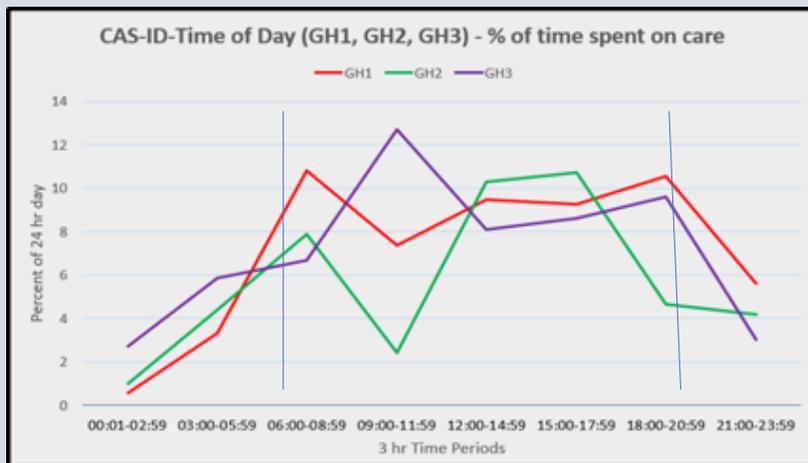
Legacy residents



Aging in place

- Long-term residents age in place and mean age of residents progressively rises
- New entry residents, if younger, lead to lower mean age, but eventually also show aging in place
- Implications – with aging, comorbidities increase need for health and medical care

Staff time care patterns by home



- Staff care time patterns varied by homes as well as the caregiving focus
- Most time was spent on
 - **toileting aid** (GH1/GH3)
 - **eating/drinking assistance** (GH1/GH2)
 - **behavior management** (GH2)
- *Chart shows 3hr block pattern variations by home (averaged over 3 times – T1, T5 & T8)*

Staff Assigned to Each Home

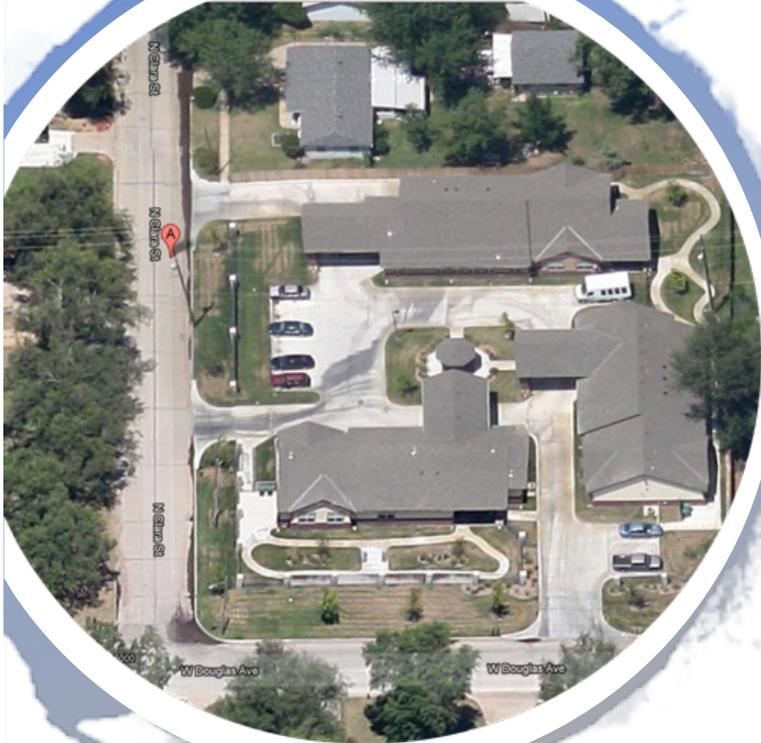


Staff assignments by home

- More staff were assigned to GH3 – the advanced dementia home
- Mean staffing: 4.3 full-time and 2.3 part-time
- Implication – consider staffing patterns at home
 - Need more staff during times of peak activities and care
 - Need specialized staff
 - Plan for turn-overs

Findings

- Of the 15 legacy residents 11 died and were replaced by 15 others (*greater mortality was noted among legacy residents with ID compared to DS*)
- All 30 residents (legacy and replacements) – exhibited features related to decline (*increasing problems, more comorbidities with age, and lessened function with dementia progression*)
- With multiple homes, over time there were inter-home transfers and new admissions, and the GHs trended toward stage/level specialty care
- There was an ebb and flow of movement related to stage of dementia and changes in character among the 3 dementia GHs, as well as variations in staffing patterns and periods of focused staff care and intensity during the day
- Costs and staffing patterns varied among the homes



Implications for dementia care housing

Location	Safety	Utility	Design
<ul style="list-style-type: none">* Normative appearance and siting* Ease of access to off-housing resources and amenities	<ul style="list-style-type: none">* Control egress and facilitate outdoor use* Evacuation factors* Wandering paths* Minimizing risk	<ul style="list-style-type: none">* Single story* Ambulation ease* Wheelchair use* Privacy vs public spaces	<ul style="list-style-type: none">* Planful transitions with decline* Functionality (bathing, common areas, colors, lighting, etc.)



