



Gateway Hotel and Conference Center ~ Ames, Iowa  
Friday, April 5, 2024

***Dementia-Specific Advanced Directives: Confusion or Clarity?***

Mercedes Bern-Klug, PhD, MSW, Professor, School of Social Work, Univ. of Iowa

***Advocating for Family Members Concerned about Loved One's Pain***

Claire Shaw, PhD, RN, Assistant Professor, School of Nursing, Univ. of Iowa

***Supporting Those Who are Grieving***

Chris Klug, MA, CT, Grief Counselor

***Schizophrenia: Introduction to Behavioral Health via Telehealth***

Randal Beckett, DNP, FNP-C, PMHNP-BC Adult Psychiatric Mental Health Nurse Practitioner & Family Nurse Practitioner. Specializing in Geriatric Psychiatry, Encounter Telehealth

**AGENDA**

*Friday, April 5, 2024*

- 8:00-8:25 a.m. Registration
- 8:25-8:30 a.m. Announcements
- 8:30-10:00 a.m. *Dementia-Specific Advanced Directives – Mercedes Bern-Klug, PhD, MSW*
- 10:00-10:15 a.m. Break
- 10:15-11:45 a.m. *Loved One's Pain – Claire Shaw, PhD, RN*
- 11:45-12:30 p.m. Lunch
- 12:30-1:30 p.m. *Grief Support – Chris Klug, MA, CT, Grief Counselor*
- 1:30-1:45 p.m. Break
- 1:45-2:45 p.m. *Schizophrenia & Telehealth – Randal Beckett, DNP, FNP-C, PMHNP-BC*
- 2:45 p.m. Evaluations and Adjournment

This Program Complies with the Iowa Board of Social Worker Examiners Rules for Continuing Education,  
meeting 5.0 general continuing education contact hours

# LTCSWI 2024 SPRING CONFERENCE

Gateway Hotel and Conference Center ~ Ames, Iowa  
Friday, April 5, 2024

## **Dementia-Specific Advanced Directives: Confusion or Clarity? – Bern-Klug**

The goal of this program is to build understanding and confidence related to social work practice with people receiving long-term care services and supports in Iowa, regarding advance directives. Discover how dementia-specific advance directives compare to advance directives. Answer the question, In what ways could the instruction to “not feed when the ability to self-feed is lost” be challenging in the nursing home setting? Learn how social workers can support people considering a dementia-specific advance directive.

## **Advocating for Family Members Concerned about Loved One’s Pain – Shaw**

The goal of this program is to build understanding and confidence related to social work practice with people receiving long-term care services and supports in Iowa, regarding pain. Learn which health care professional is responsible for assessing pain. Name two pain assessment tools you are comfortable using in your social work practice. Discover what patient/resident characteristics can complicate pain assessment.

## **Supporting Those Who are Grieving - Klug**

Explore the basic dynamics of the grieving process; the mental, emotional, physical, and spiritual characteristics of grieving; what it means to normalize and validate one's own experience and the experience of others; and the central role of attitude and intention when supporting those who are grieving. Learn to accept that grieving is the normal, healthy response to the experience of loss. Understand the basic dynamics of the grieving process. Recognize, validate, and normalize the experience of grieving. There will be time for questions and discussion.

## **Schizophrenia: Introduction to Behavioral Health via Telehealth - Beckett**

Enhance your understanding of schizophrenia and schizoaffective disorder to improve resident care and prevent inappropriate diagnosis of these disorders. Understand the advantages and limitations of behavioral health telemedicine to improve mental health care for your residents.

### **About Our Presenters...**

**Mercedes “Merce” Bern-Klug**, PhD, MSW, is a gerontological social work researcher and has been faculty at the University of Iowa for the past 20 years. She co-edited the 2024 book, “Nursing Home Social Work Research” (Routledge Press) based on results from her 2019 nationally representative study of nursing home social services directors. Merce also coordinates the national poetry contest for social workers.

**Claire Shaw**, PhD, RN, is an assistant professor at the University of Iowa College of Nursing. She researches person-centered dementia care with a focus on preventing reactive aggression across care settings. She was a former emergency department nurse.

**Chris Klug, MA, CT**, is a grief counselor, educator, and consultant in private practice in Iowa City. He has 26 years' experience working with individuals, couples, and families who are grieving the death of a family member or friend, or some other significant loss. He is Certified in Thanatology: Death, Dying and Bereavement (C.T.), from Association for Death Education and Counseling. He has worked as a grief counselor at Iowa City Hospice and a consultant to the Palliative Care staff at the University of Iowa Hospitals and Clinics. Chris is also a mindfulness meditation instructor offering classes through Prairiewoods Franciscan Spirituality Center in Hiawatha, Iowa.

