

# Assessing and Treating Pain in People Living with Dementia (PLWD)

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Carrie Rubenstein, MD

Swedish Medical Center, Seattle WA

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# Objectives

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- Review issues unique to PLWD when assessing and treating pain
- Share screening tools for pain which can be used for PLWD
- Review the evidence for assessing and treating pain in PLWD
- Consider a stepwise approach when treating pain in PLWD

# Why should you care?

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6.5 people living with dementia in the US (PLWD)

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By 2050, the number of people 65 and older with Alzheimer's dementia is projected to reach 12.7 million.

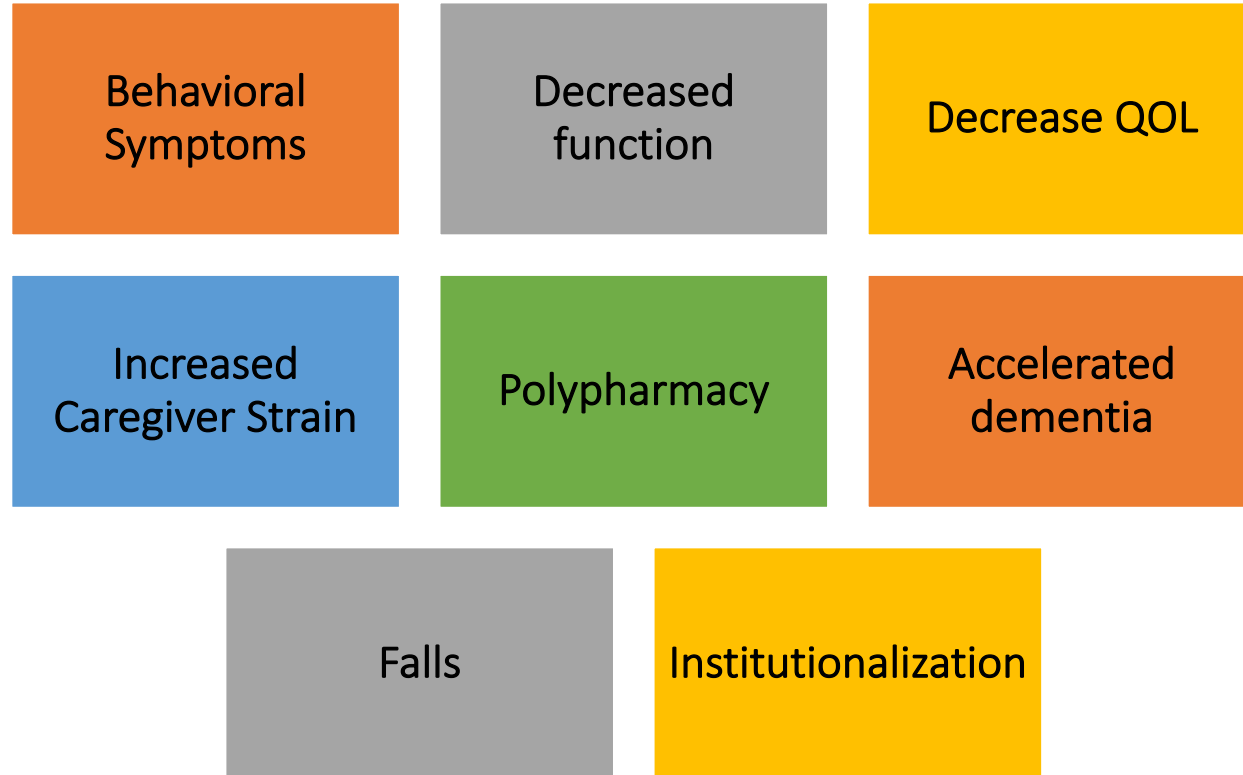
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A common comorbidity associated with aging is painful conditions (eg, musculoskeletal pain)

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It is estimated that approximately 50% of people with dementia have a painful condition, concordant to older adults without dementia.

# Why is this so important?



## Age-Friendly Health Systems Benefit Everyone

The 5Ms for Age-Friendly Health define how we care for older adults. At Providence, we believe this framework can apply to anyone, regardless if you're 65 or older. Age-Friendly Health is everyone's health.