What to think about...

- Is the **building** set up for dementia care? (single level, lighting, barrier free, yard)
- Have **staff** received specialized training?
- At what point does the agency **'admit'** to the home? Criteria? Matching to level of other residents?
- At what point does the agency **'terminate'** care? What are the policies? End-of-life options?
- How is the daily **support program** individualized? Involvement in community? How adapted to change in functions? How long do people **stay** at the home? Adaptable for advanced dementia?
- What are the attitudes and **capabilities** of staff? Is there comfort with dementia-capable care? Comfort with skills?
- What are the training and **clinical supports**?



Last thoughts

- Dementia care expectations
 - **varied trajectories of decline**
 - **mortality linked to complexity of pre-existing conditions and progression of dementia**
 - **changes in the focus of care needs over time** (including advanced dementia and end-of-life care)
- Effective in-community dementia care is contingent on understanding
 - **what dementia does** to behavior and function
 - how well **staff are trained**
 - how agencies **provide supports** – *such as*
 - clinicians who can consult on care issues
 - help with planning when changes occur
 - staffing levels based on needs for care

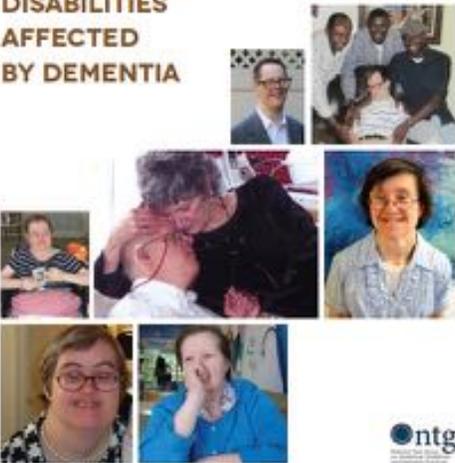
NTG Guidelines



Guidelines for Dementia-related Health Advocacy for Adults with Intellectual Disabilities and Dementia of the National Task Group on Intellectual Disabilities and Dementia Practices.



GUIDELINES FOR STRUCTURING COMMUNITY CARE AND SUPPORTS FOR PEOPLE WITH INTELLECTUAL DISABILITIES AFFECTED BY DEMENTIA




DIAGNOSIS AND TREATMENT GUIDELINES
Consensus Recommendations

The National Task Group on Intellectual Disabilities and Dementia Practices Consensus Recommendations for the Evaluation and Management of Dementia in Adults With Intellectual Disabilities

Julie A. Moron, DO; Michael S. Ruff, MD, PhD; Seth M. Keller, MD; Baldev K. Singh, MD; and Matthew P. Jenike, PhD

Abstract

Adults with intellectual and developmental disabilities (ID/DD) are increasingly presenting to their health care professionals with concerns related to growing older. One particularly challenging clinical question is related to the evaluation of suspected cognitive decline or dementia in older adults with ID/DD, a question that most physicians feel ill-prepared to answer. The National Task Group on Intellectual Disabilities and Dementia Practices was convened to help formally address this topic, which remains largely underrepresented in the medical literature. The task group, comprising specialists who work extensively with adults with ID/DD, has promulgated the following Consensus Recommendations for the Evaluation and Management of Dementia in Adults With Intellectual Disabilities as a framework for the practicing physician who seeks to approach this clinical question practically, thoughtfully, and comprehensively.

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The National Task Group on Intellectual Disabilities and Dementia Practices (NTG) was formed as a response to the National Alzheimer's Project Act, legislation signed into law by President Barack Obama. One objective of the NTG is to highlight the additional needs of individuals with intellectual and developmental disabilities (ID/DD) who are affected or will be affected by Alzheimer's disease and related disorders. The American Academy of Developmental Medicine and Dentistry, the Rehabilitation Research and Training Center on Aging With Developmental Disabilities (Gayatri, Health and Pavilion at the University of Illinois at Chicago, and the American Association on Intellectual and Developmental Disabilities) conducted their efforts to form the NTG to ensure that the concerns and needs of people with intellectual disabilities and their families, when affected by dementia, are and continue to be considered as part of the National Plan to Address Alzheimer's Disease¹ issued to address the requirements of the National Alzheimer's Project Act.