**Randall Beckett**, DNP, FNP-C- PMHNP-BC, is a board-certified family nurse practitioner and adult psychiatric mental health practitioner. He completed his Doctor of Nursing Practice program with a special interest in geriatric psychiatry. He has provided telehealth to long-term care residents, conducting over 23,000 telehealth visits across eight states.

# Dementia-Specific Advanced Directives Confusion or Clarity?

*Long-term Care Social Workers of Iowa*  
April, 2024

Mercedes Bern-Klug, PhD, MSW  
Professor, School of Social Work  
University of Iowa



**IOWA**

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## Objectives

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- How do dementia-specific advance directives compare to advance directives?
  - Review of Iowa law
  - Review two dementia-specific advance directive forms
- In what ways could the instruction to “not feed when the ability to self-feed is lost” be challenging in the nursing home setting?
  - Discuss finds from research with 12 NH employees
- \* How can social workers support people considering a dementia-specific advance directive?

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# Iowa Laws

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ACCESSED APRIL 1, 2024

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<https://www.law.cornell.edu/regulations/iowa/iowa-Admi...>

## Iowa Admin. Code r. 441-79.12 - Advance directives

- [State Regulations](#)
- [Compare](#)

"Advance directive" means a written instruction, such as a living will or durable power of attorney for health care, recognized under state law and related to the provision of health care when the person is incapacitated. All hospitals, home health agencies, home health providers of waiver services, hospice programs, and health maintenance organizations (HMOs) participating in Medicaid shall establish policies and procedures with respect to all adults receiving medical care through the provider or organization to comply with state law regarding advance directives as follows:

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(1) A hospital at the time of a person's admission as an inpatient, a home health care provider in advance of a person's coming under the care of the provider, a hospice provider at the time of initial receipt of hospice care by a person, and a health maintenance organization at the time of enrollment of the person with the organization shall provide written information to each adult which explains the person's rights under state law to make decisions concerning medical care, including the right to accept or refuse medical or surgical treatment and the right to formulate advance directives, and the provider's policies regarding the implementation of these rights.

(2) The provider or organization shall document in the person's medical record whether or not the person has executed an advance directive.

(3) The provider or organization shall not condition the provision of care or otherwise discriminate against a person based on whether or not the person has executed an advance directive.

(4) The provider or organization shall ensure compliance with requirements of state law regarding advance directives.

(5) The provider or organization shall provide for education for staff and the community on issues concerning advance directives.

Nothing in this rule shall be construed to prohibit the application of a state law which allows for an objection on the basis of conscience for any provider or organization which as a matter of conscience cannot implement an advance directive.

This rule is intended to implement Iowa Code section 249A.4.

### ISBA Provided Forms

#### Durable Power of Attorney for Healthcare Decisions (Medical Power of Attorney)

A power of attorney is a written document by which one person gives to another person (the attorney-in-fact) the authority to act on behalf of the first person in one or more matters.

MORE INFORMATION

MEDICAL POWER OF ATTORNEY FORM

#### Declaration Relating to Use of Life-Sustaining Procedures Declaration (Living Will)

Living wills, also called advance care directives, are documents that set forth your personal wishes with respect to medical care.


MORE INFORMATION

LIVING WILL FORM

#### Combined Medical Power of Attorney and Living Will

MEDICAL POWER OF ATTORNEY AND LIVING WILL FORMS



 Iowa State Bar Association  
[https://www.iowabar.org/?pg=Legal\\_Forms](https://www.iowabar.org/?pg=Legal_Forms)

### Legal Forms - iowabar.org

Web Living wills, also called advance care directives, are documents that set forth your personal wishes with respect to medical care. More Information. Living Will Form. Combined ...



## **DURABLE POWER OF ATTORNEY FOR HEALTH CARE DECISIONS (Medical Power of Attorney)**

I, \_\_\_\_\_, born \_\_\_\_\_, designate

\_\_\_\_\_  
(Type or Print) Name of Agent, Street Address, City, State, Zip Code and Phone Number.

as my attorney in fact (my agent) and give to my agent the power to make health care decisions for me. This power exists only when I am unable, in the judgment of my attending physician or attending physician assistant, to make those health care decisions. The attorney in fact must act consistently with my desires as stated in this document or otherwise made known.

Except as otherwise specified in this document, this document gives my agent the power, where otherwise consistent with the laws of the State of Iowa, to consent to my physician or attending physician assistant not giving health care or stopping health care which is necessary to keep me alive.

This document gives my agent power to make health care decisions on my behalf, including to consent, to refuse to consent, or to withdraw consent to any care, treatment, service, or procedure to maintain, diagnose, or treat a physical or mental condition. This power is subject to any statement of my desires and any limitations included in this document.

I hereby revoke all prior Durable Powers Of Attorney for Health Care Decisions.

