Pain and Dementia
How Dementia Impacts Pain Assessment & Intervention

When will DEMENTIA be a factor for you?
- End of dementia – end of life
- Mid-dementia - with another terminal disease
- Early dementia –
  - a caregiver
  - a ‘non-compliant’ person
  - new diagnosis or non-diagnosis
  - side effect of treatment for another condition

In Dementia
There is certainly physical pain…
BUT
It is other pain that may be more important
  - emotional pain
  - spiritual pain
SO
Interventions MUST go beyond the physical!
Interventions WILL involve caregivers
What happens with Alzheimer’s Disease?

- Two processes
  - Cells are shrinking & dying
  - Cells are producing less chemical to send messages
Positron Emission Tomography (PET)
Alzheimer’s Disease Progression vs. Normal Brains

<table>
<thead>
<tr>
<th>Normal</th>
<th>Early Alzheimer’s</th>
<th>Late Alzheimer’s</th>
<th>Child</th>
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So How Does This Impact Pain Assessment?

- Assume that your clients will have pain
  - Lack of response doesn’t mean lack of pain
- Use more than your questions and their answers to assess for pain
  - Health history
  - Physical exam findings
  - Functional and behavioral changes
  - Beyond the person to the situation
  - Reassess routinely and with greater frequency

AND...

- Assess with more than your ears…what you see, what you feel with your fingers…and with your heart.
Dementia

- People with dementia and hip fracture
  - Received as many procedures
  - Received ¼ of the pain medications when compared with people without dementia (JAMA 2000)

Questions

- Do people with dementia have less pain?
- Do people with dementia have more pain?
- Do people with dementia have the same amount of pain?

DEMENTIA

- Alzheimer’s Disease
  - Early onset
  - Normal onset

- Vascular (Multi-infarct) Dementia

- Fronto-Temporal Lobe Dementias

- Other Dementias
  - Huntington’s
  - Creutzfeldt-Jakob
  - White matter disease
  - HIV/AIDS
  - Depression
  - Schizophrenia
  - Parkinson’s
Pain Management Guidelines

- Establish relationship
- Assume there will be pain
- Be alert - Look, listen, feel for pain
- If "it" would hurt you assume "it" hurts them
- When there is a change in ‘BEHAVIOR’ check out the possibility of PAIN first!
- Connect to the person before you try to ‘fix’ it
- Use acetaminophene REGULARLY not prn

Pain Behaviors Change as the Disease Progresses

Your assessment and management will need to change as well

Rating of Progression

- GDS – 1-7
- Cognitive Disability Theory – ACL – 6-1
- Early-Middle-Late – 1-3

OR

- GEMS – based on ACL –
  - Precious, unique, and valuable
  - Familiar framework for caregivers
Now for the GEMS…

- **Sapphires**
- **Diamonds**
- **Emeralds**
- **Ambers**
- **Rubies**
- **Pearls**

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 & Go – No Fine Control
- **Pearls** – Hidden in a Shell - Immobile

What Can & Does the **Level 5 - Diamonds** Person Do?

- Completes personal care without help
- Follows simple directional signs
- Follows prompted schedules
- Follows familiar routes to get around
- Looks for places, people, activities that are desired BUT gets lost easily
- Becomes easily frustrated when things don’t go well or others won’t “behave right”
Common Pain Behaviors - Diamonds
Somatic Complaints
Bursts of anger
Refusals
Appetite or sleep changes
Worsening cognition
Referred pain – previous pain sites/old injuries
Hiding – denial
Over medicate self unintentionally
Strange explanations of pain/discomfort
Refusals of pain medications
Withdrawal – social
Depression - Anxiety

Helpful Responses for Diamonds
Asking “where…” not “if…”
Ask what has helped before
Consider ‘more intensive’ referral
Use distractions & redirection
Use activity and engagement
Monitor for response for meds (narcotics)
Heat – baths & packs
Mobility enhancement
Rest breaks and healthy sleep environments
Music to calm
Provide control options

What Can & Does the Level 4 - Emeralds Person Do?
• Needs some supervision for personal care sequences
• Follows simple gestures & demonstration
• Follows familiar others to locations
• Uses environmental cues to locate places
• Looks for places, people, activities that look or sound interesting or are familiar
• Becomes upset if unable to figure out what should or needs to be done
Common Pain Behaviors for Emeralds
Repeated activities with increasing distress
Repeated questions with increasing distress
Repeated attempts to elope with increasing distress
In the moment awareness ONLY

Shutting down – isolating from all
Guarding, rubbing, touching, handling
Striking out or swearing if you ‘hit the spot’
Yell out when moving
Mis-remember and report their pain

Helpful Responses for Emeralds
Connect, meet need, then redirect or distract
Rocking, massage, warmth
Visual distraction & engagement
Environmental change – new place

Schedule meds pre-activity
Careful info sharing between caregivers
Use more visual guidance rather than ‘physical assist’
Careful physical exam

What Can & Does the Level 3 - Ambers Person Do?