### Providence's 5Ms for Age-Friendly Health:



Achterberg WP, Pieper MJ, van Dalen-Kok AH, et al. Pain management in patients with dementia. *Clin Interv Aging*. 2013;8:1471-1482. doi:10.2147/CIA.S36739

# Why is this so hard?



Communication  
difficulties

The diagram consists of four identical, horizontally aligned boxes. Each box is composed of a dark blue rounded rectangle in the background and a light gray rounded rectangle in the foreground. The boxes overlap slightly from left to right. Each light gray box contains one of the four reasons listed below.

Delay in  
treatment

Lack of  
Evidence

Bias –  
Personhood

# Pain Types

Pain Type	Nociceptive Somatic	Nociceptive Visceral	Neuropathic	Nociplastic
Examples	Arthritis, fracture, bone metastases, postoperative, etc	Renal colic, constipation, etc	Radiculopathy, drug toxicities, post-herpetic neuralgia, diabetic neuropathy, etc	Fibromyalgia, myofascial pain syndrome, complex regional pain syndrome
Palliative/provocative factors	Movement	Variable; may be provoked by oral intake	Position changes may provoke radiculopathy	Variable, may be provoked by movement, may be accompanied with sensory changes
Quality	Throbbing, aching, stabbing, gnawing	Cramping, tearing, dull, aching, squeezing, deep	Burning, numb, tingling, sharp, shooting, “electric shock”	Can have features of nociceptive and neuropathic
Radiation	Well localized	May refer to other sites	Nerve or dermatome distribution	May be localized or referred to other sites
Timing	Constant	Colicky, intermittent	Constant or paroxysmal	Constant or paroxysmal

# How do we assess for pain in dementia?

- Must be **multidimensional** approach to pain assessment
  - Self-report assessments – should always include if possible
  - Pain history information
  - Considering coping, psychological, attitude, belief
  - Physical examination - focus on common conditions that are painful in adults
  - Understand type of pain:
  - Informant-based ratings
  - Observation of pain behaviors



# What does the evidence say about assessment tools for pain in PLWD?

- In a 2014 systematic review article of 28 pain assessment tools for the individuals with dementia, it was noted that none had sufficient evidence of reliability and validity and, thus, there was no recommendation for the use of one tool over any of the others.



# Simplest Assessment Tools for Pain

**Numeric Rating Scale**



**Wong-Baker FACES® Pain Rating Scale**



# Assessing and Screening for Pain in PLWD

## **PAINAD**

- Pain Assessment in Advanced Dementia Scale
- Simple to utilize and requires minimal, if any, training
- Breathing, negative vocalization, facial expression, body language, consolability
- Reliable and Valid when used with older adults with moderate to severe cognitive impairment without variance in the use of the measure across racial groups (Resnick, et al, 2021)

Behavior	0	1	2	Score
Breathing Independent of vocalization	<ul style="list-style-type: none"><li>• Normal</li></ul>	<ul style="list-style-type: none"><li>• Occasional labored breathing</li><li>• Short period of hyperventilation</li></ul>	<ul style="list-style-type: none"><li>• Noisy labored breathing</li><li>• Long period of hyperventilation</li><li>• Cheyne-Stokes respirations</li></ul>	
Negative vocalization	<ul style="list-style-type: none"><li>• None</li></ul>	<ul style="list-style-type: none"><li>• Occasional moan or groan</li><li>• Low-level speech with a negative or disapproving quality</li></ul>	<ul style="list-style-type: none"><li>• Repeated troubled calling out</li><li>• Loud moaning or groaning</li><li>• Crying</li></ul>	
Facial expression	<ul style="list-style-type: none"><li>• Smiling or inexpressive</li></ul>	<ul style="list-style-type: none"><li>• Sad</li><li>• Frightened</li><li>• Frown</li></ul>	<ul style="list-style-type: none"><li>• Facial grimacing</li></ul>	
Body language	<ul style="list-style-type: none"><li>• Relaxed</li></ul>	<ul style="list-style-type: none"><li>• Tense</li><li>• Distressed pacing</li><li>• Fidgeting</li></ul>	<ul style="list-style-type: none"><li>• Rigid</li><li>• Fists clenched</li><li>• Knees pulled up</li><li>• Pulling or pushing away</li><li>• Striking out</li></ul>	
Consolability	<ul style="list-style-type: none"><li>• No need to console</li></ul>	<ul style="list-style-type: none"><li>• Distracted or reassured by voice or touch</li></ul>	<ul style="list-style-type: none"><li>• Unable to console, distract, or reassure</li></ul>	
TOTAL SCORE				