Among the NTG's charges were (1) identification of unmet dementia care and help-desire needs of dementia-related decline in adults with intellectual disabilities, (2) the development of practice guidelines for health care and supports related to dementia in adults with intellectual disabilities, and (3) the identification of models of community-based support and long-term care of persons with intellectual disabilities affected by dementia. In 2012, the NTG issued a *White Paper on Aging With Intellectual Disabilities: A National Strategy for Enabling Adults With Intellectual Disabilities Affected by Dementia to Remain in Their Communities and Realize Quality Outcomes*.²

As a byproduct of the NTG's work, consensus documents specifically on health practices, the guidelines and recommendations included in this document represent the consensus reached among staff specialists at 2 primary meetings and ongoing discussions that followed, informed by a review of the current literature and drawn

from the National Center on Aging with Intellectual Disabilities (NCAID) website. The NCAID website is available at <http://www.ncaid.org>. The NTG is a part of the National Task Group on Intellectual Disabilities and Dementia Practices, which is a part of the National Plan to Address Alzheimer's Disease.

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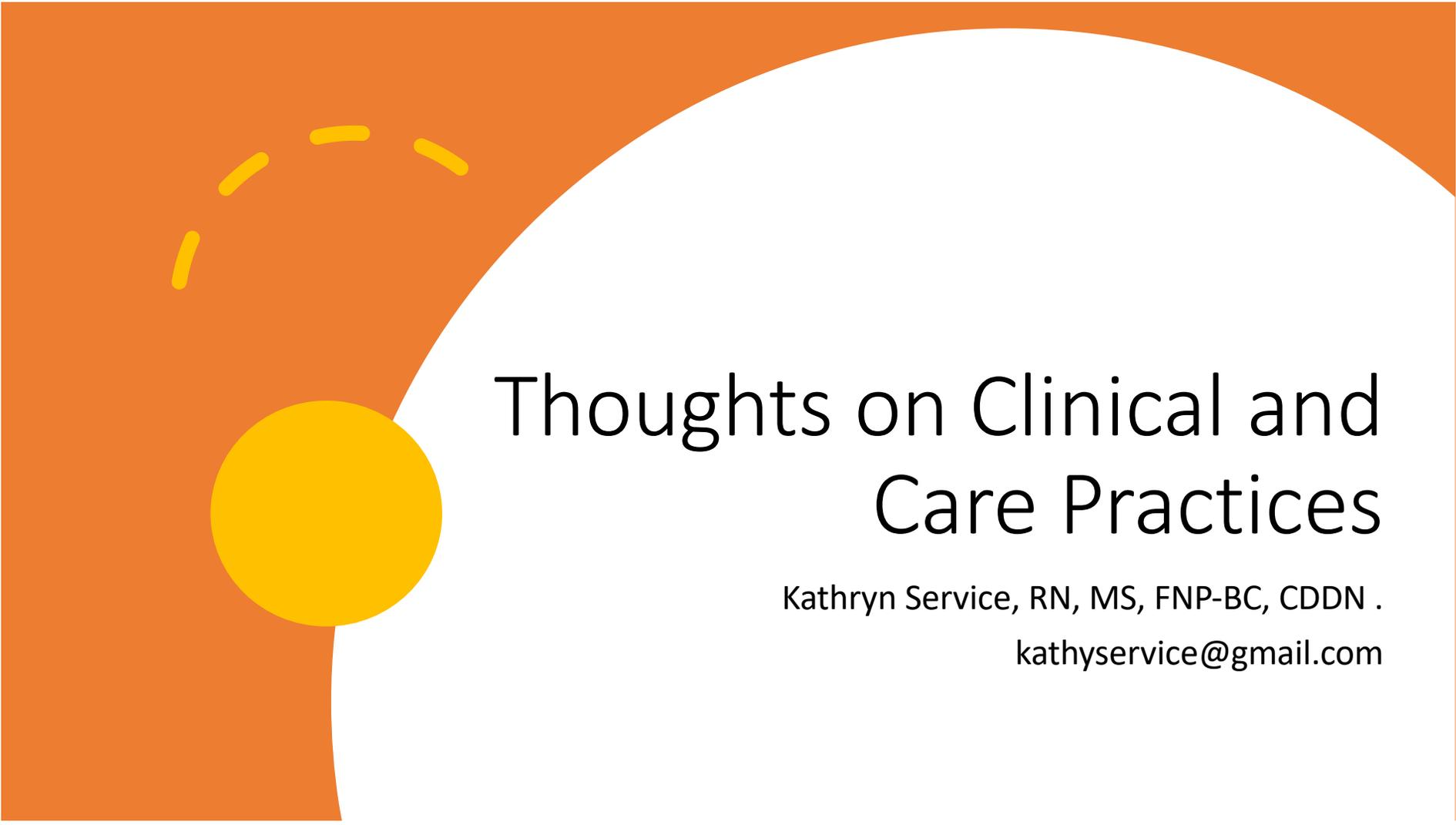
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Thoughts on Clinical and Care Practices

