What to Do in the Later Stages of Dementia
Creating Meaning for Ambers, Rubies, & Pearls

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What Does It Take To Make a Great Activity Program for Later Stages?

Know each PERSON!

Manage the ENVIRONMENT!

Understand ACTIVITIES!

Build staff SKILLS!

Make & Use a SCHEDULE!

Resources to succeed
Sensory Processing and Dementia

In Later Stages It Matters
Humans have FIVE ways of getting information from the world around them

What we:
- See
- Hear
- Feel
- Smell
- Taste
Two Major Categories

Protective

Discriminatory
Two Categories

**Protective**
- FAST
- Reflexive
- Try to keep you safe
- Autonomic – reflexive
- BIG!
- Strong Emotions!!!
- Spinal & Primitive
- Flight-Fight-Flight

**Discriminatory**
- Slower
- Brain driven
- Exploring and figuring out
- Details & differences
- Focused
- Ignore big world to experience immediate
- Want more or want less
With Dementia

Protective

- Less able to pick up on ‘danger’ signals/cues
- More likely to over-react to ‘normal’ range
- To non-demented seems ‘unpredictable’
- BUT – it’s the new predictable – set point
- May move toward ‘dangerous’ versus away from it

Discriminatory

- Either hyper-focused OR un-observant
- From multi-modal awareness to single characteristic attention
- Shortened task attention span
- Variable sensory attention
- Atypical focus on a characteristic – edges of the frame versus the picture
With Dementia All Senses are Affected:

• Miss information
• Mis-understand information
• Over-react to information
• Under-react to information
• Get stuck on a sensation
• Can’t stand a sensation
• Variable abilities
• Can’t adjust or adapt to sensation
With Dementia
It’s All About Finding the BALANCE!!!!
Balance…

<table>
<thead>
<tr>
<th></th>
<th>-</th>
<th>Good for you</th>
</tr>
</thead>
<tbody>
<tr>
<td>Like</td>
<td></td>
<td>Tolerate</td>
</tr>
<tr>
<td>Want</td>
<td></td>
<td>Unpleasant</td>
</tr>
<tr>
<td>Pleasant</td>
<td></td>
<td>Annoying</td>
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<tr>
<td>Comforting</td>
<td></td>
<td>Frightening</td>
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<tr>
<td>Stimulating</td>
<td></td>
<td>Boring</td>
</tr>
<tr>
<td>Calming</td>
<td></td>
<td>Too much</td>
</tr>
<tr>
<td>Nothing</td>
<td></td>
<td>Novel – New</td>
</tr>
<tr>
<td>Familiar</td>
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</tbody>
</table>
Sensation

A common stimulus
That causes an Individual experience
The Stimulus

- Single mode versus multi-modal
- Constant versus intermittent
- Subtle versus EXTREME
- Still versus moving
- Gradual versus sudden
- Sought out versus given
- Controlled by me versus by you
- Expected versus unexpected
### Vision Changes

<table>
<thead>
<tr>
<th>Protective</th>
<th>Discriminatory</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Peripheral awareness</td>
<td>• Organized scanning</td>
</tr>
<tr>
<td>• Visual field</td>
<td>• Saccadic eye movements</td>
</tr>
<tr>
<td>• Depth perception</td>
<td>• Color discrimination</td>
</tr>
<tr>
<td>• Light-dark accommodation</td>
<td>• Figure ground perception</td>
</tr>
<tr>
<td>• Tracking</td>
<td>• Near-far accommodation</td>
</tr>
<tr>
<td>• Blink</td>
<td>• Near acuity</td>
</tr>
<tr>
<td></td>
<td>• Night vision</td>
</tr>
<tr>
<td></td>
<td>• Object recognition</td>
</tr>
<tr>
<td></td>
<td>• Facial recognition</td>
</tr>
</tbody>
</table>
### Hearing-Comprehension Changes

**Protective**
- Direction
- Emergency signals
- Alerting communication

**Discriminatory**
- Localization
- Comprehension
- Sound recognition
- Voice recognition
- Foreground-background
- Tracking
- Following a conversation
- Interpreting meaning
- Multi-step information
Touch & Movement Changes

• This one is both complicated and IMPORTANT!!!!
• Sensation, Processing, Reactions OR Responses Happen FAST!!! Almost automatic – due to habits and procedural memories – looping once started
• Active versus passive - different
Touch …

Movement
- Balance
- Coordination
- Speed
- Accuracy
- Strength
- Bi-lateral & uni-lateral
- Gross motor
- Fine motor
- Reflexes