7

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### **GENERAL INFORMATION ON DURABLE POWER OF ATTORNEY FOR HEALTH CARE**

A durable power of attorney for health care is subject to the provisions of Chapter 144B of the Code of Iowa and reference should be made to that chapter. The following is a summary of some of the provisions of Chapter 144B of the Code of Iowa.

1. "Health care" means any care, treatment, service, or procedure to maintain, diagnose, or treat an individual's physical or mental condition. "Health care" does not include the provision of nutrition or hydration except when they are required to be provided parenterally or through intubation.
2. The following individuals shall not be witnesses for a durable power of attorney for health care:
  - a) A health care provider attending the principal on the date of execution.
  - b) An employee of a health care provider attending the principal on the date of execution.
  - c) The individual designated in the durable power of attorney for health care as the attorney in fact.
  - d) An individual who is less than eighteen years of age.
3. One of the witnesses shall be an individual who is not a relative of the principal by blood, marriage, or adoption within the third degree of consanguinity.
4. The following individuals shall not be designated as the attorney in fact to make health care decisions under a durable power of attorney for health care:

8

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4. The following individuals shall not be designated as the attorney in fact to make health care decisions under a durable power of attorney for health care:
  - a) A health care provider attending the principal on the date of execution.
  - b) An employee of a health care provider attending the principal on the date of execution unless the individual to be designated is related to the principal by blood, marriage, or adoption within the third degree of consanguinity.
5. Revocation.
  - a) A durable power of attorney for health care may be revoked at any time and in any manner by which the principal is able to communicate the intent to revoke, without regard to mental or physical condition.
  - b) Revocation may be made by notifying the attorney in fact orally or in writing.
  - c) Revocation can also be made by notifying a health care provider orally or in writing while

that provider is engaged in providing health care to the principal.

- d) A revocation is only effective as to a health care provider upon its communication to the provider by the principal or by another to whom the principal has communicated revocation.
  - e) The health care provider is required to document the revocation in the treatment records of the principal.
  - f) The principal is presumed to have the capacity to revoke a durable power of attorney for health care.
  - g) Unless it provides otherwise, a valid durable power of attorney for health care revokes any prior durable power of attorney for health care.
6. Prohibited Practices.
    - a) A health care provider, health care service plan, insurer, self-insured employee welfare benefit plan, or nonprofit hospital plan shall not condition admission to a facility, or the providing of treatment, or insurance, on the requirement that an individual execute a durable power of attorney for health care.
    - b) A policy of life insurance shall not be legally impaired or invalidated in any manner by the withholding or withdrawing of health care pursuant to the direction of an attorney in fact appointed pursuant to this Chapter.
  7. It is the responsibility of the principal to notify the health care provider (doctor) of the terms of the Durable Power of Attorney for Health Care.



## **DECLARATION RELATING TO USE OF LIFE-SUSTAINING PROCEDURES DECLARATION (Living Will)**

If I should have an incurable or irreversible condition that will result either in death within a relatively short period of time or a state of permanent unconsciousness from which, to a reasonable degree of medical certainty, there can be no recovery, it is my desire that my life not be prolonged by the administration of life-sustaining procedures. If I am unable to participate in my health care decisions, I direct my attending physician or attending physician assistant to withhold or withdraw life-sustaining procedures that merely prolong the dying process and are not necessary to my comfort or freedom from pain.

YES\_\_ NO\_\_ In the event that medical professionals determine that I may be an organ donor, I agree to the use of life-sustaining procedures, including a ventilator, for the sole purpose and time period required to complete the organ donation. Nothing in this paragraph shall be construed to expand or detract from the laws related to anatomical gifts as outlined in the Iowa Code, Chapter 142C. The purpose of this paragraph is to practically and medically make organ donation possible.

Signed on \_\_\_\_\_.

### **General Information on Declaration Relating to Use of Life-Sustaining Procedures**

By Iowa Law:

1. This Declaration will be given effect only when the Declarant's condition is determined to be terminal or Declarant is in a state of permanent unconsciousness and the Declarant is not able to make treatment decisions.
2. "Life-sustaining procedure" does not include the provision of nutrition or hydration except when required to be provided parenterally or through intubation or the administration of medication or performance of any medical procedure deemed necessary to provide comfort care or to alleviate pain. If you do not wish to have nutrition or hydration withdrawn under any circumstances, please consult an attorney for appropriate modification of this Declaration.
3. It is the responsibility of the Declarant to provide the Declarant's attending physician or health care provider with this Declaration.
4. This Declaration may be revoked in any manner by which the Declarant is able to communicate the Declarant's intent to revoke, without regard to mental or physical condition. A revocation is only effective as to the attending physician upon communication to such physician by the Declarant, or by another to whom the revocation was communicated by the Declarant.



