



**COURAGE
IGNITED**

**“Where The
Sidewalk Ends”.....**



1

**Where The
Sidewalk Ends....**

**Managing Advance
Dementia Through End of
Life**

Presented by,
Debbie Carriveau,
RN,C., CDP, QDCP
Executive Director of
Dementia Services




2

The Advanced Dementia Journey.... What does it look like, REALLY???



What are the **CRITICAL FOCUS** areas of Advanced Dementia care?

- Becoming more **FRAIL**
- Decreasing **MOBILITY** and more frequent **FALLS**
- Nutrition and Hydration- problems **SWALLOWING**, loss of **TASTE, TEXTURE** issues
- Recognition of **PAIN** symptomology
- Increasing “hands on” care needs- **ALL** aspects
- Growing need for a sense of **CONNECTEDNESS, BELONGING, and LOVE**
- Spiritual nurturing and assistance with a **PEACEFUL** and **COMFORTABLE** transition from this life to the next
- Resolving “**UNFINISHED**” Business

NORMAL Characteristics of Individuals with Advanced Dementia....

WHO do you see?



What are the **TRUE** characteristics of those with Advanced Dementia?

- Resistant to care- depending on **approach** and the **trust** and familiarity with caregiver
- Looks “**unkept**”removes unnecessary “**trappings**”
- Cannot follow or retain instructions- **LESS is MORE**
- **Peripheral losses, visual clifting**
- Emotions tend to be **irrational**- afraid of **ANYTHING** I don’t understand
- Functional age- **infant-3yo** (processing, cognitive interpretation and reaction)
- Likes having a “**BUDDY**”- Needs to be kept **BUSY**
- MY REACTIONS-based on my perceptions, based on what I **BELIEVE**

Characteristics continued.....

- Senses and sensitivity are **HEIGHTENED SIGNIFICANTLY- hypersensitivity of the skin, startle reflex, pincher reflex**
- Overstimulation response- Reacts negatively to any “**noxious**” stimuli or touch
- **Hyperorality**- everything goes in their mouth- **EVERYTHING is sensory oriented and experienced**
- Fluctuates between **hyperactivity and lethargy**- progressively sleeping more
- Cannot initiate any **meaningful** action independently

Therapeutic Programming Possibilities....I can still **BENEFIT**

But looks **Completely Different** now

- They need to **touch, feel, hear, see, and taste** everything
- **Infant to Toddler** level of function- what does that mean?
- **Engagement** happens with every interaction
- Short bursts, and **1:1 or 1:2**
- Interactions are focused on **communicating your love and their value....**

Caring **ABOUT** not just caring **FOR**

- **Touch therapy**-ADLs, hand and foot massages, back rubs, hand holding, hugs, mother to child stroke, nail care, stuffed animals, life like babies
- **Music therapy**-listening that's **meaningful for the person**, singing, rhythm mimicking, **last area** of the brain to deteriorate

Programming continued.....

- **Reminiscence**-Not necessarily two-way conversation or discussion as much as **YOU** do the storytelling **of their life**, reading familiar books, letters, lyrics, picture books of familiar things (baby animals, online baby photos that are **FUN**) , walks to places they can **see and touch**
- **Stacking and sorting**- like things that are repetitive
- **Reciting things from childhood**- Sunday school songs, prayers, rosary, nursery rhymes, simple poems or limericks
- **Baking tasting**- focus on **smells and tastes** versus the task
- **Physical activity** that is very **TACTILE and SIMPLE**- Beach ball volley or kickball, bean bag toss, parachute ball, dancing or free movement to music

Providing Care and Comfort at the END of LIFE.....



The GREAT MYSTERY....Being THERE at the end of life here and facilitating the transition to the next life....What does that look like?

Signs of the Dementia dying process:

- Terminal Restlessness- neurological sign of discomfort, constant movement, inability to relax, pushing or pulling at staff (neuroinflammation of the brain) Uncooperative, agitated as a result
- Pain- much more related to neurological discomfort. Hypersensitivity to touch and noise, can cause actual pain. Recoiling from caregiver touch, “curling inward” fetal position sitting or standing, holding their heads, rocking, rubbing forehead or temples, pushing at their eye sockets or pulling hair or ears (50-80% experience pain daily)
- Hallucinations- sudden delirium, emotional and mental turmoil, outbursts
- Irregular breathing patterns- chesty, rattling, apnea
- Sleep disturbances- cannot shut things off, not restorative sleep
- COLD discolored hands and feet

Goal of end-of-life care for a dementia person is PEACE and SUPPORT

Management of symptoms to alleviate discomfort-

- Making people more comfortable, progressive pain and anti-anxiety meds (Ativan, Morphine, Zyprexa Zydus), routine not PRN- don't let level get ahead of meds
- Pillows, repositioning, recliners versus beds, massages, warm packs
- Physical therapeutic touch-hand holding, gentle stroking of face, tops of hands, tops of feet, massages but very gentle pressure
- Quiet environment with pleasant music or comforting nature sounds on low volume
- Be present-Involve and talk to them at whatever level possible-talk, sing, pray, read
- Spiritual support- talk to the person about ways their life had meaning, talk to family members about relationships, influences, talk to them not about them, hymns playing softly, reading scripture, singing, praying
- Reassure them about what's important to them and who they are leaving behind
- Prepare family and caregivers for the possible “rally” at the end

LIFE HISTORY IS THE **CRITICAL PIECE** for **PEACEFUL** and **COMFORTABLE** transition...
 Experiencing an **intimate, person-centered** dying experience is just as **important** as
 person-centered care during my life....**Do you know who I am and what my life has
 been about? What MATTERS?**



LeadingAge
Indiana

INALA
Indiana Assisted Living Association

13

Questions and answers.....



LeadingAge
Indiana

INALA
Indiana Assisted Living Association

14