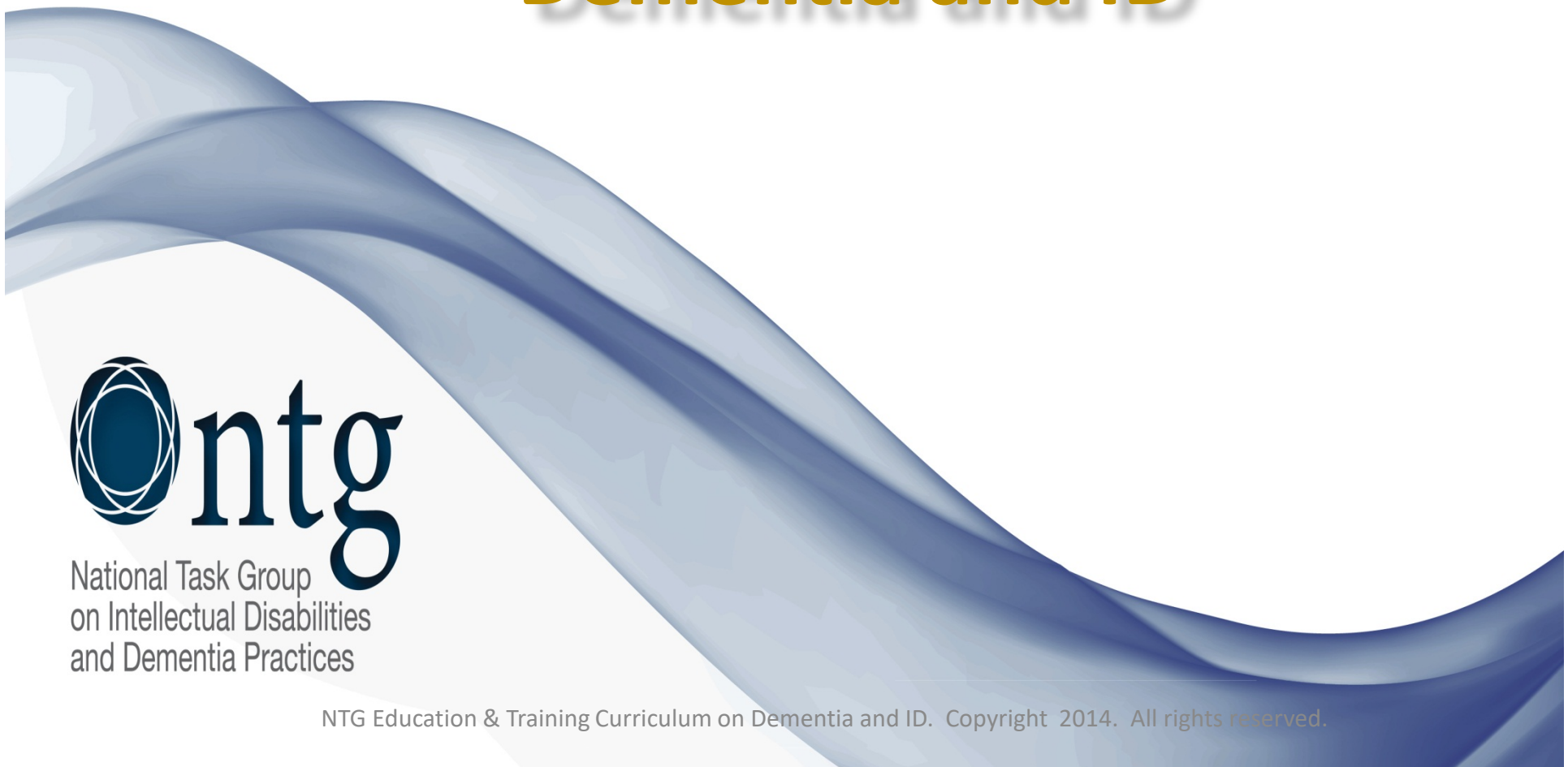
Introduction to Dementia and ID



National Task Group
on Intellectual Disabilities
and Dementia Practices

Dementia 101

Understanding the basics of dementia as it impacts adults with ID.

