Dementia in Hospice Care
Part I: Stages, Hospice Guidelines, and Assessing Pain/Discomfort

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Background

Wissahickon Hospice Geriatric Education Program Needs Assessment:

- 88% care for older adults with dementia
- 50% reported that 51-75% of their patients were over 65 years-old

Needs Assessment (cont)

- 30% reported assessing/managing delirium and pain in older adults at least once/week
- 97% reported that being comfortable caring for older adults with cognitive impairment was important to them
- 99% would like to enhance their abilities to assess pain in cognitively impaired patients

Objectives

- To define and describe dementia as a terminal illness
- To apply hospice guidelines for dementia for increased identification of eligibility
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- To educate and negotiate with families about treating pain in patients with dementia

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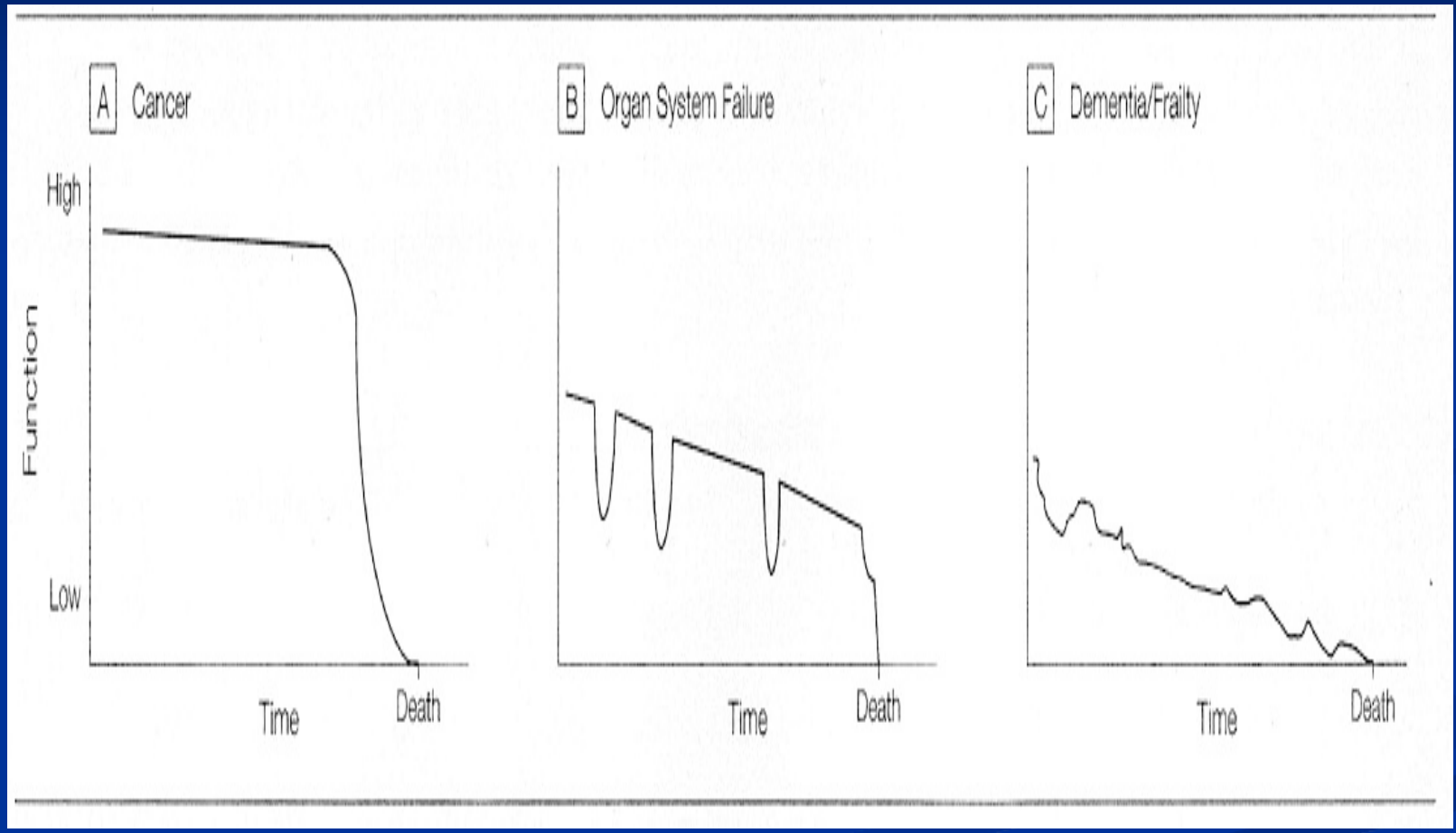
What is dementia?

www.ars.usda.gov/is/np/fnrb/fnrb0105.htm

What is dementia?