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Eight Common Principles for Supporting People with Dementia

(WHO, 2002)

- **know the early signs of dementia**
- **early diagnosis of dementia helps people receive information, support, and treatment at the earliest possible stage**
- **communicate sensitively to support meaningful interaction**
- **promote independence and encourage activity**
- **recognize signs of distress and respond by diffusing a person's anxiety and supporting their understanding of the events they experience**
- **family members and other caregivers are valued, respected, and supported just like those they care for and helped to gain access to dementia care advice**
- **managers take responsibility to ensure members of their team are trained and well supported to meet the needs of people with dementia**
- **multiagency team work to support persons with dementia**

Guiding Concepts

Lifespan

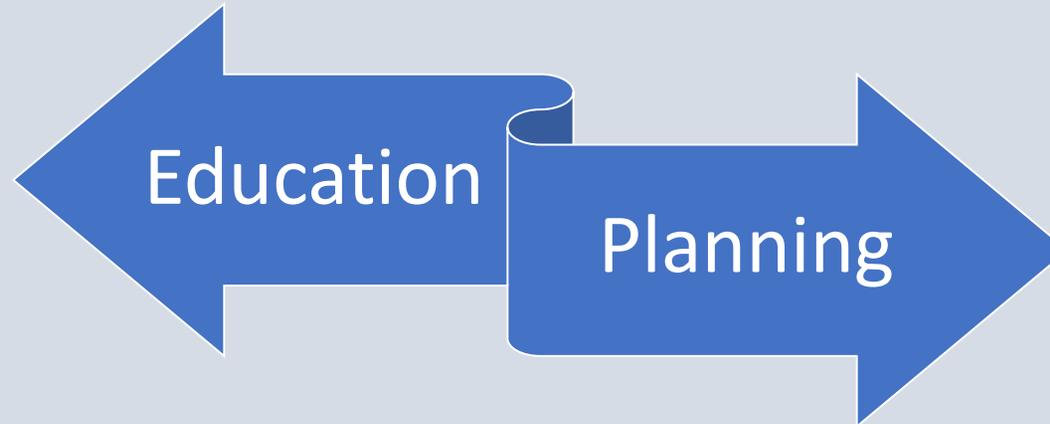
Well-Being

Centered Person &
Relationship

Yesterday, Today &
Tomorrow



Interventions



Planning

Goals

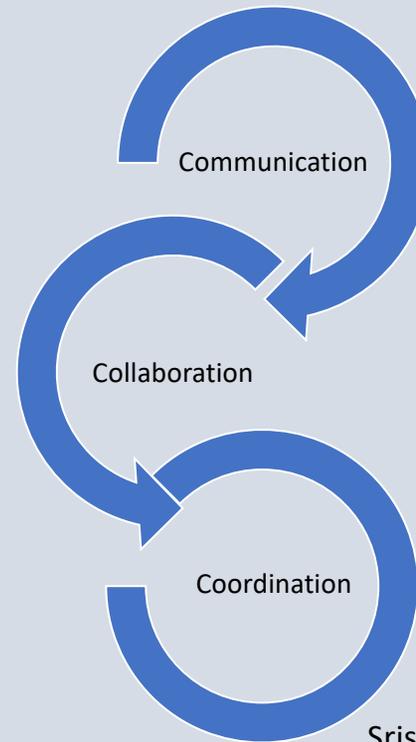
Decisions

Dynamic

Relationships

Discovery consists in seeing what everyone else has seen but understanding it for the first time.