4 Most Important Facts About Dementia

1. "A loss of cognitive (thought) function **severe enough to interfere with daily functioning."**

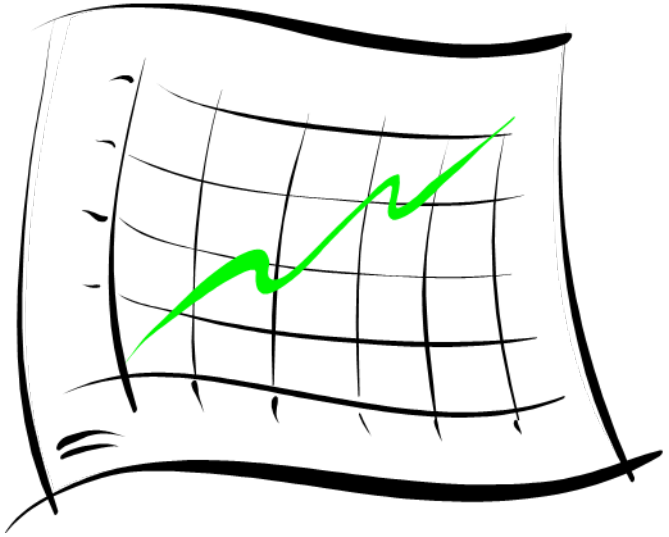
2. The term "dementia" describes a group of **symptoms**.
    a. It is **not a specific disease**!
    b. "The doctor said my son has dementia…thank goodness he doesn't have Alzheimer's!"

3. The condition we refer to as dementia may be caused by many things.
    a. Some may be **treatable** (Ex. Dehydration, B12 deficiency)
    b. Others are **irreversible** (Ex. Alzheimer's, Vascular, Lewy body).

4. Dementia is **NOT part of normal aging**.

Risk of Dementia in ID

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



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

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

Dementia Prevalence: ID vs. DS

Intellectual Disability

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

Down Syndrome

Age	Percentage
40+	22%
60+	56%

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

Challenges to Healthy Aging in Adults with ID

Medical history is often incomplete or unknown.

- Staff turnover
- Family not available for information, historical documentation unavailable
- Health care provider turn over
- Providers not understanding baseline functioning of the presenting older adult with ID
  - IDEA: Video can provide a visual of the person over their lifespan.