- Decline in mental abilities
- Decline in functional abilities
- Medical Diagnosis:
  - Cognitive impairment noted in 2 domains by cognitive testing, affecting daily life, and occurring over the past 6-12months
- Illness with progressive decline over 7-10 years
- Comparable to other illness (i.e. CHF, COPD)

Trajectory of Chronic Illness



This is why prognostication is so difficult!

Case #1

- 88 year-old female nursing home resident with Alzheimer's Dementia who has lived there for the past 5 years since her husband passed away. She requires cueing for dressing, bathing, and toileting, however eats independently when food is set up in front of her. She knows his name, but does not know the date or her residence and only sometimes she recognizes her children.
- What stage of dementia does this lady have?

Stages of Dementia

MILD	
Function	-independent of all ADLS, may need assistance with complex task
Cognition	-difficulty learning new information -memory loss interferes with everyday functions -mild word finding difficulty but maintain social conversation -mild judgment impairment
Behavior	-mild personality changes
MMSE	≥19

MMSE=Mini-Mental Status Exam (30point question cognitive test)

Stages of Dementia

MODERATE	
Function	-independent of all ADLS, may need reminders or minimal assistance -assistance or complete dependence with IADLs
Cognition	-substantial memory loss, disoriented in time and often to place -conversation disorganized, rambling -impaired judgment
Behavior	-may have psychotic behavior, wandering, agitated verbal or physical symptoms -sleep disturbance -appears well enough to be taken to functions outside of home environment
MMSE	12-19

Stages of Dementia

SEVERE	
Function	-dependent of all IADL -dependent of ADLs (incontinent, may need assistance with eating)
Cognition	-oriented to person only -only fragments of memory retained -severe language impairment -inconsistent recognition of familiar people -vary short attention span
Behavior	-emotional lability -restlessness -inability to focus on tasks -appears to ill to be taken to functions outside of the home environment
MMSE	0-11

Advanced Stages of Dementia

PROFOUND	
Function	-dependent of all IADL -dependent of ADLs (loss of ambulation, feeds with assistance)
Cognition	-speaks <6 words -consistent difficulty in recognizing familiar people
Behavior	-repetitive vocalizations, calling out
MMSE	<11

TERMINAL	
Function	-inability to walk or sit up without assistance -inability to smile or hold head up ≥10% body weight loss, pressure ulcers >stage 2, UTIs, aspirations pneumonias
Cognition	-few words spoken
Behavior	-passive
MMSE	Not testable

Cotter, VT, et al. Dementia. Geriatric Secrets 3rd Edition. Hanley & Belfus. 2004, pp53. Adapted from Cotter, VT: Forgetfulness. Goolsby, MJ. Nurse Practitioner Secrets. Philadelphia, Hanley & Belfus, 2002, pp64-70.

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Case #2

- 84y/o elderly woman with PMH of moderate dementia, HTN, and urinary incontinence who lives in assisted living with a full-time caregiver. She was admitted to the hospital for new onset confusion.

Previous 6 months

- Functional decline noted by both daughter and caregiver
- Less cooperative with care
- Less talkative and less appropriate with answers
- Needing more assistance with all basic Activities of Daily Living (ADLs)
- She has lost 20 pounds over the past 2 months

Hospital Stay

- Found to have Acute Renal Failure thought to be pre-renal due to dehydration and poor intake→resolves with intravenous fluids.
- As well as urinary tract infection-->resolves with antibiotics.
- During her hospitalization she develops a stage 3 pressure ulcer.
- Patient no longer able to get out of bed and requires maximum assistance with all ADLs. She is also not cooperating with physical therapy.

Family Discussion

- Family does not wish to pursue aggressive work-up.
- Due to the progressive decline over the past 6 months the team discusses options, including hospice.
- Healthcare-proxy, her daughter, feels that hospice is the most appropriate and would support her mother's previously expressed wishes.