(Warden et al., 2003)

### **Scoring:**

The total score ranges from 0-10 points. A possible interpretation of the scores is: 1-3=mild pain; 4-6=moderate pain; 7-10=severe pain. These ranges are based on a standard 0-10 scale of pain, but have not been substantiated in the literature for this tool.

# PACSLACII

- More comprehensive than PAINAD
- 60 items/subscales
  - Facial expression, activity, personality, mood, change in behaviors

## Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC)

Indicate with a checkmark, which of the items on the PACSLAC occurred during the period of interest. Scoring the sub-scales is derived by counting the checkmarks in each column. To generate a total pain sum all sub-scale totals.

Facial Expression	Present
Grimacing	
Sad look	
Tighter Face	
Dirty Look	
Change in Eyes (Squinting, dull, bright, increased eye movements)	
Frowning	
Pain Expression	
Grim Face	
Clenching Teeth	
Wincing	
Open Mouth	
Creasing Forehead	
Screwing Up Nose	

Social/Personality/Mood	Present
Physical Aggression (e.g. pushing people and/or objects, scratching others, hitting others, striking, kicking).	
Verbal Aggression	
Not Wanting to be Touched	
Not Allowing People Near	
Angry/Mad	
Throwing Things	
Increased Confusion	
Anxious	
Upset	
Agitated	
Cranky/Irritable	
Frustrated	

Activity/Body Movement	Present
Fidgeting	
Pulling Away	
Flinching	
Restless	
Pacing	
Wandering	
Trying to Leave	
Refusing to Move	
Thrashing	
Decreased Activity	
Refusing Medications	
Moving Slow	
Impulsive Behaviours (Repeat Movements)	
Uncooperative/Resistance to care	
Guarding Sore Area	
Touching/Holding Sore Area	
Limping	
Clenching Fist	
Going into Fetal Position	
Stiff/Rigid	

Other (Physiological changes/Eating Sleeping Changes/Vocal Behaviors)	Present
Pale Face	
Flushed, Red Face	
Teary Eyed	
Sweating	
Shaking/Trembling	
Cold Clammy	
Changes in Sleep Routine (Please circle 1 or 2) 1) Decreased Sleep ..... 2) Increased Sleep During the Day	
Changes in Appetite (Please circle 1 or 2) 1) Decreased Appetite ..... 2) Increased Appetite	
Screaming/Yelling	
Calling Out (i.e. for help)	
Crying	
A Specific Sound of Vocalization For pain "ow," "ouch"	
Moaning and groaning	
Mumbling	
Grunting	
<b>Total Checklist Score</b>	

# PEG-3 Pain Screening Tool

ORIGINAL ARTICLE

Medical Care April 2016 54(4) 414-421

Comparative Responsiveness of the PROMIS Pain Interference Short Forms, Brief Pain Inventory, PEG, and SF-36 Bodily Pain Subscale

Jacob Kean, PhD,\*† Patrick O. Monahan, PhD,‡ Kurt Kroenke, MD§¶ Jingwei Wu, PhD,‡ Zhangsheng Yu, PhD,‡ Tim E. Stump, MS,‡ and Erin E. Krebs, MD||\*\*

What number best describes your pain on average in the past week?

No  
Pain

Pain as bad as  
you can imagine

0 1 2 3 4 5 6 7 8 9 10

What number best describes how, during the past week, pain has interfered with your enjoyment of life?