5. If this form is witnessed rather than notarized, at least one witness shall be an individual who is not a relative of the Declarant by blood, marriage or adoption within the third degree of consanguinity.

The following individuals shall not witness for a Declaration:

- a. A health care provider attending the Declarant on the date of execution.
- b. An employee of a health care provider attending the Declarant on the date of execution.
- c. An individual who is less than eighteen years of age.



**DECLARATION RELATING TO LIFE-SUSTAINING  
PROCEDURES (Living Will)  
AND  
DURABLE POWER OF ATTORNEY FOR HEALTH  
CARE DECISIONS (Medical Power of Attorney)**

**I. DECLARATION RELATING TO LIFE-SUSTAINING PROCEDURES**

If I should have an incurable or irreversible condition that will result either in death within a relatively short period of time or a state of permanent unconsciousness from which, to a reasonable degree of medical certainty, there can be no recovery, it is my desire that my life not be prolonged by the administration of life-sustaining procedures. If I am unable to participate in my health care decisions, I direct my attending physician or attending physician assistant to withhold or withdraw life-sustaining procedures that merely prolong the dying process and are not necessary to my comfort or freedom from pain.

This declaration is subject to any specific instructions or statement of desires I have added in "Additional Provisions" below

# Dementia-Specific Advance Directives

15

15

<https://vtethicsnetwork.org/wp-content/uploads/2019/11/Dartmouth-Demen...>

1 of 14

STATEMENT OF TREATMENT PREFERENCE



The Dartmouth Dementia Directive

## THE DARTMOUTH DEMENTIA DIRECTIVE

*An advance care document for dementia care planning*

### What is Dementia?

Dementia is a general term for a decline in mental abilities severe enough to interfere with daily life. It is one of the most common medical conditions of late life. It is estimated that by age 80, at least 20% of people will have dementia. By age 90, 40% to 50% of people may have dementia.

16

## Gradual Loss of Decision-Making Ability

The Dartmouth Dementia Directive is a specialized advance directive. It is designed to address the **gradual** loss of decision-making ability which typically occurs in dementia. **The Dartmouth Dementia Directive is meant to supplement, not replace, the standard advance directive.**

There will be some wishes for care which are addressed in both the standard advance directive and the Dartmouth Dementia Directive. It will be important to ensure that your preferences, as expressed in your standard advance directive, agree with those expressed in the Dartmouth Dementia Directive, particularly for the severe stage of dementia.

## Wishes for Care Depending on the Stage of Dementia

The Dartmouth Dementia Directive gives you the opportunity to express different wishes for care depending on the **stage of dementia** – mild, moderate, or severe. For each stage of illness, the Dartmouth Dementia Directive addresses three main areas of care:

- (1) Medical Illness
- (2) Nutrition and Fluids
- (3) Location of Care

17

17

## C. Severe Dementia

**Severe Dementia** usually occurs after an individual has been ill for a number of years. Persons with severe dementia are not able to function in any manner without considerable assistance from others. Memory, use of language, awareness of the surroundings, and other basic cognitive abilities are significantly impaired. Individuals with severe dementia are generally not able to make medical or other important decisions independently.

### 1. Medical Illness (Severe Dementia)

*When my doctor or nurse practitioner certifies that I lack the capacity to make health care decisions and determines that I am in the stage of **severe dementia** I now declare the following:*

Indicate your preference for the type of care you wish to receive by initialing the appropriate box next to your choice. If a box is initialed, it indicates that you agree with the statement. If a box is left blank, it indicates that you do not agree with the statement.

18

18

Choice	Options for Medical Care (Severe Dementia)
	I want to remain alive as long as possible, no matter the circumstance, and <b>I want to undergo all medical treatments and other interventions in order to prolong my life.</b>
	I want to receive treatment to prolong life, but <b>if my heart stopped beating or I could not breathe on my own, I would not want resuscitative measures</b> (e.g. CPR, ventilator).
	<b>I want to receive only “comfort” care</b> focused on relieving current suffering (e.g. pain or anxiety). I would <b>not</b> want care that would prolong my life.
	<b>I have no preference</b> regarding medical treatment and wish my DPOA to make this decision in consultation with my primary physician.

**Additional Comments:**

19

19

Choice	Options for Nutrition (Severe Dementia)
	I want to receive nutrition deemed appropriate by my caregivers and physicians. <b>I would accept assisted feedings, tube feedings or intravenous nutrition.</b>
	I want to receive nutrition deemed appropriate by my caregivers and physicians. I would accept assisted feedings until I am no longer willingly opening my mouth or am otherwise indicating that I do not want to continue to receive nutrition. At that point, <b>I would be willing to receive oral comfort care in the form of mouth swabs or ice chips. However, I do not want tube feeding or intravenous nutrition.</b>
	<b>I want to receive no nutrition if I cannot feed myself.</b> I do not want to be offered food or fluids in any form if I cannot feed myself. I would be willing to receive oral comfort care in the form of mouth swabs or ice chips.
	<b>I have no preference</b> regarding nutrition and fluids and wish my DPOA to make this decision in consultation with my primary physician.

