Pain and Dementia:
How to Recognize and Intervene When Pain is a Possibility

In Dementia:
There is certainly physical pain but it is other pain that may be more important, such as emotional and spiritual pain so...
Interventions must go beyond the physical!

So, What is Dementia?
Four Truths About Dementia:

1. At least 2 parts of the brain are dying:
   - One related to memory and one other
2. It is chronic – can’t be fixed
3. It is progressive – it gets worse
4. It is terminal – it will kill, eventually

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Positron Emission Tomography (PET)
Alzheimers Disease Progression vs. Normal Brains

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G. Small, UCLA School of Medicine.

Dementia

Alzheimer’s Disease:
- Young onset
- Down syndrome
- Other associated
- Late-life onset

Vascular

- Multi-infarct
- Dementia

Lewy Body Disease:
- Parkinsonism
- Dementia

Other Dementias:
- Frontal Lobe Dementia
- Normal pressure hydrocephalus (NPH)
- Other causes of dementia

Positron Emission Tomography (PET)
Alzheimers Disease Progression vs. Normal Brains

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Four Truths About All Dementias:
- At least two parts of the brain are dying
- It is not curable or fixable — chronic
- It gets worse and continuing worse — progressive
- It results in death — terminal

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Primitive Brain is in Charge of:

Survival:
- Autonomic protective: Fright, flight, fight + hide or seek
- Pleasure seeking: Meeting survival needs and finding joy

Thriving – Running the Engine:
- Maintain vital systems: BP, BS, Temp, Pain, Oxygen
- Breathe, suck, swallow, digest, void, defecate
- Circadian rhythm
- Infection control

Learning New and Remembering:
- Information
- Places (spatial orientation)
- Passage of Time (temporal orientation)

Amygdalae:

<table>
<thead>
<tr>
<th>Threat</th>
<th>Pleasure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dangerous Alert/Aware</td>
<td>Need Want Like</td>
</tr>
<tr>
<td>Aroused/Risky</td>
<td>Need Want Like</td>
</tr>
</tbody>
</table>

If I’m ‘hurting’ and I need relief…

Amygdala turns on and I need it now!!!
So How Does Dementia Impact Pain Assessment?

- Assume that they will have pain
- Lack of response doesn’t mean lack of pain
- Use more than your questions and their answers to assess for pain – use observations
- Know health history
- Check physical exam findings
- Monitor functional and behavioral changes
- Look beyond the person to the situation
- Reassess routinely and with greater frequency

And:

Assess with more than your ears: use what you see, what you feel with your fingers…and with your heart

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?
What Makes ‘Painful Situations’ Happen?

Six Pieces of the Puzzle:
1. The person and who they have been: personality, preferences, and history
2. Health: other conditions, sensory status, and meds/fluids/fuels
3. The type and level of cognitive impairment(s)
4. People: how the helper helps, and others’ approach, behaviors, words, actions, and reactions
5. The environment: setting, sound, sights, 4 F’s
6. The whole day: how things fit together, finding balance

Brain Changes:
- Dementia:
  - Type(s)
  - Awareness
  - Delirium
  - Depression
  - Note GEM Level(s):
    - Changed abilities
    - Related abilities
    - Variability
    - Self-awareness
    - Onset & duration

The Person:
- Past and Present:
  - Life story/history
  - Personality traits
  - Preferences
  - How sickness
  - Key values
  - Joys and traumas
  - Roses, Watch-Tab-Do

Wellness, Health, and Fitness:
- Health Conditions and Physical Fitness:
  - Fuel and Fluids
  - Meds and Supplements
  - Emotional and Psychological Condition
  - Sensory Systems
  - Health Beliefs of Note
  - Recent Changes
  - Acute/Diabetes

The Environment:
- Explore the Four F’s:
  - Friendly
  - Familiar
  - Functional
  - Forgiving
  - Space
    - Intimate, personal, public
  - Sensations
    - See, hear, feel, smell, taste
  - Surfaces
    - Sit, stand, postrate, work
  - Social
    - People, activity, role, expectations

People - Us:
- Care Partners and Others Around
  - History - background
  - Knowledge
  - Skills
  - Competence
  - Relationship(s)
  - Agenda(s)

Time:
- Time Awareness:
  - Where in life
  - Time of day
  - Passage of time

How Might Personality Traits Affect Pain Behaviors and Assessment?
Understanding and Responding to Challenges:

What is happening?
Why is it happening?
What helps? What makes it worse?
How can we prevent it from happening in the first place?
If it happens again, what can we do to make it better?