Sensations
- Pressure
- Temperature
- Moving touch
- Texture
- Shapes
## Touch

**Protective**
- Extreme Temperature
- Sharp – Cutting
- High velocity impact
- Sustained pressure
- Friction

**Discriminatory**
- Variation in temperature
- Variable textures
- Massage
- Wet/dry
- Manipulation
- Grasp
Movement

Protective
• Balance against gravity
• Block incoming
• Avoid contact
• Catch balance
• Maintain upright

Discriminatory
• Voluntary movements to meet goals
• Tool use
• Object manipulation
• Construction
## Olfactory – Smell Changes

<table>
<thead>
<tr>
<th>Protective</th>
<th>Discriminatory</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Limited</td>
<td>• Emotional memories</td>
</tr>
<tr>
<td>– Smoke</td>
<td>• Emotional reaction</td>
</tr>
<tr>
<td>– Chemicals or gas</td>
<td>• Pleasant-unpleasant</td>
</tr>
<tr>
<td>– Spoiled food</td>
<td>• Smell identification</td>
</tr>
<tr>
<td>– Body odor</td>
<td>• Stimulate hunger or thirst</td>
</tr>
<tr>
<td>– Urine or feces</td>
<td>• Stimulate nausea</td>
</tr>
<tr>
<td></td>
<td>• Localization &amp; tracking</td>
</tr>
</tbody>
</table>
Gustatory – Taste Changes

• Less able to pick up on sweet and salty
  SO – they want MORE
• Still keep bitter and sour
  SO – they may not like things they used to

SPECIAL EVENTS
Things may ‘taste’ wrong
May order something then refuse to eat
Create a Sensory Preference List for YOU... for the Person

- Visual likes – stimulating & calming
- Auditory likes – stimulating & calming
- Touch likes – stimulating & calming
- Movement likes – stimulating & calming
- Smell likes – stimulating & calming
- Taste likes – stimulating & calming
Create a Sensory INTOLERANCE List FOR YOU… for the Person

- Visual Irritants
- Auditory Irritants
- Touch Irritants
- Movement Irritants
- Smell Irritants
- Taste Irritants
Gem Changes

• Sapphires – you and me as is
• Diamonds – more vocal and rigid
• Emerald - visual and auditory MOST
• Amber – ALL SENSES critical
• Ruby – Touch, movement, personal & intimate space awareness
• Pearl – Touch, Movement – intimate space KEY!
Ambers

Amber Alert

Caution!

Caught in a moment

All about Sensation

Explorers
Ambers

Private & Quiet OR Public & Noisy
All About Sensory Tolerance & Needs
Touching - Tasting – Handling – Exploring
Attraction – Avoidance
Over-stimulated – Under-stimulated
No safety awareness
Ego-centric
Amber

• LOTS of touching, handling, mouthing, manipulating
• Focus on fingers and mouth
• Get into things
• All about sensation....
• Invade space of others
• Do what they like
• AVOID what they do NOT
Amber Interests

• Things to mess with (may be people)
• Places to explore
• Stuff to take, eat, handle, move…
• Visually interesting things
• People who look or sound interesting OR places that are quiet and private
• Textures, shapes, movement, colors, numbers, stacking, folding, sorting…
Amber Issues

• Getting into stuff – taking stuff
• Bothering others
• Not able make needs known
• Not understanding what caregivers are doing
• Not liking being helped/touched/handled
• Not like showers or baths
• Repetition of sounds/words/actions
Visual Cues that Help

- Automatic social greeting signals
- Lighted work surfaces with strong props
- Demonstrations – work along side
- Model the actions
- Do the action one time, then offer the prop
- Show one step at a time
- Show a NEW item, then cover the old
Verbal Cues that Help

• Call name
• Use simple noun, verb, or noun + verb
  – “Cookie?”
  – “Sit down”
  – “Let’s go” (with gesture)
• Give simple positive feedback
• Listen for their words, then
  – use a few and leave a blank at the end of the sentence
Physical Cues that Help

- Show the motion or action wanted
- Touch the body part of interest
- Position the prop for use – light touch
- Show the motion on yourself
- Use hand under hand guidance
- Offer the prop once started – encourage their use of the item
Hand-Under-Hand Assistance
How to Help

• Provide step-by-step guidance & help
• Give demonstration – show
• Hand-under-hand guidance after a few repetitions, uses utensils (not always well)
• Offer something to handle, manipulate, touch, gather
• Limit talking, noise, touch, other activities
• SUBSTITUTE don’t SUBTRACT
To Connect with Ambers

• Make an Emotional Connection
  – Use props or objects
  – Consider PARALLEL engagement at first
    • Look at the ‘thing’, be interested, share it over…..
  – Talk less, wait longer, take turns, COVER don’t confront when you aren’t getting the words, enjoy the exchange
  – Use automatic speech and social patterns to start interactions
  – Keep it short – Emphasize the VISUAL
BAD Helper Habits to Break!