- Follows demonstrations and hand-under-hand guidance after a few repetitions, uses utensils (not always well)
- Likes to handle, manipulate, touch, gather, place things
- Will not respect others’ space or belongings
- Goes to places or activities that are interesting visually, tactualy, auditorily
- Leaves places or activities that are TOO busy or crowded
Common Pain Behaviors for Ambers

- Pacing
- Repetitive gestures, hand actions, facial grimacing, vocalizations
- Increased eye contact with caregivers and personal space invasion
- Picking and pulling at clothing/stuff/non-localized
- Striking out during care attempts
- Shutting down – inactive
- Non-processing of pain

Helpful Responses for Ambers

- Use of ‘comfort’ touch and actions
- Environmental modifications for calming and comfort – light, sound, temperature, seating, smells
- Use mirroring
- Use music
- Use prayer or rhythmic speech or reading
- Warm blankets and comfort food/drink
- Balance
  - rest & activity
  - together & alone

What Can & Does the Level 2 - Rubies Person Do?

- Walks/wheels around a majority of the time when awake
- May carry objects or rub/clap/pat with hands
- Tends toward movement unless ‘asleep’
- Uses hands poorly, not spontaneously, inconsistently
- Follows gross demonstration & big gestures for actions
- Limited awareness of others - may invade personal space
- Gets stuck in ‘tight’ places
- Leaves during ‘unpleasant’ experiences
Common Pain Behaviors for Rubies
Walking or rocking
Vocalizations
Forceful actions — pushing, grabbing, banging or hitting
Full body startle
Falls & gait changes
Loss of appetite — food/fluid refusals
Sleeping or lying not sleeping
Restless movements
Rigidity — Stiffness
Guarding
Vomiting or drooling
Teeth grinding or growling
Staring

Helpful Responses for Rubies
SLOW DOWN
Go with first... then
Model the behavior you want to see/get
Warm spaces, warm covers, layers
Massage — feet, hands, back, head
Aromatherapy
One hand moves the other stays still
Once in touch — stay connected
Music and singing
Rhythmic & circular movement
Deep and rhythmic voice
Don’t stop pain meds

What Can & Does the Level 1 - Pearls Person Do?
• Is bed or chair bound
• 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
Common Pain Behaviors for Pearls

- Writhing
- Grasping
- Grinding teeth
- Total body withdrawal
- Moaning
- Screaming
- Wide eyes - stares
- Calling out during movement

Visible evidence of injury or wounds - without a "response"
- Pressure sores
- Friction areas
- Bruising
- Rashes
- Nails in flesh
- Skin tears
- Swelling/inflammation

Helpful Responses for Pearls

- YOU!!! And how you move, touch, look, speak, listen, & respond
- SLOW WAY DOWN!

Guidelines for Assessment

- What you see, hear, feel…

- Use of tools: early stages only (diamonds)
  - Visual
  - Pictures
  - Try to see what works
  - Then use consistently
**Individualize Your Pain Scale**

- Red
- Orange
- Yellow
- Green
- Blue
- Gray

**Pain Thermometer**

- The pain is almost unbearable
- Very bad pain
- Quite bad pain
- Moderate pain
- Little pain
- No pain at all

**Medications**

**What works:**
- Scheduling medications
- Providing for breakthrough pain
- Balance pain relief with function
- Using right class for the type of pain
- Monitoring for response: positive or negative

**What doesn’t work:**
- Antipsychotics
- Anxiolytics
- Treating the symptoms…not the cause
- Over responding to pain
- Ignoring medications as options
How can we help better?

It all starts with *your approach!*

How you talk…

- **How** you say it…
- **What** you say…
- How you **respond**…

Use empathy &
Go with the flow

- Reality Orientation
- Telling Lies
How you help...

- Sight or Visual cues
- Verbal or Auditory cues
- Touch or Tactile cues

Hand-Under-Hand Assistance

Some KEY Helping Behaviors

- A Positive Physical Approach
- Strong & Desirable Visual Cues
- Short & Effective Verbal Cues
- Minimal & Familiar Tactile Cues
- Use what you know about the person
- Change the environment to help
How You Do
What You Do MATTERS!

Assess for Pain!
Manage Pain!
They are in YOUR Hands!