Albert Szent-Gyorgyi, Nobel Laureate in physiology & medicine



Srisic –Stoehr, 2013

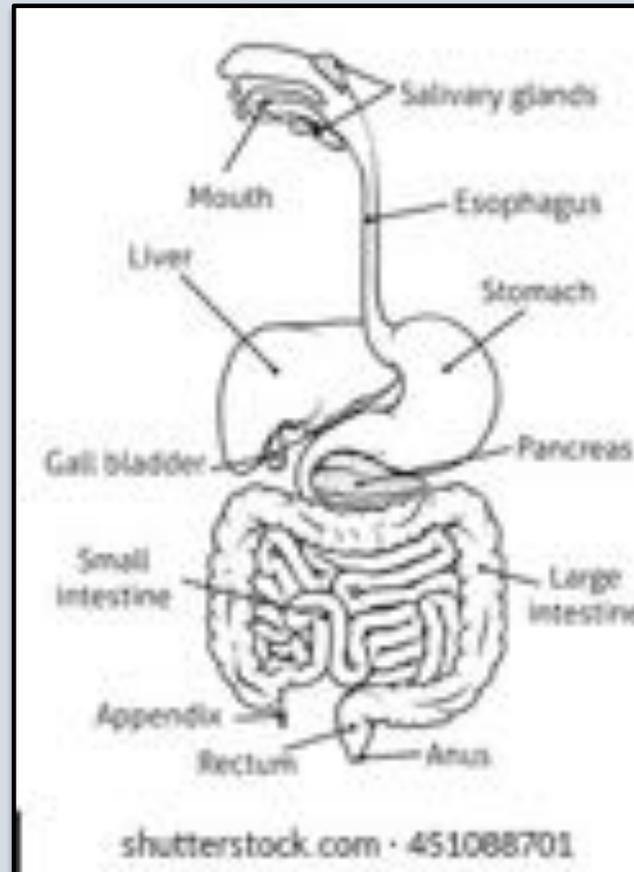
Factors for
'Well-Being'
across the
lifespan –

6 Pillars of Brain Health



Nutrition Intake and Output

- Risk Malnutrition & Weight Loss (>5%)
- Preferences
- Routines
- Expression of hunger/thirst
- Appetite
- Dysphagia
- Dental
- Constipation
- Dehydration
- Keeping Track of the GI Tract!



Resources

- 2020-2025 Dietary Guidelines for Americans. U.S. Department of Health and Human Services and U.S. Department of Agriculture.
<https://www.dietaryguidelines.gov>
- <https://www.nia.nih.gov/health/healthy-eating-and-alzheimers-disease>
- [Eating well for older people and older people with dementia: Practical guide](#)
This 2011 guide from the Caroline Walker Trust explains why eating good food matters for older people with dementia, suggests types and amounts of food that might be appropriate to meet nutritional needs, and includes sample menus.
- **STAY TUNED**



Exercise & Movement

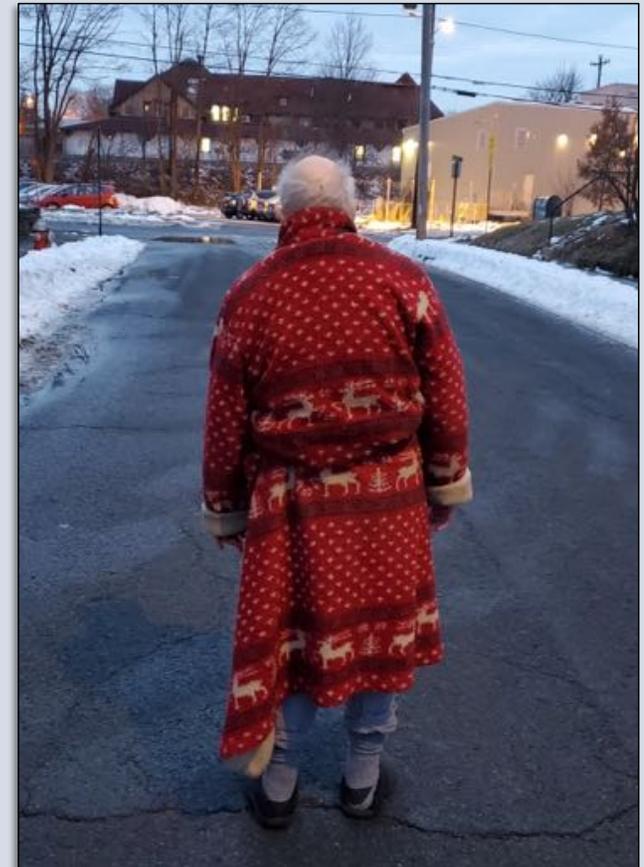
- improved mood
- better sleep
- reduced likelihood of constipation
- maintenance of motor skills
- reduced risk of falls because of improved strength and balance
- reduced rate of disease-associated mental decline
- improved memory
- <https://www.alz.org/help-support/caregiving/daily-care/activities>

