End of Life Care

How to Focus on 'Letting Go' rather than 'Giving Up'

Terms to Know:

- Advanced Directives – you do
- Living Will – you develop
- DNR Orders – MD does – based on your input
- Durable HC-POA – who will decide?
- Palliative Care – Comfort care, not curing
- Hospice Care – Entire system of end of life care

Why is Dementia Different as the End of the Journey Approaches?

- It has taken a LONG TIME
- The person has changed, and changed, and changed,...
- You have lost the person, even as they remain
- You have changed over the journey
- How it WAS is not how it IS
- What should happen/work, DOESN'T

What are the Different Care Approaches to Consider?

- Health Promotion
- Curative
- Restorative - Rehabilitative
- Maintenance
- Compensatory
- Palliative
Health Promotion:
- Check-ups
- Annual vaccinations
- Lower the numbers
- Increase activity level
- Eat well – moderately
- Monitor all conditions for careful control
- DO WHAT YOU SHOULD to be the BEST YOU CAN BE!

Curative:
- Fix what is wrong
- Test to figure out what is happening, then DO SOMETHING ABOUT IT:
  - Surgery
  - Medications
  - Treatment
- Full recovery of function – GOOD as NEW!

Restorative:
- Recovery of SOME degree of function or ability
- Focuses on the PERSON regaining skills and abilities with help
  - Rehab personnel
  - Special equipment
  - New techniques
- Not perfect, but BACK to a higher level of function

Maintenance:
- Maintaining the ‘status quo’, keepin’ on
- Not losing ground
- Depends on:
  - Physical environment not changing
  - Caregiver consistency
  - Sustained abilities of the person
  - All other things staying the same
- It’s HARD WORK … SO…is what I have worth keeping???

Compensatory:
- Providing what the person can’t do to ‘fill in the gaps’ so that life goes on
- Supportive
  - Physical environment changes
  - Caregiver cueing and helping changes
  - Expectations change
  - Schedules and routines change to accommodate
- End point is the same, but how we get there changes

Palliative:
- Comfort Care
- Top Priorities:
  - Honor personal preferences and choices
  - Manage Pain, Distress, Anxiety, Fear, Discomfort
  - Identify and seek to meet social, physical, psychological, and spiritual needs
- Let go of FIXING and MOVE ON to comforting
Acute Illness vs. Dementia:

You can FIX IT!
It gets better and goes away
It lasts only a short time
Doctors know what to do to make it better
The person goes back to how they were pre-illness
You can't change it
It keeps getting WORSE no matter what you do
It lasts a long time — maybe years
Doctors can offer only help — they can't fix it
You can't go home again — the person is never the same

Progression of Dementia:

- Early Loss: Habits and Routines
- Moderate Loss: Just get it DONE!
- Middle Loss: Hunting and Gathering
- Severe Loss: Constant Go or Down and Out
- Profound Loss: Stuck in Glue

Review of Progression:

Who are we talking about?
- Sapphires
- Diamonds
- Emeralds
- Ambers
- Rubies
- Pearls

Seeing GEMS
Not Just Loss…
- Sapphires: True Blue, Slower but Fine
- Diamonds: Repeats and Routines, Cutting
- Emeralds: Going — Time Travel — Where?
- Ambers: In the moment, Sensations
- Rubies: Stop or Go, No Fine Control
- Pearls: Hidden in a Shell, Immobile

‘Letting Go’

Versus

‘Giving Up’

- When is it time?
- How will you know?
- What is enough?
- Who should help decide?
- How to balance old wishes/promises and the current realities
- How can we make it happen?
- What do we do instead?
So When Should You Say ‘WHEN’?
- Cost versus benefit to the person
- What is possible versus what is probable
- Best case outcome: is it worth it?
- See the ‘big picture’ for the person
- What did they tell you before?
- Who are they and are they still able to be that person?
- Is this about them or about you or about someone else???

Skills for Success:
- Meeting unmet needs using words: using empathy and validation and detective work
- Meeting unmet needs without words: using observation, empathy, and detective work
- Coping with and resolving distress one on one
- Helping with challenging behaviors using a problem solving approach
- Providing coaching support and guidance to teammates

What if There are NO WORDS?
- Observe their cues to you:
  - Visual
  - Auditory
  - Touch and movement or lack of it
  - Olfactory: any unusual smells or odors
  - Taste: changes in eating/drinking/preferences
- Use your other cueing systems
- Make your cues BIGGER and SIMPLER and SLOWER

Indications that You Are Getting Near the End of the Journey…
Ambers… Rubies … Pearls

Signs that it may be time…
Repeated infections
Antibiotics seem ineffective
Refusals to eat – even favorite items
Holding food in mouth – spitting it out
Soft coughs – wet voice
Stop moving – curling up
Sleeping a lot
Lots of low grade fevers
Primitive reflexes show up
Withdrawal from those around – closing eyes
Drifting in and out
Says ‘good-bye’
Talks about ‘going home’
Asks permission to go
Albumin drops very low
Wounds won’t heal
Can’t keep weight on
Skin and bones
Moaning – not actively communicating

What Does This Mean?
- Reduce or stop monitoring if there is not a ‘treatment’ that will be pursued
- Provide what the person wants or needs, not what is ‘best’ for them
- Provide comfort
- Assess for and manage pain, discomfort, or distress
- Give permission to GO….
What Does This Mean?