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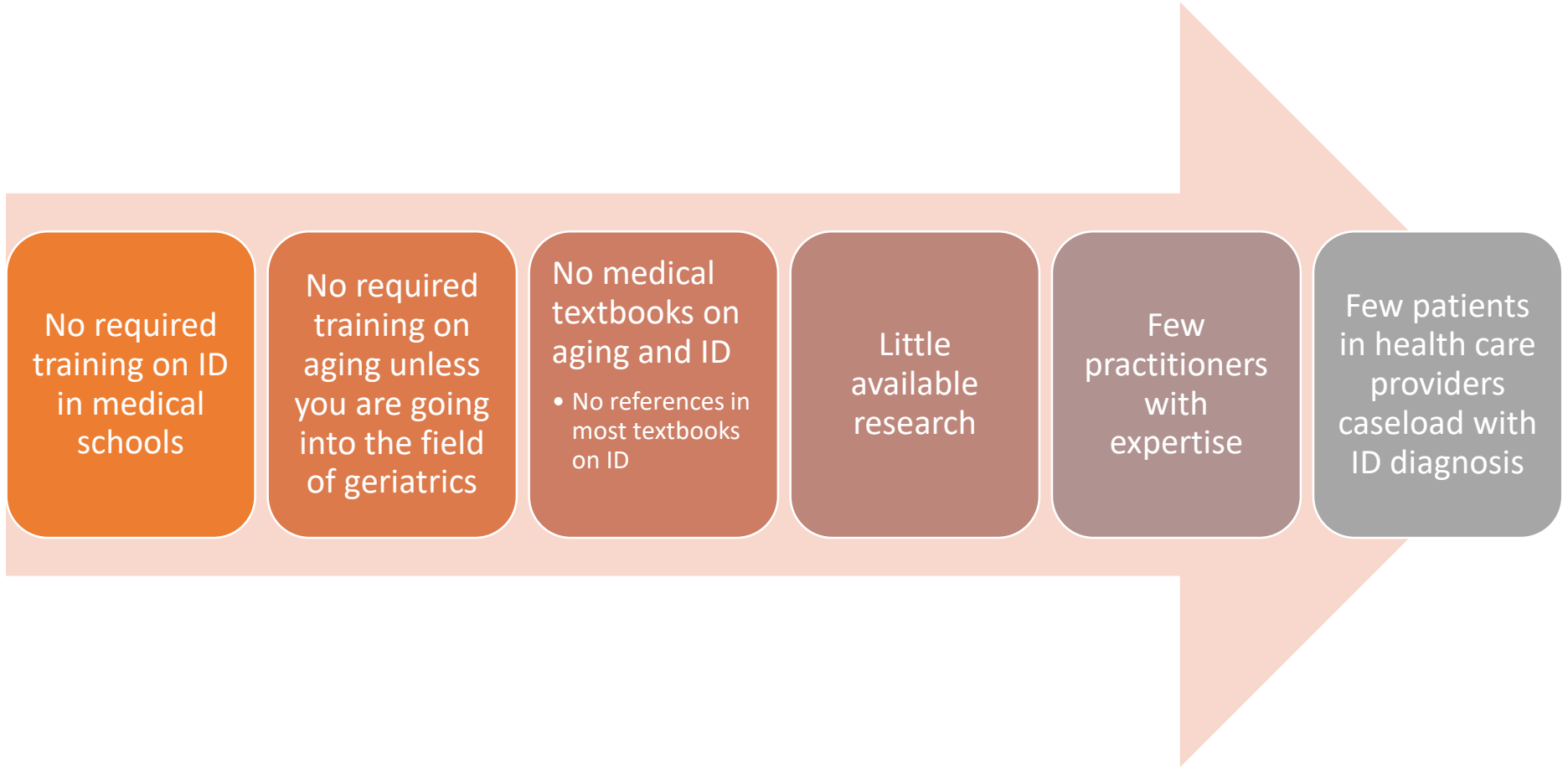
Lack of systems for health advocacy :

- Information provided for the appointment may not include all necessary information.
- Staff/family attending health care appointments may not be the most knowledgeable about the symptoms.

Health Care Disparities for Adults with ID



Prevalence of Dementia and Impact on Intellectual Disability Services.

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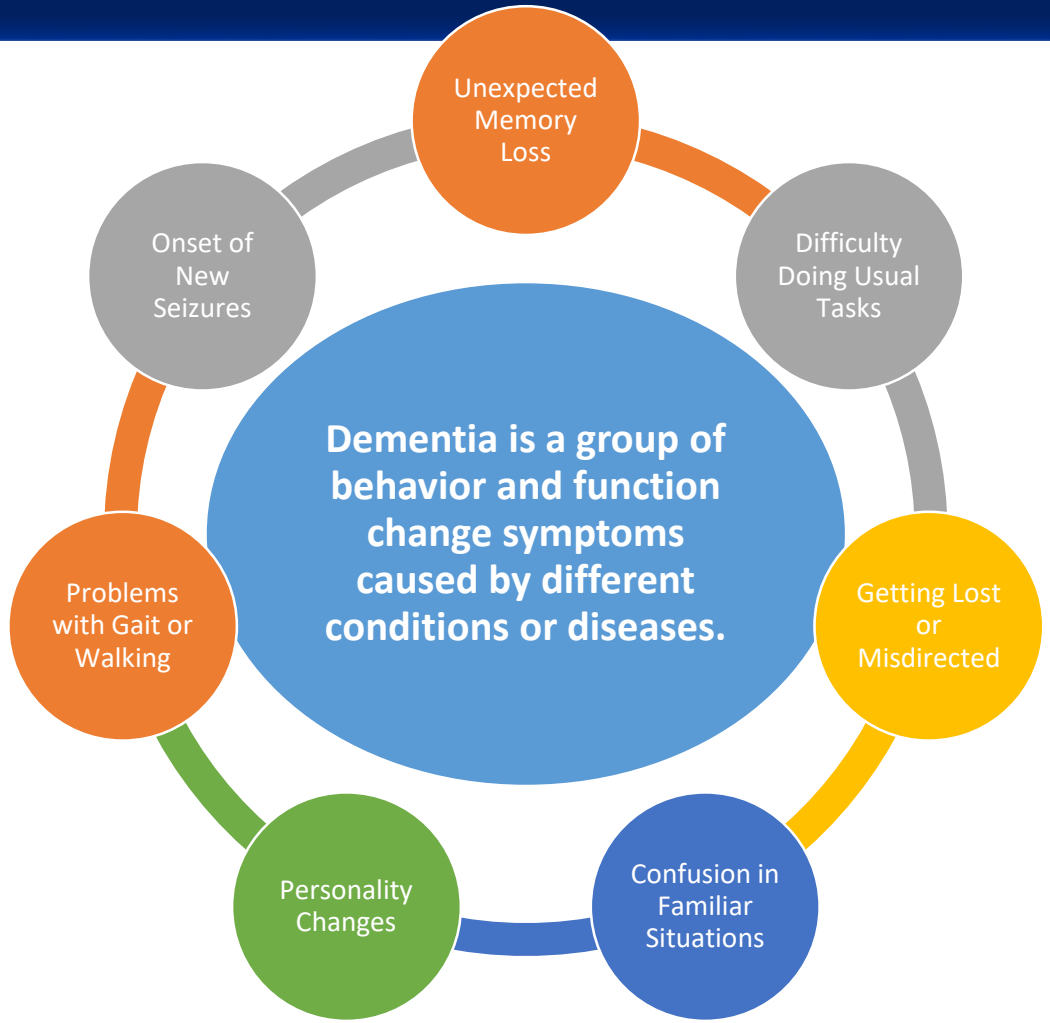
Increased lifespan = Increase in dementia.