Top Five Unmet Needs:

Physical Needs:
- Hydration and Nourishment
- Wake-sleep and active-rest cycles
- Elimination: all forms
- Find Comfort: 4Fs 4Ss

Pain-free:
- Physical – body
- Emotional – relationships
- Spiritual – belonging/purpose

Signals of Emotional Distress:
- Angry
- Sad
- Lonely
- Scared
- Bored – Lacking Purpose
Guidelines for Pain 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:

PAIN ASSESSMENT TOOL

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Pain</td>
<td>Mild</td>
<td>Moderate</td>
<td>Severe</td>
<td>Very Severe</td>
<td>Worst Pain Possible</td>
<td></td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>0</td>
<td>1-3</td>
<td>4-6</td>
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Pain Thermometer:

The pain is almost unbearable
Very bad pain
Quite bad pain
Moderate pain
Little pain
No pain at all
Pain Management Guidelines:
- Establish a 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!
- Establish a relationship: connect to the person before you try to ‘fix’ anything
- Use acetaminophen regularly, not prn

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

Progression:
The GEMS® States

Sapphires: True Blue, Healthy Brain
Diamonds: Clear/Sharp, Routines and Routines
Emeralds: Green/On the Go with Purpose, Naturally Flawed
Ambers: Caught in a Moment of Time, Caution Required
Rubies: Deep and Strong, Others Stop Seeing What is Possible
Pearls: Hidden in a Shell, Beautiful Moments to Behold
What Can and Does a Diamond 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
- Hiding/denial
- Over medicate self unintentionally
- Strange explanations of pain/discomfort
- Refusals of pain medications

Bursts of anger
- Withdrawal – social

Refusals
- Depression and Anxiety

Appetite or sleep changes
- Refused pain medications

Worsening cognition
- Provide control options

Referred pain: previous pain sites/old injuries
- Monitor for response to meds (narcotics)

Helpful Responses for Diamonds:
- Asking “where...” not “if...”
- Ask what has helped before
- Consider ‘more intensive’ referral
- Use distractions and redirection
- Use activity and engagement

- Heat: baths and packs
- Mobility enhancement
- Rest breaks and healthy sleep environments
- Music to calm

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What Can and Does an Emerald Do?
- Needs some supervision for personal care sequences
- Follows simple gestures and 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

Helpful Responses for Emeralds:
- Connect, meet need, then redirect or distract
- Rocking, massage, warmth
- Visual distraction and engagement
- Environmental change to a new place
- Schedule meds pre-activity
- Careful info sharing between caregivers
- Use more visual guidance rather than ‘physical assist’
- Careful physical exam
**What Can and Does an Amber Do?**

- Needs step-by-step guidance and help for personal care
- Follows demonstration and Hand-under-Hand™ guidance after a few repetitions, uses utensils but not always well
- Likes to handle, manipulate, touch, gather
- Will not respect others’ space or belongings
- Goes to places or activities that are interesting visually, tactiley, auditorily
- Leaves places/activities that are too busy/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 or other non-localized spots
- Striking out during care attempts
- Shutting down – inactivity
- 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 of: rest and activity, together and alone
What Can and Does the Ruby Do?
- Walks/wheels around a majority of the time when awake, but gets stuck in tight places
- May carry objects or rub/clap/pat with hands
- Tends toward movement unless asleep
- Uses hands poorly, not spontaneously, inconsistently
- Follows gross demonstration and big gestures for actions
- Limited awareness of others, may invade personal space
- Leaves during ‘unpleasant’ experiences

Common Pain Behaviors for Rubies:
Walking or rocking
Vocalizations
Forceful actions: pushing, grabbing, banging or hitting
Full body startle
Falls and gait changes
Loss of appetite: food/fluid refusals
Sleeping or lying awake
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 and circular movement
Deep, rhythmic voice
Don’t stop pain meds
What Can and Does the Pearl 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 or inflammation

Helpful Responses for Pearls:
You!!!
How you move, touch, look, speak, listen, and respond
Slow way down!!!
Interventions Should Involve:

- Care providers
- Environmental supports
- Schedule re-consideration
- Dynamic assessment

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