- Schedule routine for opportunities for movement throughout the day
- Make it fun!
- Create pathways in and outside of house (enclosed yard)
- Safeguards for falls
- Concept of movement-wayfaring vs wandering (Graham , 2017)

Wandering

- Keep a routine, supervision and structure. **Anticipate** and address basic needs
- Keep schedule for **movement throughout the day**
- Look at the **person's life story** to anticipate and plan for possibilities
- Know who may be a risk and **plan accordingly**; e.g., if it occurs at the same time, plan meaningful activities during this time
 - Know what side is dominant as people may tend to wander in the direction of the dominant hand
- Remove or **reduce any hazardous situations** such as gates at stairs
- Camouflage doorways and other potential invitational opportunities using **visual deterrents**
- **Install locks** and alarms such as motion sensor devices, door chimes and locks, baby monitors, GPS devices, and other commercially available products
 - Some group homes may need to follow certain protocols such as Human Right Review to implement, but documentation with rational reasons can support this intervention
- **Have a plan** in place that outlines typical tendencies meaningful sites and includes a picture of the person, medical information, emergency facts sheet.
- Know your home, neighborhood and neighborhood for potentially **dangerous spots**
- **Develop relationships** with local police and neighbors and close friends and inform them of this possibility
 - Group homes will need to consider HIPPA related protocols and plan accordingly
- Enroll the person in **Safe Return** which is a registration (for a small fee) with the Alzheimer's Association.

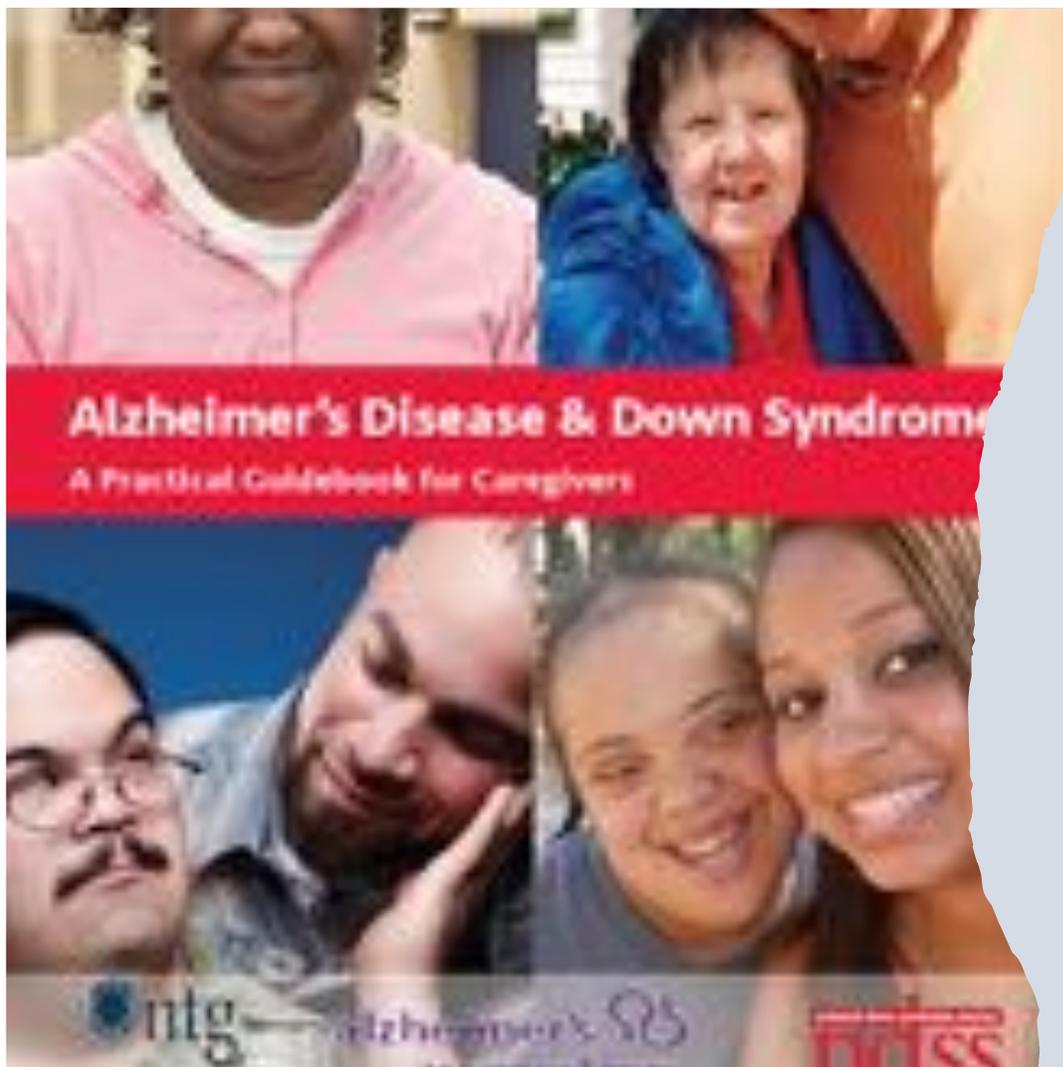
Wait no more than 15 minutes before calling 911