Does not  
interfere

Unable to carry on  
any activities

0 1 2 3 4 5 6 7 8 9 10

What number best describes how, during the past week, pain has interfered with your general activity?

Does not  
interfere

Completely  
interferes

0 1 2 3 4 5 6 7 8 9 10

# electronic Pain Assessment Tool (ePAT)

- A point-of-care App, it utilizes facial recognition technology to detect facial micro-expressions indicative of pain. ePAT also records the presence of pain-related behaviors under five additional domains (Voice, Movement, Behavior, Activity, and Body)
- ePAT has psychometric properties which make it suitable for use in people with moderate to severe dementia.
- Now called:  
**PainChek® Universal**

*M. Atee et al. / Pain Assessment in Dementia*



Image 1. Face detection and tracking in the ePAT App during a clinical encounter.

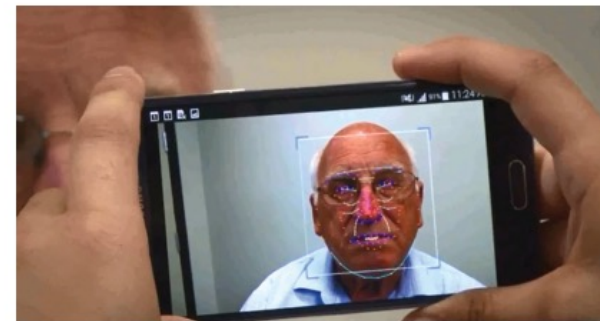


Image 2. Facial features extraction of the ePAT App.



# How do we use these tools?

- People with dementia should be assessed for pain problems on a regular basis.
- Self-reporting tools (like the PEG-3) are appropriate for people with early to middle stage dementia
- Professionals should consider that pain is most probably present in patients who have conditions that usually accompany pain.
- All direct caregivers should have specialized training in pain recognition and management in this population.

# What do we know about treatment of pain in PLWD?

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- Widely accepted that PLWD are underrecognized and undertreated for pain
- In nursing home settings, evidence to date has found people with dementia are prescribed less pain medication than their matched controls.
  - Systematic review of hip and pelvic fracture found 50% less pain medication in PLWD vs cognitively intact older adults (Moschinski, 2017)
- There is conflicting evidence from neuropathological, neuroimaging, experimental, and clinical research regarding the impact of dementia neuropathology on pain processing and perception.
- Experimental evidence suggests people with dementia may require more analgesia to reach the appropriate level of pain relief

# What else do we know about **treatment** of pain in PLWD?

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- Small study on treating agitation in PLWD with opioid: 13/25 people improved in 4 weeks (Manfredi, 2003)
- Study on PLWD in NH and treatment of pain (Husebo, 2014, N=352)
  - Stepwise protocol pain assessment and behavior
  - Less pain
  - Improved ADL function



# Prescribing principles for pain

- Educate that need multimodal approach.
  - Meds are one of several approaches
- Ask about beliefs and attitudes
- Ask about goals and expectations, with emphasis on FUNCTION
- Use shared decision making to agree on management goals
- Low threshold when deprescribing – esp polypharmacy

# Changing Pharmacokinetics and Pharmacodynamics

Table 1—Age-Associated Changes in Pharmacokinetics and Pharmacodynamics

Parameter	Age effect	Disease factor effect	Prescribing implications
Absorption	Rate and extent are usually unaffected	Achlorhydria, concurrent medications, tube feedings	Drug-drug and drug-food interactions are more likely to alter absorption
Distribution	Increase in fat:water ratio; decreased plasma protein, particularly albumin	Heart failure, ascites, and other conditions increase body water	Fat-soluble drugs have a larger volume of distribution; highly protein-bound drugs have a greater (active) free concentration
Metabolism	Decrease in liver mass and liver blood flow decrease drug clearance; may be age-related changes in CYP2C19, while CYP3A4 and 2D6 are not affected	Smoking, genotype, other medications, alcohol, and caffeine have more effect than aging on metabolism	Lower dosages may be therapeutic
Elimination	Primarily renal; age-related decrease in glomerular filtration rate	Acute and/or chronic kidney impairment, decreased muscle mass can result in worse kidney function than serum creatinine (Cr) levels might suggest	Serum Cr not a reliable measure of kidney function; best to estimate Cr clearance using formula
Pharmacodynamics	Less predictable and often altered drug response at usual or lower concentrations	Drug-drug and drug-disease interactions may alter responses	Prolonged pain relief with opioids at lower dosages; more sedation and postural instability from benzodiazepines; altered sensitivity to $\beta$ -blockers

