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“End of Life Care & Letting Go”

Providing Care in the Final Stages of Dementia
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, 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...
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 cure care
• Hospice care – whole system - end of life care
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 –
  – How we get there Changes
Palliative

• Comfort Care

• TOP PRIORITY –
  – Honor personal preferences and choices
  – Manage Pain, Distress, Anxiety, Fear, Discomfort

• Identify & seek to meet social, physical, psychological, and spiritual needs

• Let go of FIXING and MOVE ON to Comforting
Acute Illness Versus Dementia

- You can FIX IT!
- IT gets better & 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 – 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 & Out
- Profound Loss – Stuck in Glue
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?
• Big Picture for the person
• What did they tell you before?
• Who are they... are they still able to be that person?
• Is this about them or about you or about someone else???
Positron Emission Tomography (PET)
Alzheimer’s Disease Progression vs. Normal Brains

Normal
Early Alzheimer’s
Late Alzheimer’s
Child

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Hearing Sound – Not Changed
Sensory Strip
Motor Strip
White Matter
Connections
BIG CHANGES

Automatic Speech
Rhythm – Music
Expletives
PRESERVED

Formal Speech &
Language
Center
HUGE CHANGES

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Executive Control Center

Emotions
Behavior
Judgment
Reasoning
What IF There are NO WORDS?

• Observe their CUES to you
  – Visual
  – Auditory
  – Touch & 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 & SIMPLER & SLOWER
The Basics for Success...

• Be a Detective NOT a Judge
• Look, Listen, Offer, Think...
• Use Your Approach as a Screening Tool
• Always use this sequence for CUES
  – Visual - Show
  – Verbal - Tell
  – Physical – Touch
• Match your help to remaining abilities
Now for the GEMS...

Sapphires – True Blue – Slower BUT Fine

Diamonds – Repeats & 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
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 treat infections, IF...
• Don’t force INTAKE
• Don’t Push Fluids or Put in IVs
• Don’t Force movement
• Don’t Just ‘DO CARE’ – and leave alone
• Don’t Force Interaction

• Treat the discomfort of infections...
• Offer tastes, textures
• Offer fluids – decide about thickened...
• Use touch, massage, controlled repositioning
• Be present, balance offerings of silence & space with communication & contact
Changes Near the End

- Primitive reflexes become strong
- Flexor tone pre-dominates – can’t move out
- Temperature control is broken
- Skin & bones – not hungry or thirsty
- Spends more time drowsy or ‘inside’
- Infections are common
- Startles easily – harder to calm
- Pain – stiffness, immobility, dry mouth/skin…
The care that WORKS is
COMFORT CARE!!!
Pearls

Hidden in a Shell
Still & Quiet
Easily Lost
Beautiful - Layered
Unable to Move – Hard to Connect
Primitive Reflexes on the Outside
Pearls

• Can’t move
• Not aware of the world around – most of the time
• Problems swallowing
• Hard to get connected
• How we touch and help matters
• SLOW!!!!
• Varies a LOT
Pearls

Hidden in a Shell
Still & Quiet
Easily Lost
Beautiful - Layered
Unable to Move – Hard to Connect
Primitive Reflexes on the Outside
Pearls

• The end of the journey is near
• Multiple systems are failing
• Connections between the physical and sensory world are less strong
• We are often the bridge – the connection
• Many Pearls need our permission to go –
  – They are still our moms, dads, spouses, friends
  – They will go in their own time
  – IF we don’t try to change what is
Pearl

- Immobile – can’t get started
- Bed or chair bound – frequently falls to side or forward
- Has more time asleep or unaware
- Has many ‘primitive’ reflexes present -Startles easily
- May cry out or mumble ‘constantly’
- Increases vocalizations with distress
- Difficult to calm
- Knows familiar from unfamiliar
- Touch and voice make a difference in behaviors
Pearl Interests

• Internal cues
• Pleasant and familiar sounds & voices
• Warmth and comfort
• Soft textures
• Pleasant smells
• ‘Good’ tastes
• Smooth and slow movement
• Just right touch and feel
Primitive Reflexes to Consider

• Startle reflex –
  – Sudden movement causes total body motion

• Grasp reflex–
  – touch palm – grips hard can’t release

• Sucking reflex –
  – sucks on anything near mouth

• Rooting reflex –
  – Turns toward any facial touch and tries to eat
More Reflexes

• Bite reflex
  – Any touch in mouth causes bite down

• Tongue thrust
  – Anything in mouth causes tongue to push forward and out

• Withdrawal – rebound
  – Pull away from stretch

• Gag reflex –
  – Any touch to tongue causes gag
Typical Positioning – Why?

• Constant muscle activity causes ‘contractures’ – shortening – can’t relax
• Stronger muscles cause typical ‘fetal’ positioning
• Pulling against contractures is painful
• Shortened muscles cause some areas to:
  – Not get air – become ‘raw’ or ‘irritated’
  – Rub or press against other body parts
  – Get too much pressure – can’t move off
Pearl Care Issues

• Not interacting much
• Crying out – can’t make needs known
• Skin & hygiene problems
• Weight loss
• Reflexes make care challenging
• Repeated infections
• Not eating or drinking
• Not able to sit up safely
Visual Cues to Help

• Get into supportive position
• Place your face in the central field of vision
• Make sure light comes from behind the person – into your face
• Bring up lights carefully
• Move slowly so they can follow you
• Place items to be used in central field
Verbal Cues to Help

• Keep your voice deep & calm
• Put rhythm in your voice
• Tell what you are doing and what is happening while you give care
• Reflect emotions you think you see
• Offer positive comments & familiar phrases as you offer care
• Quiet down, if signaled to do so
Touch Cues to Help

• Use firm, but gentle palm pressure at joints to make contact
• Always try to maintain contact with one hand while working with the other
• Once physically connected keep it
• Use flats of fingers and palms for care
• Always use hand under hand when doing something ‘intense’
How to Help

• Hand under hand help & care – or hand on forearm, if hand/arm movement is poor
• Check for reflexes – modify help & approach to match needs
• GO SLOW
• Use calm, rhythmic movements & voice
• Come in from back of extremities to clean
• Stabilize with one hand & work with other
How to Help?

• Gather all supplies for the task before getting started
• Increase warmth of the room for bathing
• Use warm towels & light weight blankets
• GO SLOW
• Use circular, rotational movements to relax joints for care
• Provide skin care – fragile & dry skin
BAD Help Habits to BREAK

• Hurry - Get it done quickly
• Don’t talk to – talk over or about
• Don’t check for primitive reflexes prior to helping
• Use both hands to give care
• Clean from the front – use prying motions
• Focus on tasks not the relationship
• Forget to look for the Pearl

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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 & Resolving Distress – 1:1
• Helping with Challenging Behaviors – Using a Problem Solving Approach
• Providing coaching support and guidance to team mates