Sleep & Relaxation

- Have a consistent wakeup time, no matter when the person goes to sleep
 - Discourage napping during the day
 - Keep the house brightly lit both day and night
 - Establish a bedtime ritual which is consistent every night -avoid upsetting activities in PM.
 - Do not offer liquids three hours before bedtime and be sure that toileting has occurred
 - Offer a “warm, fuzzy” object or soothing music for comfort
 - Avoid caffeine, excess sugar, and alcohol. Review medications for side effects
- Offer any prescribed pain medications a half hour before bedtime ***PRN
 - Temperature in room
 - Check mattress comfortability
 - Weighted or cozy blankets
 - Fiddle Mitts
 - Document
 - SAD Light
 - 5-10 min AM
 - 5-10 min noon





Mental Stimulation

- Make it meaningful
- Lifestory
- Provide help to extent it is needed
- Failure free
- Make it fun familiar and pleasurable and capitalize on existing strengths and abilities
- Take time
- Sensorimotor Enhancement
- Toolbox

<https://www.ndss.org/about-down-syndrome/publications/caregiver-guide-order-form/>

Medical Health

- Keep routine appts up-to-date
- Vaccinations
- Regular reviews of medications
- Communication amongst the health care providers
- Transitions
- Falls
 - Describe (ABC's)
- Chronic Disease Management/Multimorbidity
- Relationships
 - Providers
 - Guardians
 - Family



Delirium

- People w/dementia had 15 times the risk of developing delirium than those without (primary care)
- Risk factors: sensory impairment, pain, polypharmacy, dehydration, intercurrent illnesses, such as urinary tract infections or constipation/impaction, and an unfamiliar or changing environment
- Neurodegenerative losses increase vulnerability to stress and triggers
- Interventions: hydration, medication reviews, sleep promotion- 'familiarity' & back to routine
- NB: Hospitalization – Adverse unintended consequences

<https://www.nia.nih.gov/health/going-hospital-tips-dementia-caregivers>,
https://memory.ucsf.edu/sites/memory.ucsf.edu/files/wysiwyg/acute_hospitalization_and_alzheimers.pdf



Social Interaction

- Education
- Communication
- Lifestory
- Environment
 - Internal
 - External
- Connections
- Combination

The continuum continues



Early



Middle



Late



Early Stage (from Jokinen et al 2013)

Engage	Engage the individual and their family, and/or other carers or guardians in advance care planning (and prepare advance directives) consistent with state or other requirements.
Identify and plan	Identify and plan to remediate the environmental challenges to help maintain community living
Establish	Establish a daily regime that provides for purposeful engagement based on individual needs and preferences, yet is organized so as not to cause anxiety and confusion
Provide	Provide ongoing clinical supports to address behavioral and psychological symptoms associated with dementia
Redesign	Redesign day activities and programs so that participation in valued activities and opportunities for interaction with others continues and respite for families and other caregivers is possible

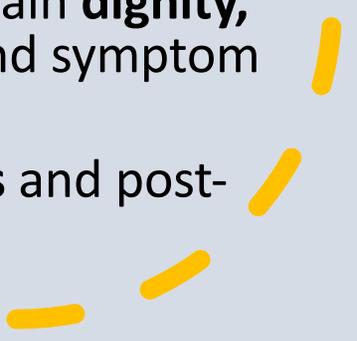
Mid Stage

(from Jokinen et al.,
2013)

- Provide increased assistance with **personal care and hygiene** when needed
- Secure appropriate residential supports and consider housing options to **accommodate increasing losses** in independent functioning
- Continue surveillance and periodic **assessments** to determine extent of change and progressive dysfunction as well as the possible development of comorbid conditions
- Monitor any **medications** being taken to prevent ADRs
- Enhance **training of staff and family** as well as consultation to carers around coping with behaviors and adapting routines
- Institute planning for **long-term services** and supports
- Ensure **protections are in place** to preclude abuse or harm in both formal and informal settings.