20

20



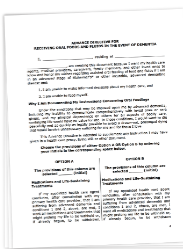
# Dementia Directive

## *About the Advanced Directive for Receiving Oral Foods and Fluids in Dementia*

In collaboration with attorneys, palliative care clinicians and others, End of Life Choices New York developed an **advance directive** specifically designed for those with an early stage of Alzheimer's or another dementing disease, or for those with a significant family history of dementia and fears of developing such a disease in the near future.

***Click here for a copy of the directive.***

***Click here for a copy of the press release.***



## **ABOUT THE ADVANCE DIRECTIVE FOR RECEIVING ORAL FOOD AND FLUIDS IN DEMENTIA**

### **Introduction**

There are two purposes to completing an Advance Directive for Receiving Oral Food and Fluids In Dementia. The first is to document your wishes about when to stop efforts to provide assisted oral feeding because of an advanced dementia. The second is to ensure that your appointed health care agent is empowered to honor and implement those choices if you suffer from advanced dementia.

The accompanying Directive (beginning on page 4) provides two alternatives concerning assisted oral feedings:

A. The Directive permits you to direct, in a particular clinical situation, that ALL assisted feeding of food and fluid be stopped.

B. The Directive also permits you to direct, in that same clinical situation, that comfort-focused feeding be provided.

23

A person who is diagnosed with Alzheimer's or another incurable dementing disease may wish to have control over the circumstances and timing of his or her death. While Alzheimer's is considered a terminal disease, because the duration of the disease can be long, the terminal stage of the disease may not occur for many years, and long after decision-making capacity and the ability to self-feed are lost. The average time from diagnosis to death is 7 years, but many individuals live considerably longer. So long as those with advanced dementia receive good physical care and are assisted with eating and drinking, it can be difficult to predict when death will finally occur.

In the final, 'terminal' stage of all dementias, a person may become unable to swallow what is placed in his or her mouth, and lose the ability to ambulate, speak, recognize loved ones, and control bowel or bladder functioning. Individuals with Alzheimer's disease who contact End of Life Choices New York want to know how they can avoid the final stages of this disease. It is for those individuals, and others who fear being diagnosed with dementia in the future, that the Directive about assisted oral feeding has been created.

24

## OPTION A

The provisions of this column are selected \_\_\_\_\_ (initial)

### Medications and Life-Sustaining Treatments

If my appointed health care agent concludes, after consultation with my primary health care provider, that I am suffering from advanced dementia and conditions 1 and 2, above, are met, I want all medications and treatments that might prolong my life to be withheld or, if already begun, to be withdrawn,

1. I am unable to make informed decisions about my health care, and
2. I am unable to feed myself.

### Assisted Hand Feeding

If I am suffering from advanced dementia and appear willing to accept food or fluid offered by assisted or hand feeding, my instructions are that I do NOT want to be fed by hand even if I appear to cooperate in being fed by opening my mouth.

25

25

## Relevance

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Over 50 percent of people living with a dementia diagnosis will die in nursing homes (Cross et al., 2020)

26

26

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# Impact on caregivers?

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CLARITY OR CONFUSION?

DISCUSS

27

27

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## Study with 12 NH employees

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28

28



## My study co-author

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Manuscript under review



The Harry and Jeanette  
**Weinberg Center for Elder Justice**  
AT THE HEBREW HOME AT RIVERDALE

29

29

## Research Question

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What are perspectives of nursing home staff regarding implementation of dementia-specific advance directives that include the option of no assistance with feeding, once the ability to self-feed is lost?

30

30

## FAST - 7

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Respondents asked to keep in mind residents in the late stages of dementia - with a FAST dementia score of 7a (severe dementia, able to say 5-6 words daily)

31

31

### Functional Assessment Staging Tool (FAST Scale)

1. No difficulty either subjectively or objectively.
2. Complains of forgetting location of objects. Subjective work difficulties.
3. Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity. \*
4. Decreased ability to perform complex tasks, e.g., planning dinner for guests, handling personal finances (such as forgetting to pay bills), difficulty marketing, etc.
5. Requires assistance in choosing proper clothing to wear for the day, season, or occasion, e.g., patient may wear the same clothing repeatedly, unless supervised. \*
6.
  - A. Improperly putting on clothes without assistance or prompting (e.g., may put street clothes on over night clothes, or put shoes on wrong feet, or have difficulty buttoning clothing) occasionally or more frequently over the past weeks. \*
  - B. Unable to bathe properly (e.g., difficulty adjusting bathwater temp.) occasionally or more frequently over the past weeks. \*
  - C. Inability to handle mechanics of toileting (e.g., forgets to flush the toilet, does not wipe properly or properly dispose of toilet tissue) occasionally or more frequently over the past weeks. \*

<https://www.cpsc.org/documents/download/962/>

32

32

7.