- Talking too much, showing too little
- Keep on pushing
- Doing for NOT with
- Stripping the environment
- Leaving too much in the environment
- Getting in intimate space
- Over or under stimulating
- Getting loud and forceful
Rubies

Hidden Depths
Red Light on Fine Motor
Comprehension & Speech Halt
Coordination Falters
Wake-Sleep Patterns are Gone
Rubies

Balance & coordination
Eating & drinking
Wake time & sleep time
Ruby

• Big movements – walking, rolling, rocking
• Hand actions – not fingers
• Tends toward movement unless ‘asleep’
• Follows gross demonstration & big gestures for actions
• Limited visual awareness
• Major sensory changes
• Major movement skill loses
• Fine motor skill lost – mouth & hands
Ruby Interests

• Walking a routine path
• Going forward
• Watching others – checking them out
• Being close or having space
• Things to pick up, hold, carry, push, wipe, rub, grip, squeeze, pinch, slap
• Things to chew on, suck on, grind
• Rhythmic movements and actions
Ruby Care Issues

• Safe mobility – fatigue, wandering, & falls
• Intake – amount and safety
• Hydration – interest, amount, safety
• Rest time & place – night time waking
• Shadowing others – invading places
• Not staying – not settling for meals
• Reactions to hands on care – sensation
• Identifying & meeting needs
More Ruby Issues

• Contractures
• Skin well being – bruises, tears, rashes
• Pressure or friction
• Infections – UTI, yeast, URI, pneumonias
• Swallowing
• Circulation
Visual Cues that Help

• Demonstrate what you want
• Give big movements to copy
• Move slowly & with rhythm
• Present cues in central visual field about 12-18 inches out
• Hold things still – allow exploration
• Offer your hand
• Smile while offering support
Verbal Cues that Help

- Call name to get attention – at 6’ out
- Use ‘song’ to connect
- Give 1-3 words only
- Combine verbal direction with gesture or demo
- Give one ‘action’ cue at a time
- Match tone/inflection to intent
- Give positive ‘Strokes’ with attempts
Physical Cues that Help

- Hand-under-hand
- Touch body part to be moved or used
- Place hand/foot then gesture
- Offer comfort touch as desired before task attempt
- Back rubs –
  - Flat and slow – to calm
  - Finger tips and quick circles – to awake
How to Help

• SLOW yourself DOWN
• Hand under hand
• Move with first – then guide
• Learn about patterns of ‘needs’
• Use music and rhythms – help get or stop movement
• Use touch with care
• Combine cuing & do SLOW
BAD Helper Habits to Break!

- Touching too quickly – startling
- Leaning in – intimate space invasion
- Talking too loudly
- ‘Baby-talking’
- Not talking at all
- Not showing by demonstrating
- Trying to understand what is said, by being confrontational
Pearls

Hidden in a Shell
Still & Quiet
Easily Lost
Beautiful - Layered
Unable to Move – Hard to Connect
Primitive Reflexes on the Outside
• 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
• 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
Examples of Meaningful Activities

• **Productive Activities** – sense of value & purpose
• **Leisure Activities** – having fun & interacting
• **Self-Care & Wellness** – personal care of body & brain
• **Restorative Activities** – re-energize & restore spirit
**Moderate Disease - Amber**

- LOTS of touching, handling, mouthing, manipulating
- Focus on fingers and mouth
- Get into things
- All about sensation....
- Invade space of others
- Do what they like AVOID what they do NOT
How to Help

• Provide step-by-step guidance & help
• Give demonstration – show
• Hand-under-hand guidance after a few repetitions, uses utensils (not always well)
• Offer something to handle, manipulate, touch, gather
• Limit talking, noise, touch, other activities
• SUBSTITUTE don’t SUBTRACT
Hand-Under-Hand Assistance
Level 2 - Ruby

- Big movements – walking, rolling, rocking
- Hand actions – not fingers
- Tends toward movement unless ‘asleep’
- Follows gross demonstration & big gestures for actions
- Limited visual awareness
- Major sensory changes
- Major movement skill loses
- Fine motor skill lost – mouth & hands
How to Help

• Hand under hand
• Move with first – then guide
• Learn about patterns of ‘needs’
• Gradual transitions - go to stop
• Use music and rhythms – help get or stop movement
• Use touch with care
• Combine cuing & do SLOW
Level 1 - Pearl

- Immobile – can’t get started
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- Touch and voice make a difference in behaviors
How to Help

• Hand under hand help & care
• Check for reflexes – modify help and approach to match needs
• Guide movements
• Use calm, rhythmic movements and voice
• Come in from back of extremities to clean
• Stabilize with one hand and work with other
How can we help... better?