History of the Dementia Guidelines

- Guidelines NOT criteria for admission to hospice!
- Consensus NOT evidence-based!
- Luchins study was completed around the same time as the initial guidelines were published in the late 1990s

Evidence Based Medicine for Dementia Prognosis…What there is of it!

- 1997 Luchins' Study published in JAGS around the same time as development of Dementia Criteria for hospice admission, used FAST

- 2004 Mitchell Study published in JAMA

Functional Assessment Staging

Stages

1. No difficulties
2. Subjective forgetfulness
3. Decreased job functioning and organizational capacity
4. Difficulty with complex tasks, instrumental ADLs
5. Requires supervision with ADLs
6. Impaired ADLs, with incontinence
7. *A. Ability to speak limited to six words*
   B. Ability to speak limited to single word
   C. Loss of ambulation
   D. Inability to sit
   E. Inability to smile
   F. Inability to hold head up

Fast Fact and Concept #150: Prognostication in Dementia. Sing Tsai MD and Robert Arnold MD
http://www.aahpm.org/cgi-bin/wkcgi/view?status=A%20&search=185&id=659&offset=225&limit=25

Luchins' Study

- Followed two cohorts separated by time and place (N=47) of hospice patients for 2 years
- Of both groups: median survival time of 4 months, average of 6.9months, and 37% survived longer than 6months
- ***Score >7c had mean survival time of 3.2months***
- ***Score <7c had mean survival time of 18months***

Mitchell's Dementia Prognosis Study

Mortality Risk Index (MRI)

- Modified specific MDS (minimum data set) used in long-term care facilities
- Much larger sample size
- More consistent and effective with prediction of prognosis of <6months

(see handout)

Current Hospice Dementia Guidelines

NHPCO guidelines state severity of dementia (FAST >7a) is appropriate for hospice enrollment, based on an expected six month or less prognosis, if the patient also exhibits one or more specific dementia related co-morbitities ***within the past 6 months***:

- Aspiration pneumonia
- Pyelonephritis
- Septicemia
- Multiple, progressive stage 3-4 decubitus ulcers
- Fever after antibiotics
- Unable to maintain fluid/caloric intake to sustain life
- If feeding tube in place, weight loss>10% in 6 months or serum albumin <2.5gm/dl are helpful indicators

- Ongoing controversy about dementia and other chronic illnesses
- New York Times article—out living hospice
- Reimbursement and CMS sending bills to hospices to pay back services that they already reimbursed
- As hospice providers what are we to do?

Important to Document

- Downward Trends over the past 6 months-1 year:
  - Weight
  - Albumin levels
  - Intake
- Skin integrity
- Changes in function, behavior and cognition

"Decline in Health Status" (non-cancer) Hospice Guidelines

- **Progression** of disease as documented by symptoms, signs, and test results
- **Decline** in Karnofsky Performance Status or Palliative Performance Score
- Weight loss; decreased anthroporphorphic measures (med-arm circumference, etc.), decreasing albumin or cholesterol
- Dependence on assistance for 2 or more ADLs
- Dysphagia→inadequate nutritional intake
- Recurrent aspiration
- Decline in systolic blood pressure to <90 or progressive postural hypotension
- Increasing ER visits or hospitalizations related to hospice primary diagnosis
- Decline in FAST for dementia
- Progressive stage 3-4 pressure ulcers in spite of optimal care

Case #2:
Back to Our Patient

- She is enrolled in home hospice.
- She receives home visits from RN 1-2x/week and agency caregiver for 8 hours/week from hospice.
- She is mainly bedbound and is put in a reclining chair with hoyer lift 2-3x/week.
- She does not have any pain or symptom management issues during this time.

While on Hospice…

- She has gained weight
- Her lab values are all within normal limits
- She does not have any skin breakdown
- She does not have any pain or symptom management issues
- She is able to carry on a conversation, possibly using more than 6 words

Should we consider recertifying this patient for the Medicare Hospice Benefit?