- A. Ability to speak limited to approximately a half-dozen intelligible different words or fewer in the course of an average day or in the course of an intensive interview.
- B. Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview (the person may repeat the word over and over).
- C. Ambulatory ability is lost (cannot walk without personal assistance).
- D. Cannot sit up without assistance.
- E. Loss of ability to smile.
- F. Loss of ability to hold head up independently.

*\* Scored primarily on the basis of information obtained from knowledgeable informant.*

Adapted from: Reisberg B, Ferris SH, Franssen E. An ordinal functional assessment tool for Alzheimer's-type dementia. *Hosp Community Psychiatry*. 1985 Jun;36(6):593-5. doi: 10.1176/ps.36.6.593. PMID: 4007814.

33

33

## Dementia Advance Directive Language

### Dartmouth (2021 version)

"I want to receive no nutrition if I cannot feed myself. I do not want to be offered food or fluids in any form if I cannot feed myself. However, I would be willing to receive oral comfort care in the form of mouth swabs or ice chips."

Note: I realize it may not be possible to honor this preference in every circumstance. For example, it may not be possible to honor this preference if I am in a facility that does not permit the withholding of nutrition or hydration, or if I clearly request to eat or drink, or appear receptive to eating and drinking (show signs of enjoyment or positive anticipation), such that I would become agitated or upset by non-feeding."

**This NOTE has been removed in current version**

### End of Life New York Option A (as of 2/20/24)

"If unable to make informed decisions and feed myself "I want all medications and treatments that might prolong my life to be withheld or, if already begun, to be withdrawn, including cardio-pulmonary resuscitation and the provision of nutrition and hydration whether provided artificially or medically or by hand or by assisted oral feeding."

"If I am suffering from advanced dementia and appear willing to accept food or fluid offered by assisted or hand feeding, my instructions are that I do NOT want to be fed by hand even if I appear to cooperate in being fed by opening my mouth."

34

34

## Sample

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12 staff members at 1 SNF  
in NE US

### **Professions:**

- 3 CNAs
- 3 MSWs
- 3 RDs
- 2 RN Supervisors
- 1 MD

### **Experience in the field:**

- 11 had at least 5 yrs
- 8 had 15+ years

### **Basic demographics:**

- 10 women, 2 men
- 7 identified as white, 4 as Black, 1 undisclosed

35

35

## Data Collection

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Qualitative in person interviews, onsite  
during the workday

Open-ended semi-structured interview

< 20 minutes for nursing assistants

~ 40 minutes for others

36

36

# Analysis

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Interviews tape recorded and transcribed verbatim

Fundamental Qualitative descriptive content analysis  
(Sandelowski, 2000) [stay close to data]

Both authors read all transcripts multiple times,  
developed coding scheme and applied it to all  
interviews to develop themes.

37

37

# Findings: Theme 1

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**“Self-feeding” is Confusing and Doesn’t Take  
into Account Daily Fluctuations in Functional  
Ability Common in Advanced Dementia**

38

38

## “Self-feeding” is Confusing and Doesn’t Take into Account Daily Fluctuations in Functional Ability Common in Advanced Dementia

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*“Some people can just hold a cup, they can’t hold utensils. Some people can just take small pieces with their fingers but don’t use utensils...some just use spoons... there are just so many variabilities in terms of devices, where they can do different things, or pieces of it, but not the entire process that I wouldn’t know where to go with this... Self-feeding is not just I do it or I don’t.”*

39

39

## “Self-feeding” is Confusing and Doesn’t Take into Account Daily Fluctuations in Functional Ability Common in Advanced Dementia

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*“Some residents are very independent in the morning, feed themselves and then at dinnertime due to sun-downing may need more assistance so it can vary tremendously. It’s hard for a staff member to understand what to do in that situation since they’re not consistently unable to feed themselves. It leaves a lot of questions and interpretation by the caregiver. .... So I think it would be difficult because I think you’d feel torn about whether did someone truly try them today? Did someone make the effort today? Did they go back more than once? How far do you go?”*

40

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## Findings: Theme 2

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### Consensus on the Importance of Honoring Resident Self-Determination, but Which Self?