# General Principles of Pharmacologic Management of Pain in Older Adults LWD

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Treat to improve function and quality of life

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High risk of adverse effects due to age related changes should lead to cautious prescribing but not limit consideration

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Use the least invasive and reliable method

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Start low and go slow

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De-prescribe when appropriate

NONPHARMA- COLOGIC MANAGEMENT	NONPHARMACOLOGIC TREATMENT OF PERSISTENT PAIN		
	Intervention*	Problems Studied	Outcomes
	Exercise	Lower extremity osteoarthritis, chronic pain	Positive
	Acupuncture	Back, knee, shoulder, neck pain	Positive
	Massage	Back, neck pain	Positive
	Cognitive behavioral training	Chronic pain	Positive
	Guided imagery with progressive muscle relaxation	Chronic osteoarthritis pain	Positive
	Music	Chronic pain	Positive
	Self-management education	Chronic pain, low back pain	Positive
	TENS	Knee, back pain	Mixed
	Qigong	Back, neck pain	Mixed
	Mindfulness-based meditation	Low back pain	Mixed
*All interventions have shown short-term efficacy and are typically well tolerated, with low risk and low cost.			

The Geriatrics Review Syllabus: A Core Curriculum in Geriatric Medicine, 10th Edition (GRS10)



# Interventional pain management

- I couldn't find any studies looking at these interventions in PLWD
  - ***Joint and Soft-Tissue Injection***
  - ***Trigger Point Injection***
  - ***Epidural Injection***
  - ***Pulsed Radiofrequency (PRF) Treatment of Chronic Pain***

# Topicals



## Topical analgesics for acute and chronic pain in adults - an overview of Cochrane Reviews (Review)

Derry S, Wiffen PJ, Kalso EA, Bell RF, Aldington D, Phillips T, Gaskell H, Moore RA

- Diclofenac
- Lidocaine
- Capsaicin

## Paracetamol for low back pain

Review Intervention

Bruno T Saragiotto , Gustavo C Machado, Manuela L Ferreira, M  
Christopher G Maher

First published: 6 June 2016

Editorial Group: [Cochrane Back and Neck Group](#)

DOI: 10.1002/14651858.CD012230 [View/save citation](#)

*We found high-quality evidence that paracetamol (4 g per day) is no better than placebo for relieving acute LBP in either the short or longer term.*

- First Line
- Safer
- Minimal toxicity
  
- Effective?

Acetaminophen (not specifically in PLWD)

# What about acetaminophen for PLWD?

- Mixed evidence!
- One included 25 participants (mean age 85.9 years, 88% female) living in LTCFs in which the authors concluded that paracetamol improved social interaction
- The second study included 39 participants (mean age 85.7, 87% female, mean Global Deterioration Score 5.7) living in LTCFs. The researchers of this study found no significant difference in discomfort between the placebo and paracetamol groups

van Dam, P.H., Achterberg, W.P., Husebo, B.S. *et al.* Does paracetamol improve quality of life, discomfort, pain and neuropsychiatric symptoms in persons with advanced dementia living in long-term care facilities? A randomised double-blind placebo-controlled crossover (Q-PID) trial. *BMC Med* **18**, 407 (2020).



# Prescribing Considerations for NSAIDs

- Choose when other safer therapies have failed in those with relatively lower risk
- Ongoing assessments of risks and therapeutic benefits
- Use at low effective dosage for shortest period of time



# Non-opioid Meds and Starting Doses

Acetaminophen 325–500  
mg every 4 h or 500–1,000  
mg every 6 h

Maximum dose usually 4 g  
daily. Reduce maximum  
dose 50% to 75% in patients  
with hepatic insufficiency or  
history of heavy alcohol use.