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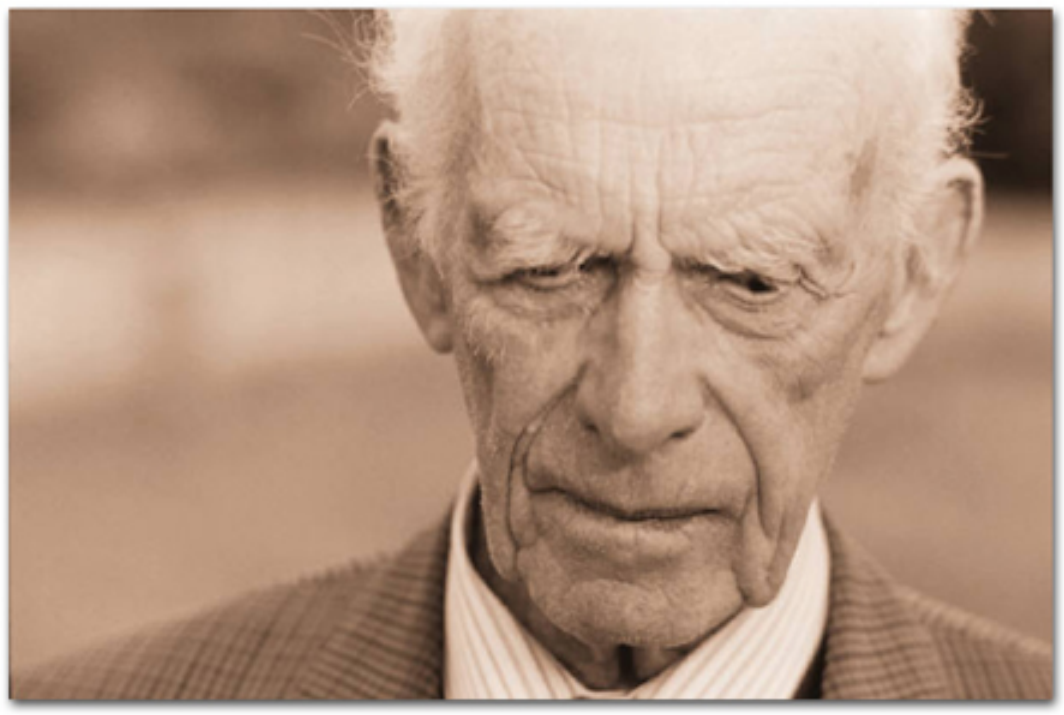
Does he look like he is in pain or deep thought?