Late / End Stage

(from Jokinen et al.,
2013)

- Reorganize care management toward **nonambulatory care**
 - Reassign staff to activities more structured around nursing and **personal care** including the support of family carers who wish to maintain the person at home
 - Obtain support from **palliative care** or hospice specialists
 - Institute procedures to maintain **dignity, comfort, and address pain** and symptom management
 - Organize **end-of-life supports** and post-death arrangements
- 

Proactive Planning Dementia : Ponderings

Keeping the person at
the center

Own personal values

Limits to anticipatory
choices

On going

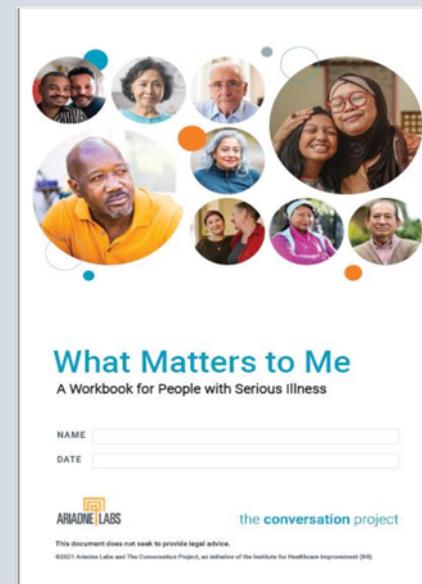
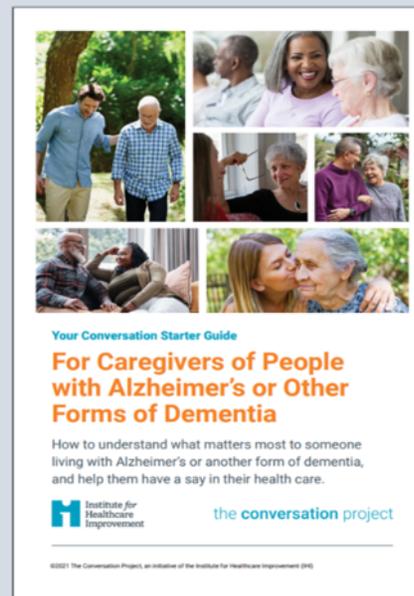
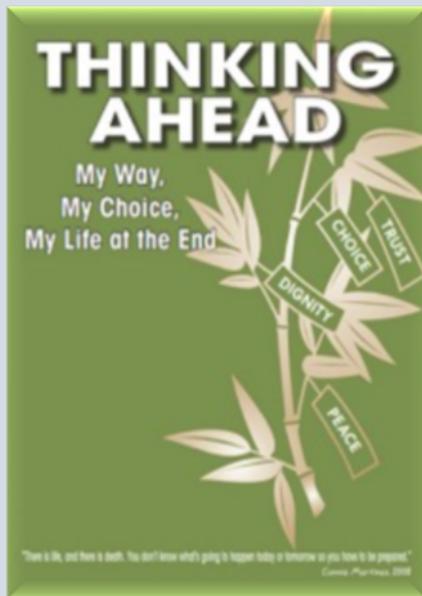
Prognostic uncertainty

Increasing 'hands-on'
for the caregiver

Conflicts & Obligation

Think about goals:
Living longer,
maintaining current
health, comfort care?

Tools to help:



<https://www.coalitionccc.org/CCCC/CCCC/Resources/People-With-Developmental-Disabilities.aspx>

<https://theconversationproject.org/wp-content/uploads/2020/12/DementiaGuide.pdf>



Development of a Plan of Care

FOCUS ON THE INDIVIDUAL

How do we feel about this person and what is happening to them and what will be happening to them? Remember the meaning of relationships.

WORK TOGETHER

Support each other, be honest and truthful about what it is “going to take”, what decisions need to be made, and whose lives will be affected. Share responsibility and listen to each other.

EDUCATE OURSELVES

What is the disease and what can we expect? What resources are available?

DEVELOP A SUPPORT PLAN

Plan actions by balancing emotions with facts. Be good observers and reporters of information. Explore all avenues.

MONITOR FEELINGS

Acknowledge feelings but watch reactive behavior.

BE REALISTIC

Grieve for the losses that are experienced, but also enjoy the memories and live for the day.

BE KIND

To others as well as yourselves (Painting by Barbara, a woman w/DS & AD, 1996)

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