41

41

## Which Self?

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*“And if, for instance – see that man sitting there, what if he made the will. And he’s going to see food passing by, he’s going to open his mouth and want the food. But I couldn’t pass by and not feed him. I couldn’t pass by and not feed him. How could I?”*

*“I think it would be very hard to have a resident clearly stating, “Can I have a cookie, can I have something to drink?” That means – yes, you made that decision then, you know what you wanted then, but at this point, right now, as a person, this is the place you are in, this is your mental state – you’re able to enjoy it, you’re able to ask for it. For me to say, I can’t give it to you because 50 years ago, not knowing exactly what stage you’d be in, you decided you wouldn’t want a cookie, or you wouldn’t want a juice.”*

42

42

# Findings: Theme 3

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## Potential for Harm - Residents, Staff, Family, Institution

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43

## Potential for Harm

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### Resident

- Isolation during mealtime
- Causing discomfort and hunger
- Tools for financial exploitation and abuse

*"My fear is always that it gets introduced to the poorest of the poor, the most uneducated, the people who are in the places where they can't get help or get better information or better medication."*

Beneficiaries could pressure people into signing dementia directives to hasten death and protect their own financial interests: *"basically how fast can I get to the will?"*

### Family

- Not knowing about directives, not understanding SED process or being uncomfortable with the process

*"I could see if the family came in and saw that we were withholding food from the person, especially if it seemed like they wanted to eat, I could imagine that would be a very big problem"*

44

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## Potential for Harm (con't)

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### Staff

- Violation of religious beliefs:  
*"For me, that would be a sin"*
- Violation of core values:  
*"I would not stand by and say – well, I would be watching you starve to death, which I cannot do"*
- Conflict with professional identity:  
*"I think as CNAs integral to their role is assisting with ADLs, so their role is about helping the individual who can't do their own ADLs. I think they would want to help feed the person who is just sitting there and looking and can't eat."*

### Institution

- Department of Health citations  
*"I think [with the New York Directive], they might say that we're aiding and abetting people to commit suicide...I don't believe that, but DOH [Department of Health] might go there."*

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45

## No Consensus on Preferred SED by AD Language

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- 10 participants believed people should have the ability to complete SED directives – but all qualified their opinions by expressing serious concerns
- Some preferred flexibility in feeding; others preferred clarity
- One person wanted to add Dartmouth to their AD
- No one brought up the “now self’s” incapacity as a reason to devalue their current wishes

46

46

## Limitations

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### 1 NH

Only interviewed people once

Having larger sample size would have allowed comparisons between professions

47

47

## Discussion: Logistic challenges

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- Staff struggled to understand what it means to “self feed”
- Is it all or some of: knowing what a utensil is? what food is? able to get food to mouth? chew? Swallow? could all be considered part of self-feeding.
- Do all parts need to be absent to be considered unable to self-feed?

48

48

## Discussion: Logistic Challenges

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- Person living with dementia has fluctuating abilities throughout the day – how should staff respond?
- How to write these medical orders and when? NPO?

49

49

## Logistic Challenges

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- No best practices – each NH has to figure out their own internal policy for implementation.
- High turnover in NHs over 3 shifts means there are a lot of people to keep on the same page

50

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## Moral challenges

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- Perceived harm to “now-self” outweighs concern for “then-self’s” self-determination
- Burden on staff
- Participating in “starvation” when someone wants to eat
- Lack of power for CNAs in this position – moral injury “a betrayal of what’s right by someone who holds legitimate authority in a high stakes situation” (Shay, 2014).
- PHI reports that 90 percent of nursing assistants in the United States are women, 20 percent are immigrants, and over 50 percent identify as a racial minority. 36 percent rely on at least one form of public assistance (PHI National, 2019)

51

51

## Summary

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Directives not ready for primetime – will be problematic to implement in NH.

Staff want to provide care consistent with resident current wishes – don’t want to force feed and don’t want to withhold when resident appears hungry/appreciates food.

52

52

## Summary (con't)

---

NH staff need to be at the table when dementia-specific advance directives are being developed.

Half of the people living with dementia are dying in NHs

53

53

## References

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Cross, S. H., Kaufman, B. G., Taylor, D. H., Kamal, A. H., & Warraich, H. J. (2020). Trends and factors associated with place of death for individuals with dementia in the United States. *Journal of the American Geriatrics Society*, *68*(2), 250–255. <https://doi.org/10.1111/jgs.16200>

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Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, *23*: 334-340.

Shay, J. (2014). Moral injury. *Psychoanalytic Psychology*, *31*(2), 182–191.

54

54

# Social Work

How can social workers support people considering a dementia-specific advance directive?

- \* Conversation
  - With PWD and/or loved ones
  - What is the concern?
  - Has concern been shared with primary care provider?
- \* Clarity re what is possible at facility
- \* Other related resources: hospice, IPOST
- \* Information *AND* SUPPORT (emotional, connect to resources)

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# Comments?