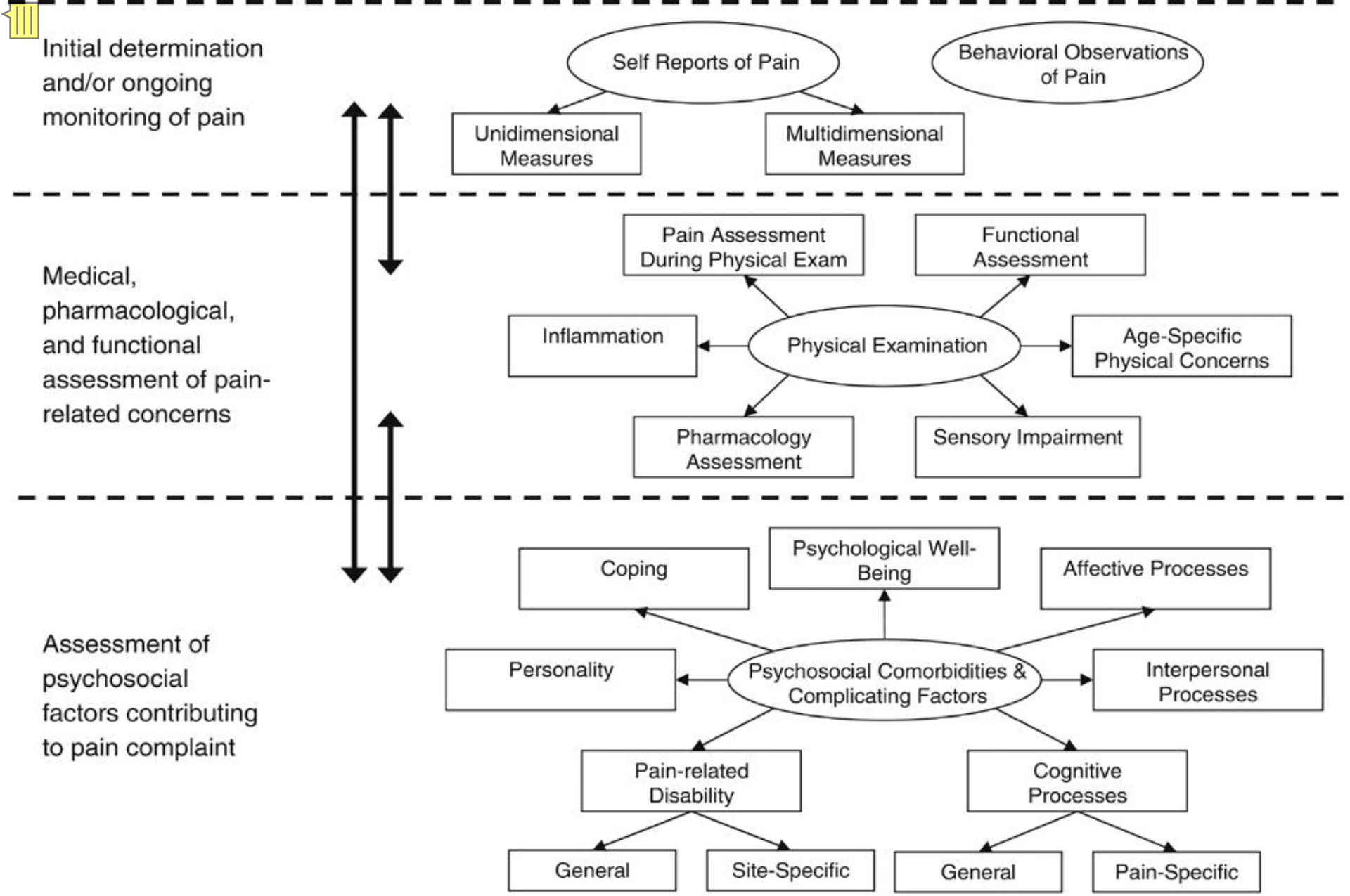


Case #3

- 103 year-old hospice patient with terminal dementia who is actively dying. She has been on tramadol twice daily with acetaminophen as needed for history of osteoarthritis-type pain and is now no longer taking much by mouth.
- How do you assess her for pain or discomfort?

Adequate Pain Assessment

- Requires repeat comprehensive assessments
- Older adults under-report pain→"normal aging"
- Scales—choose a scale that is appropriate based on cognitive and communication abilities of the individual (re-assess using the SAME scale)
  - 1-10
  - Faces
  - Non-verbal assessment



Hadjistavropoulus T., et al. An Interdisciplinary Expert Consensus Statement on Assessment of Pain in Older Persons.

Clinical Journal of Pain. January 2007 Supplement. Volume 23 (1):S1-43.

Assessment in Older Adults With or Without Cognitive Impairment

What type of questions would you ask?

- How limited in basic activities?
- How is their sleep?
- How is their appetite?
- Can they rate the pain?
- How is their mood?
- How are their interpersonal interactions?
- Any change in mental status?

Feldt's Checklist Nonverbal Pain Indicators (CNPI)

At rest AND with movement

- Nonverbal vocalizations
- Facial grimacing and wincing
- Bracing
- Rubbing
- Restlessness
- Vocal complaints

(see handout)

Other Assessment Tools

- MANY SCALES out there!
  - PAIN-AD (Alzheimer's Disease)
    - Needs special training
    - May be picking up symptoms other than pain
  - Discomfort Scale-DS-DAT (Discomfort Scale for Dementia of Alzheimer's Type)
    - Looking more at fever, NOT pain
  - Why not FLACC?
    - Studies were in nonverbal pediatric patients (preverbal, recommended for those under 1 years of age)

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Educating the Caregivers and Family

Commonly asked questions:

- How can I tell if my loved one is in pain?
- What if the pain medication makes my loved one “act funny” or sleepy or “kills them”?

What are the clues?

American Geriatric Society Guide for Family

- Facial expressions
- Verbalizations/vocalizations
- Body movements
- Behavioral changes
- Mental status changes

Case#3 (cont)
Back to Our Patient

- Restless at rest (moving her legs)
- Nonverbal, barely opening her eyes
- Grimacing with any movement of her body

Case#3 (cont)

After negotiating a plan of care with the family, all agreed to started her on liquid morphine 5mg sublingual twice daily and more frequently as needed

Summary

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Acknowledgements

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References

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