What this means for programs:

- Need to raise the “index of suspicion” among staff and families,
- Programs and services need to become “dementia capable,”
- Need to improve:
  - Diagnostic and technical resources,
  - Care management supports (to prolong the “aging in place” of adults affected by dementia).

Warning Signs

These problems must be notable and usually occur in a cluster



Behavioral Triggers

Identifying precipitants of behavior.

Pain

- Conflicting evidence from neuropathological, neuroimaging, experimental, and clinical research regarding the impact of dementia neuropathology on pain processing and perception
- Pain is thought to be one of the most important causal factors of BPSD. Assessment and treatment of pain in people with dementia. *Corbett A, Husebo B, Malcangio M, Staniland A, Cohen-Mansfield J, Aarsland D, Ballard C., Nat Rev Neurol. 2012 Apr 10; 8(5):264-74.*
- Assessment of pain is particularly challenging due to the loss of communication ability.
- Pain processing – as indicated by brain responses in electroencephalography and functional magnetic resonance imaging (fMRI) studies, pain reflexes, and facial responses to noxious stimuli – does not appear to be diminished in Alzheimer patients. Pain sensitivity and fMRI pain-related brain activity in Alzheimer's disease. *Cole LJ, Farrell MJ, Duff EP, Barber JB, Egan GF, Gibson SJ., Brain. 2006 Nov; 129(Pt 11):2957-65.*
- People with AD require a higher dosage of pain medication, to achieve the analgesic result that would normally be expected in a cognitively healthy adult. Loss of expectation-related mechanisms in Alzheimer's disease makes analgesic therapies less effective.*Benedetti F, Arduino C, Costa S, Vighetti S, Tarenzi L, Rainero I, Asteggiano G., Pain. 2006 Mar; 121(1-2):133-44.*

More on Pain

- The literature indicates that about 50% of patients with dementia are regularly in pain. Assessment and treatment of pain in people with dementia. *Corbett A, Husebo B, Malcangio M, Staniland A, Cohen-Mansfield J, Aarsland D, Ballard C., Nat Rev Neurol. 2012 Apr 10; 8(5):264-74.*
- Research has shown that the elderly in general, but especially those with dementia, receive less pain medication than their cognitively healthy counterparts, even in the same painful situations – for example, after a hip fracture. A comparison of pain and its treatment in advanced dementia and cognitively intact patients with hip fracture. *Morrison RS, Siu AL., J Pain Symptom Manage. 2000 Apr; 19(4):240-8.*
  - Advanced dementia patients received one-third the amount of opioid analgesia as compared to cognitively intact subjects.

