

Envisioning the Future 2020 & BEYOND

## Turning Dementia from Stigma into Esteem

Presented by:  
Kim Eichinger, Maureen Sirianni, & Stephen Klotz

Pioneer Network

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### Welcome! Thanks for joining us!

- You are invited to participate via Chat and Poll/Vote during the session, and a 15 minute live Q & A segment at the end.
- The segments of this session will focus on:
  - The stigma of dementia (even the word "dementia") – Steve
  - Roadblocks to participation in exercise and movement – Kim
  - Culture-change friendly Principles and Practices of Validation – Maureen
  - Better goals & better approaches for exercise and movement – Kim
  - Commitment to Implement – Steve
  - Q & A

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### Starting on Common Ground

- Please translate our presentation to fit your setting – your people = residents, clients, care partners, seniors, etc.
- Also to fit your preferred descriptions of older adults living with dementia, those with cognitive changes and memory impairment, etc.
- We all share some basic dementia interaction approaches – be centered/grounded, pay close attention to the whole person, give warm eye contact at the person's eye level, use appropriate closeness and nurturing touch.
- Emotions can be as important, if not more, than information.
- If you agree, please vote YES or give us a thumbs up

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### Dementia – a synonym for Disable & Doom?

- There many stigmatizing common words and phrases around:
- Misrepresentations
- Judgmental
- Demeaning
- Nearly all are De-personalizing
- **What are some other words and phrases you have heard and seen?**  
*Please enter them via the CHAT button toward the bottom of your Zoom screen.*
- Do these affect individuals living with dementia?




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Those were misnomers rooted in the past.

This gathering of Pioneer-minded people does not just look to the future; we are here to shape the future – including dementia care.

“You see things; and you say ‘Why?’ But I dream things that never were; and I say ‘Why not?’”

George Bernard Shaw – playwright, social critic, political activist (1949); later adapted by both Pres. John F. Kennedy and Sen. Robert Kennedy




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“I don’t call *throwing a ball* at a person with dementia *exercise*”

Quote from family member regarding physical activity program.




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As activity and fitness leaders are we trying to:  
Do it to them?  
Do it with them?  
Empower them to do it and Praise/Encourage/Join in?



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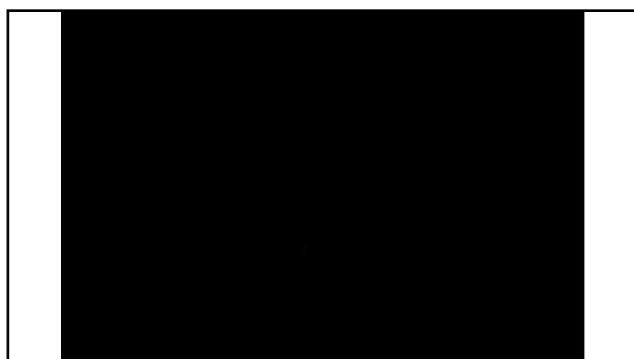
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As a Fitness Instructor/Activity Director  
Sometimes we need to get outside of our own head to  
see things from a different perspective and  
reframe our expectations



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Consider-

Will the structured format you have planned make sense?

Can you identify and go with the natural momentum or energy that is present?

How might you change your language to cue movement?

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**Albert Einstein once said  
“Time in other words, is an illusion”**

**We recall time as relative and flexible it is our guide  
between the past, the present, and the future.**

**Is time an illusion? Is reality Timeless?  
Can the past and present blend as we look to build a  
life affirming culture of aging in the future?**

**Yes, the answer is yes.**

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**Naomi Feil is quoted as saying, “I learned Validation  
from the people with whom I worked. I learned that  
they have the wisdom to survive (present reality) by  
returning to the past.”**

**\*Naomi Feil ACSW developed Validation Method  
working with people who were over the age of 80  
living with the diagnosis of Alzheimer’s disease and  
related dementias.**

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**Validation Method**

**Validation Method is a form of communication that connects us through empathy, so that older persons living with dementia can communicate their emotions and needs to us- their capable, trusted, caring listeners .**

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**Validation Attitudes:**

- Respect**
- Empathy**
- Acceptance**
- Caring**
- Honesty – (this requires sensitivity)**