It all starts with your approach!
How you help...

- Sight or Visual cues

- Verbal or Auditory cues

- Touch or Tactile cues
Believe -

People with dementia
Are doing
The BEST they can!
What shouldn’t we do???

• Argue
• Tell ‘WHOPPERS’ – that relate to emotions
• Ignore problem behaviors
• Try a possible solution only once
• Give up
• Let them do whatever they want to
• Force them to do it
How Can You Be Prepared & Respond When Something Does Happen?

• Think..., then act & respond
• Use the positive physical approach
• Reflect on the emotional message
• Figure out the ‘need’
• Use old & familiar to help with new
• Take time & energy to problem solve... after
• If its not working ... STOP, Back off, try again
So... What Should You Do?

- Plan for the probabilities
- Create environments that reduce risk
- Get skilled or find someone who is
- Get others on board
- Keep track of ‘what is’
- Watch for signs of changes
- Get help early – call or contact
- Be flexible
How *You* Feel is **REAL & Important**!

- However you feel is OK, its how you feel!
- It’s not about judgment, its about support!
- Acknowledge the feelings...
- Then decide what to do about it...
- Is it what you want to feel?
- IF YES, go with it...
- If NO, work to change it!
If You are having a HARD TIME...

• Think about...
  – What HELPS YOU
  – What you NEED
  – What is MISSING
  – What you are struggling with
  – Who else might help
  – What will happen if you don’t do something
  – What might happen if you do...
Some Ideas for changing...

• Pick one thing
• Plan on baby steps
• Get support for you
• Build a routine
• Check in on your feelings
• Add something before giving something up
• Believe it - Not everyone is meant to do hands on care
• Give it a try... not permanent... just try
A Few More Ideas

• Set aside a few minutes – use a timer!
• Breathe
• Smile ... Laugh! – look for some funnies
• Remember a good time
• What do you get out of the relationship
• Use at least one of the STRESS TAMERS
10 Minute Stress Tamers

• *Sit quietly* in calm surroundings with soft lights and pleasant scents.
• *Aromatherapy* – lavender, citrus, vanilla, cinnamon, peppermint, fresh cut grass.
• *Breathe deeply* – rest your mind & oxygenate
• *Soak* - in a warm bath, or just your hands or feet
• *Read* - Spiritual readings, poetry, inspirational readings, or one chapter of what you like…
• *Laugh and smile* - Watch classic comedians, Candid Camera, America’s Funniest Home Videos, look at kid or animal photos…
• *Stretch* – front to back, side to side, & across
• *Garden* – work with plants
10 Minute Stress Tamers

• **Beanbag heat therapy.** Fill a sock with dry beans and sew or tie closed. Heat bag and beans in a microwave for 30 seconds at a time. Place on tight muscles and massage gently; relax for ten minutes.

• **Remember the good times** - Record oral memories - scrapbooks, photo journals, keepsake memory picture frames. Just jot!

• Do a little on a favorite hobby.

• Have a **cup of decaffeinated tea or coffee**

• Play a **brain game** – crosswords, jigsaws, jeopardy, jumbles...

• Look through the **hymnal** and find a favorite – hum it all the way through...
10 Minute Stress Tamers

• *Books on Tape* - Rest your eyes and read
• *Soothing sounds* –
  – Music you love
  – Music especially for stress relief
  – Recorded sounds of nature
• Listen to *coached relaxation recordings*
• *Pamper Yourself* – think of what you LOVE and give yourself permission to do it for 10 minutes
• *Neck rubs or back rubs* – use the ‘just right’ pressure
• *Hand Massages* – with lotion or without – its up to you...
10 Minute Stress Tamers

• *Take a walk.*
• *Sit* in the sun.
• *Rock* on the porch.
• *Pray* or read a passage from scripture
• *Journal* - Take the opportunity to “tell it like it is.”
• Cuddle and stroke a *pet*.
• Have that cup of coffee or tea with a *special friend* who listens well.
• Pay attention to *your personality*.
  – If you rejuvenate being alone, then *seek solitude*.
  – If you rejuvenate by being with others, *seek company*. 
BREATHE!!!

- Take a deep breath in
- BLOW it all the way out
- Take another breath in
- BLOW it out
- Take one final breath in AND
- SING IT OUT....

- Feel what happened to you...
- Look at what happened to the people around you...
- Think about how and when you might do this...
Let Go:

• How it “used to be”

• How it “should be”

• How you “should be”
Identify

• What you’re good at...and what you’re not

• Who can help...and how they can help

• What really matters
Final Suggestions

• Back off, change something and try again

• Adopt a “SO WHAT” mentality

• Try a support group

• Accept yourself, and the person with dementia

• Look for the JOY!!!