Things to Consider…

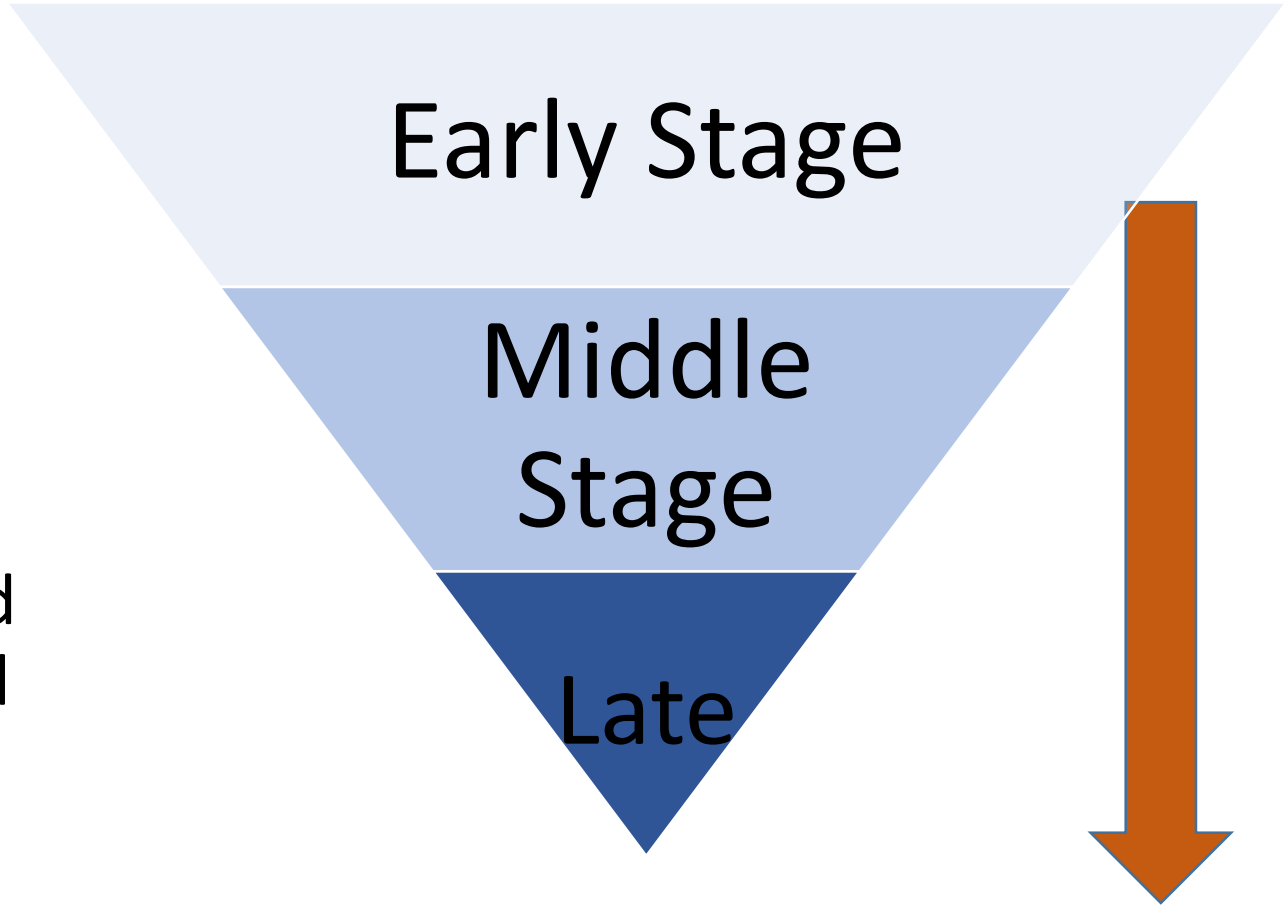
- Does this person have any known medical conditions that may produce pain:
  - Ex. Arthritis, migraines, osteoporosis, stomach problems
- Has there been a recent change in medications?
  - Ex. New medication or increased dosage – side effects?
- Could there be the onset of a new acute illness?
  - Urinary tract infection, impaction, pneumonia can cause delirium and produce a sudden change in mental status. Delirium is a medical emergency.
- Is the person too hot, too cold, clothes uncomfortable, need to change their position, etc.
- Are they in emotional pain?
  - Ex. Frustrated at being expected to do a task that is beyond their ability, scared, feeling threatened, depressed, anxious?