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**Think of those you care for. Where do you recognize the phase they are living within ?**

- 1 – Mal-Orientation: Communicate well, mostly oriented. Deny their fragile mind, and fearfully clings to what they have not lost yet lost.
- 2 – Time Confusion: Communicates- mostly living in their personal reality. Verbally expressing needs and feelings with few filters.
- 3 – Repetitive Motion: Still communicating, mostly internalizing needs and feelings. Expressing themselves through movements and sounds as many begin to lose their verbal ability.
- 4 – Withdraw: Communication can be barely perceptible. Internalizing their needs and feelings.

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**Old age is not a disease.  
We respect and accept their wisdom.**

**Elders with dementia have different goals than those of their care partners. They are drawn to the past in order to satisfy their needs. They turn inward.**

**RETREAT-  
RELIVE-  
RELIEVE-  
RESOLVE-  
and EXPRESS**



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**There is a reason behind the behavior of very old Maloriented and disoriented people.**



**Look for connections to their past. We may not always know why the person behaves or expresses themselves in a certain way, we can help him or her express emotions to resolve unfinished business**



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**There is a reason behind the behavior of very old Maloriented and disoriented people.**

**Validation Technique:**



**\*Anchored Touch-**

**A special and specific place (usually on the face) where touch triggers feelings and memories of past relationships. This is used when engaged in a person to person visit/ in an intimate conversation.**

**\*example- connecting anchored touch to behavior.**



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**Validation Technique:**

**Listening with Empathy.**

**Empathy**, also involves **mirroring**, or reflecting back, the feeling that was expressed– in your voice and body language so that they know you understand their feelings and feel them too.

**We are feeling it with them.** They are no longer alone in this moment. We never negate or try to distract them from the way they feel or express themselves. We do not dismiss their feelings and needs.

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**Validation Techniques**

**Mirroring or Reflecting Back begins by:**

- Observing Emotions**
- Matching their Emotions**
- Expressing their Emotions with Emotion**

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**Validation Techniques**

**Help the resident imagine if the opposite were true.**

**What would life be like if he didn't die?**  
**If he was here right now, what would you tell him?**  
**What do you think he would say to you?**

**Then connect**

**Is it scary to be brave?**  
**Can we be brave together?**

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**Something that WE SHOULD NEVER FORGET.....**

**When you are caring for someone with Alzheimer’s disease or related dementia there are opportunities for you to communicate both verbally and non verbally. Music, movement, and engagement at all levels of cognition symbolize life, a connection that enables us to experience their world and show them that we care, they are not alone on this journey.**

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Observe and adjust activities by

- Changing cueing to prompt natural movements
- Inviting vocal participation
- Associating with authentic experiences
- Recognizing time for rest between bouts of movement
- One to one engagement within a group setting

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Demonstration with participation

- North, South, East, West (cues prompt natural movement)
- Sweet Caroline (Music, Vocal Participation) 1969 Hit Song by Neil Diamond
- Tuck your shirt and straighten your collar (Authentic experiences)
- Deep Sigh/Moan & Groan (prompts breathing and rest)
- Circulate and Stimulate (get in their visual zone 1-1 engagement)

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### Structured Exercise or Natural Movement?




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### COMMITMENT TO IMPLEMENT

*Take a moment to reflect and write down:*

- One **existing** program or practice to make more validating, and one way you will do so,
- AND
- One **new** validating program or activity that you will put into action
- Please share these on the **CHAT** board!




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### In Summary...

- Dementia isn't spelled S-T-I-G-M-A
- There are common roadblocks to exercise and movement
- Description of some familiar and unfamiliar, culture-change friendly Validation principles and practices
- There are better, more validating ways to engage our people in exercise and movement
- A call to action, implementing a couple of new approaches




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### Q & A

- This part will feature our three presenters live online, able to take live questions and respond in the moment.
- It will still be helpful to submit questions via **CHAT** so we can sort them out and answer as many as possible.

• **THANKS FOR PARTICIPATING IN OUR WORKSHOP!**

- Please reach out to us by email at KEichinger, or MSirianni,, or SKlotz @countrymeadows.com!



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