Don't just treat infections, treat the discomfort of infections
Don't force intake, but offer tastes and textures
Don't push fluids or put in IVs, but offer fluids (possibly thickened)
Don't force movement, but use touch, massage, and controlled repositioning
Don't just 'do the care' then leave alone, but be present
Don't force interaction but balance offerings of silence/space with communication/contact

Changes Near the End:

- Primitive reflexes become strong
- Flexor tone dominates
- Temperature control is broken
- 'Skin and bones' appearance, not hungry or thirsty
- Spends more time drowsy or 'inside' themselves
- Infections are common
- Startles easily, harder to calm
- Pain from stiffness, immobility, dry mouth/skin, etc.

The care that WORKS is COMFORT CARE!!!

Building Skills to Help in Late Stages

Special Programming:

- Focuses on the spirit of the person
- Recognizes the changing needs of the person
- Provides support to meet those needs
- Provides a space where a caregiver can provide for the care of several residents in a meaningful way
- Reducing distress and discomfort
- Addressing caregiver distress over behaviors
- Reducing distress of other residents

What is It?

- A more specific way to do what you already do: accompany the person in the final steps of this journey
- Mostly it is BEING THERE for the person who is the final stage of dementia
- Knowing the person: who is this, who has this person been, what is important to them, what offers them comfort, what distresses them
What is It?
- Using comfort measures that help
- Providing a supportive sensory and physical environment
- Meeting the needs of the body through temperature, positioning, touch, smells, taste, sight, sound, movement
- Celebrating and connecting to the spirit within
- Through your presence and involvement

Some specifics:
- Warmer room temperature
- Sunlight offered
- Warmed, lightweight blankets
- Foot and hand warmers: bean/rice socks
- Head covers
- Warm your hands before touching them
- Warm lotion and cloths for cleaning, warm towels for drying

Some specifics:
- Reclining chairs that are comfortable and support the hip angle
- Shifting position smoothly and slowly to allow circulation
- Gentle and slow rotational movements to relax muscles that cannot relax on their own

Some specifics:
- Your Touch:
  - Flats of fingers
  - Contact over joints, first
  - Still pressure first
  - Slow movement
  - Slow, rhythmic, circular motions
  - Massage: hands, feet, temples, jaw, back, hips, shoulders
  - Hand clasp: hand-under-hand, sandwich

Some specifics:
- Their Touch:
  - Be aware of grasp reflex — plan for it
  - Be aware of hand-to-mouth — plan for it
  - Offer various textures to hold, touch, handle
  - Offer familiar objects that can be explored and handled
  - A stuffed animal or doll to cuddle and nurture
  - Warm objects or cloth: use a heating pad to or a nearby clothes dryer

Some specifics:
- Taste:
  - It’s NOT about eating for nourishment
  - Connect smell and taste experience, but smell first
  - Try straws
  - Try an infant spoon: small, plastic-coated
  - Mouth care: moisten lips and mouth
  - Wet washcloth
  - Vaseline-type moisteners
Some specifics:
- Smells: connect us to our past
  - Lavender is calming
  - Citrus is arousing
  - Mint is stimulating
  - Other possibilities: cinnamon, incense, bacon, cut grass, chocolate, sun-dried cloth, etc.

Some Specifics:
- Sights:
  - Your face with a smile and a nod
  - Dim lights over head
  - A ‘candle’ or covered lamp within visual field
  - Familiar and favorite objects presented
  - Pictures or symbols that offer comfort
  - Nature posters, videos, or DVDs, or a window
  - Objects at a distance that move, spin, blow

Some specifics:
- Sounds:
  - Silence at times, with your presence
  - Quiet rhythmic sounds: waves, streams, wind
  - Wind chimes
  - Favorite music from their youth
  - Your calm, deep, gentle, still voice
  - Prayers of their faith
  - Readings from their faith, poetry, favorite books
  - Bird song, cat purr, your deep and slow breathing

Some Specifics:
- Movement:
  - Glide rockers that offer smooth rhythmic movement
  - Trips outside: go slowly
  - Trips to new location in the room
  - Slow shifts, give info as you go, watch responses
  - Support at the hips and shoulders
  - Draw sheets/blankets up close to the body

With Dementia...
It’s not the destination,
It’s how you get there!!!!