Environment

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

Task

- Too complicated
- Too many steps
- Unfamiliar
- Not modified for increased impairment



Caregiver Interaction/Communication

Is it something I did?

- Attitude – relaxed or anxious?
- Body language – tense?
- Tone of voice – cheerful or demanding?
- Facial expression – smiling?

Key Concepts in Dementia Care

Knowledge and skills needed for dementia capable care.

Caring for a person with dementia means we must understand that…

- S/he does not see the world the same way we do.
- What we see as normal can be very confusing and threatening.
- We must enter their reality as they cannot conform to ours.
- Need us to be patient, supportive and understanding.
- WE HAVE TO CHANGE BECAUSE THEY CANNOT.

WHO HAS TO CHANGE? WE DO!

The behaviors you see in dementia are due to a brain disease.

Trying to change or control behavior will meet with resistance.

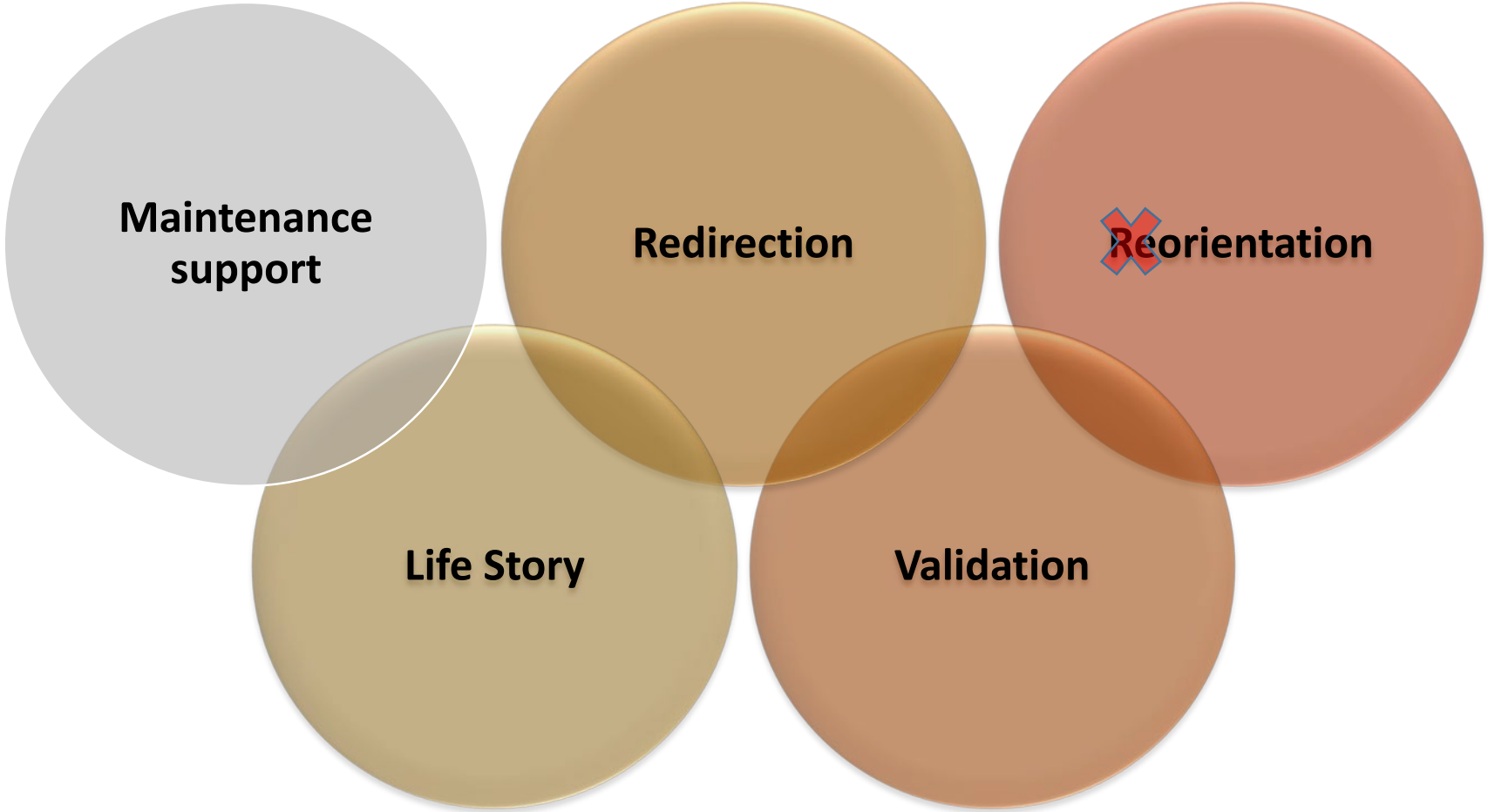
★ ***Accommodate the behavior, not control the behavior.***