Naproxen 220 mg twice  
daily

Several studies implicate  
this agent as possessing less  
cardiovascular toxicity.

Ibuprofen 200 mg three  
times a day

Food and Drug  
Administration indicates  
concurrent use with aspirin  
inhibits aspirin's antiplatelet  
effect

# Comment on Skeletal Muscle Relaxants

Poorly tolerated, **anticholinergic effects**, sedation, increased risk of fractures, cannot tolerate effective dosing

Do not use in PLWD (except for rare circumstances)



Search ID: bfrn87

"WELL, FIRST, I THINK WE'LL CUT BACK ON THOSE MUSCLE RELAXANTS!"

# Starting Doses of Short Acting Opioids

## Oxycodone 2.5–5 mg every 4–6 h

- Daily immediate-release dose limited by fixed-dose combinations with acetaminophen or NSAIDs. Immediate-release oxycodone is available without added co-analgesics

## Morphine Immediate release 2.5–10 mg every 4 h

- Available in tablet form and as concentrated oral solution, commonly used for episodic or breakthrough pain and for patients unable to swallow tablets.

## Hydromorphone 1–2 mg every 3–4 h

- For breakthrough pain or for around-the-clock dosing.

## Hydrocodone 2.5–5 mg every 4–6 h

- Daily dose limited by fixed-dose combinations with acetaminophen or NSAIDs. Prescribers need to consider the amount of nonopioid agent in each of these preparations

~~Codeine,  
Tramadol~~

# Butrans Patch

[Clin Interv Aging](#). 2018; 13: 935–946.

Published online 2018 May 16. doi: [10.2147/CIA.S161052](#)

PMCID: PMC5960239

PMID: [29805252](#)

Tolerability of buprenorphine transdermal system in nursing home patients with advanced dementia: a randomized, placebo-controlled trial (DEPPAIN.DEM)

[Ane Erdal](#),<sup>1</sup> [Elisabeth Flo](#),<sup>2</sup> [Dag Aarsland](#),<sup>3,4</sup> [Geir Selbaek](#),<sup>5,6,7</sup> [Clive Ballard](#),<sup>8</sup> [Dagrun D Slettebo](#),<sup>1</sup> and [Bettina S Husebo](#)<sup>1,9</sup>

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- Favorable pharmacodynamics/kinetics
- Does not require renal/hepatic dosing changes
- Important interaction in this study with antidepressants
- Led to reduced daytime activity

# Adjuvant Therapies

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All patients with neuropathic pain are candidates for adjuvant analgesics, can be considered in all undertreated pain

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TCAs – generally avoid in older adults, especially those with dementia

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Gabapentin (100mg) and Pregabalin (50mg)– need renal dosing if  $GFR < 60$  (prescribing cascade)

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The effects of these medications are enhanced when used in combination with other pain analgesics and nondrug strategies

CLINICAL INVESTIGATION

# Elderspeak communication and pain severity as modifiable factors to rejection of care in hospital dementia care

Clarissa A. Shaw PhD<sup>1</sup>  | Caitlin Ward PhD<sup>2,3</sup>  | Jean Gordon PhD<sup>4</sup>  |  
Kristine N. Williams PhD, FNP-BC<sup>5</sup>  | Keela Herr PhD, AGSF<sup>1</sup> 

Sweetie/buddy

You are ready  
for breakfast,  
aren't you?