- For example, if the person insists on sleeping on the floor, place a mattress on the floor to make him more comfortable.

★ ***We can change our behavior or the physical environment.***

- Changing our own behavior will often result in a change in the person with dementia's behavior.

Key Concepts in Dementia Care



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

Key Concept in Dementia Care #1

Maintenance Support

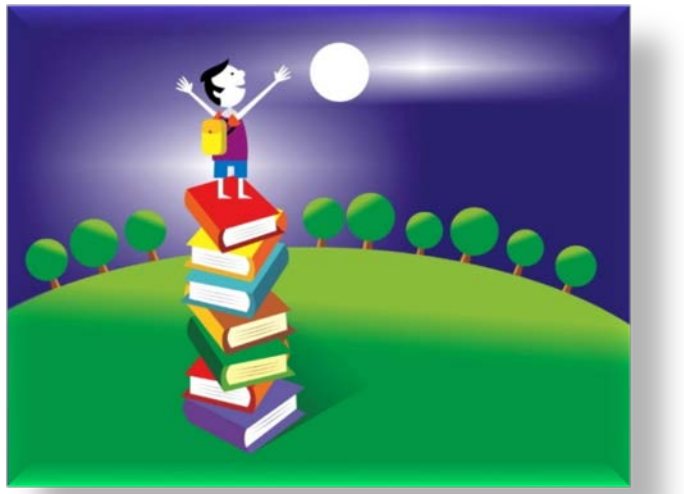
- Generally accepted as the **best practice** in dementia care.
- **Proactive** approach
  - A few minutes of pro-action can eliminate hours of reaction.
- Focus is on **support of remaining abilities**.
  - Respect changing needs of the person
  - Provide meaningful, failure-free activity.
  - Allow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

Key Concept in Dementia Care #2

Life Stories

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

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



Key Concept in Dementia Care #3

Validation Approach

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

Key Concept in Dementia Care #4

To Reorient or Not Reorient

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

Example:

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

Which response is better:

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

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

~~Re~~orientation Tips

Whose reality is it?

- A person with dementia can no longer make sense of the present and lost memories of years past will become their new reality and they even may re-live past events.
- To avoid frustration and increasing agitation you must enter their reality. *Don't argue.* This is <u>not lying</u>, it is <u>respecting their reality</u>.

Wouldn't you be upset if someone told you your parent was dead if you were sure they were alive?

Key Concept in Dementia Care #5
REDIRECTION

Distract AND Divert

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

Helpful Hints for Redirecting

- **Body Language:** People with dementia are very adept at picking up on your body language. Smile, try to relax, and be warm and open when redirecting someone with AD.
- **Ask questions.** A good all-purpose phrase is: *"tell me about it."*

Example:

Betty: *"I want to go home!"*

You: *"Tell me about your home. Is it a big house?"* Then gently redirect the conversation away from what is bothering Betty…*"I'm hungry. Betty, would you help me get a snack?"*

Be flexible…
What works today may not tomorrow.

- Solutions that are effective today may need to be modified tomorrow—or may no longer work at all.
- The key to managing difficult behaviors is being creative and flexible in your strategies to address a given issue.

Summary

There are tools adapted from dementia care in the general population that can help improve the quality of life for an adult with ID & dementia.