High-pitched  
sing song  
voices

It's ok to go  
poo-poo

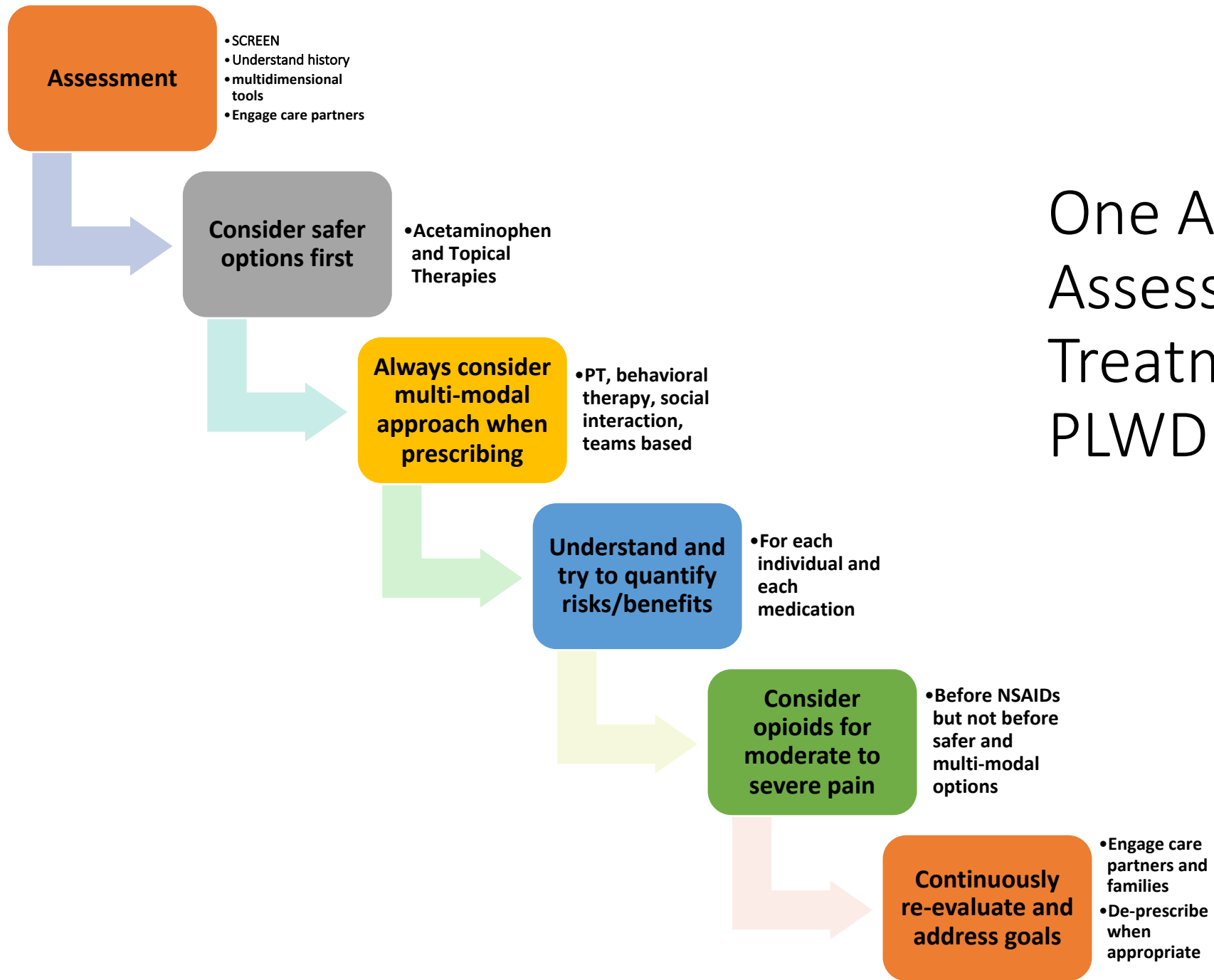
Would you take  
this medicine  
for me?

Just relax, OK?

## Key points

- Hospitalized patients with dementia exhibited rejection of care (RoC) in nearly half of the care encounter with pulling away, crying, and grabbing objects occurring most frequently.
- RoC was more likely and more severe when elderspeak communication by nursing staff was more frequent.
- RoC was more likely and more severe when patients were experiencing greater pain.





# One Approach for Assessment and Treatment of Pain in PLWD



# Summary

High index of suspicion for pain in PLWD,  
it's very common

Routine assessment for pain in PLWD

Stepwise treatment of pain for PLWD

Don't forget the issue of personhood and  
training/education of direct caregivers

# Thank you!

- Resources on Padlet