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THANK YOU

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# Advocating for Family Members Concerned about Loved One's Pain

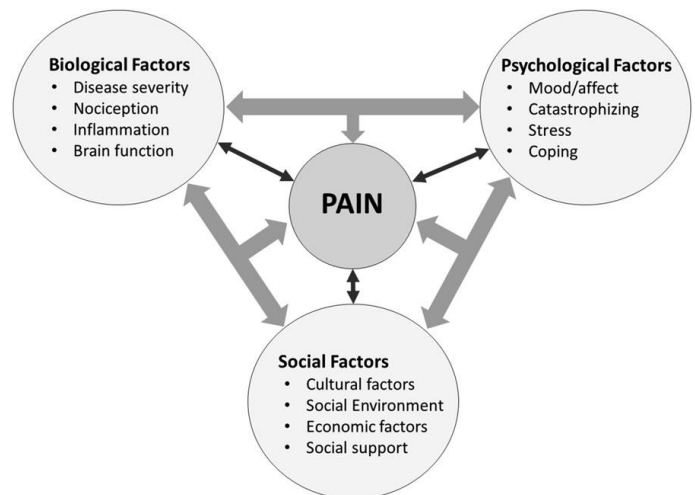
Mercedes Bern-Klug, PhD, MSW, University of Iowa School of Social Work

Clarissa Shaw, PhD, RN, University of Iowa College of Nursing

1

## What is pain?

- An **unpleasant sensory and emotional experience** associated with, or resembling that associated with, actual or potential tissue damage.



IASP 2020 Revised Definition  
Figure: Herta et al. 2023

2

## Other definitions

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- “Anything the patient says it is” – McCaffery & Pasero, 1999

## Pain Myths

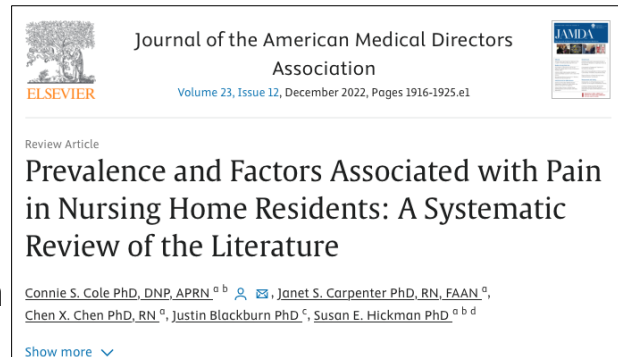
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- Pain conditions are the same for all people.
- Pain is just a part of getting older.
- Doctors and nurses are the experts about pain.
- Residents with dementia can't feel pain.



## Pain in Nursing Homes

- Up to 85% of NH residents have pain.
- Up to 58% of residents persistent pain and chronic pain.
- 22% moderate to severe pain and 32% substantial pain.



## Psychosocial effects of pain

- Negative affect
- Decreased happiness
- Decreased life satisfaction
- Increased loneliness
- Decreased quality of life
- **Challenging behaviors**

## Why does pain have these effects?

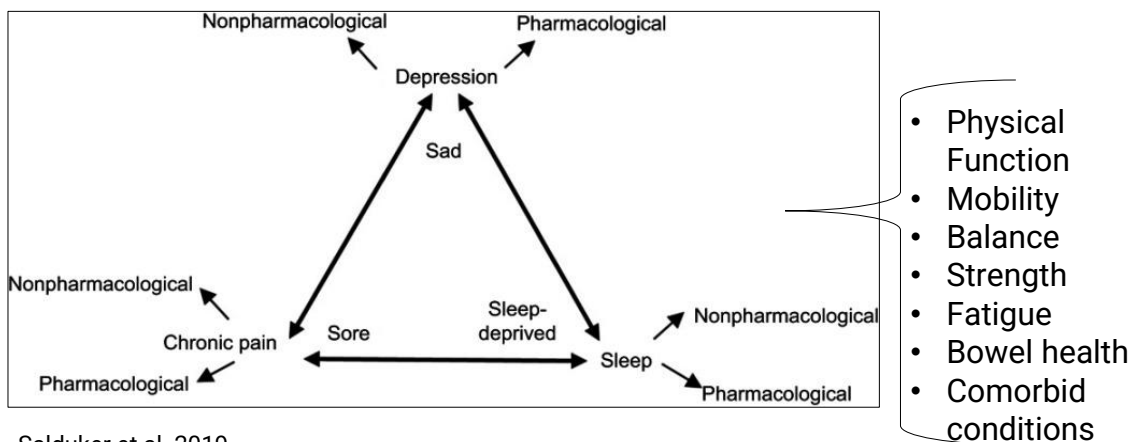
- Difficulty engaging in normal activities (ADL, mobility, socialization)
- Declines in sleep, appetite, energy, movement/exercise
- Interference with mood (depression/anxiety)

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## Cyclical outcomes of pain

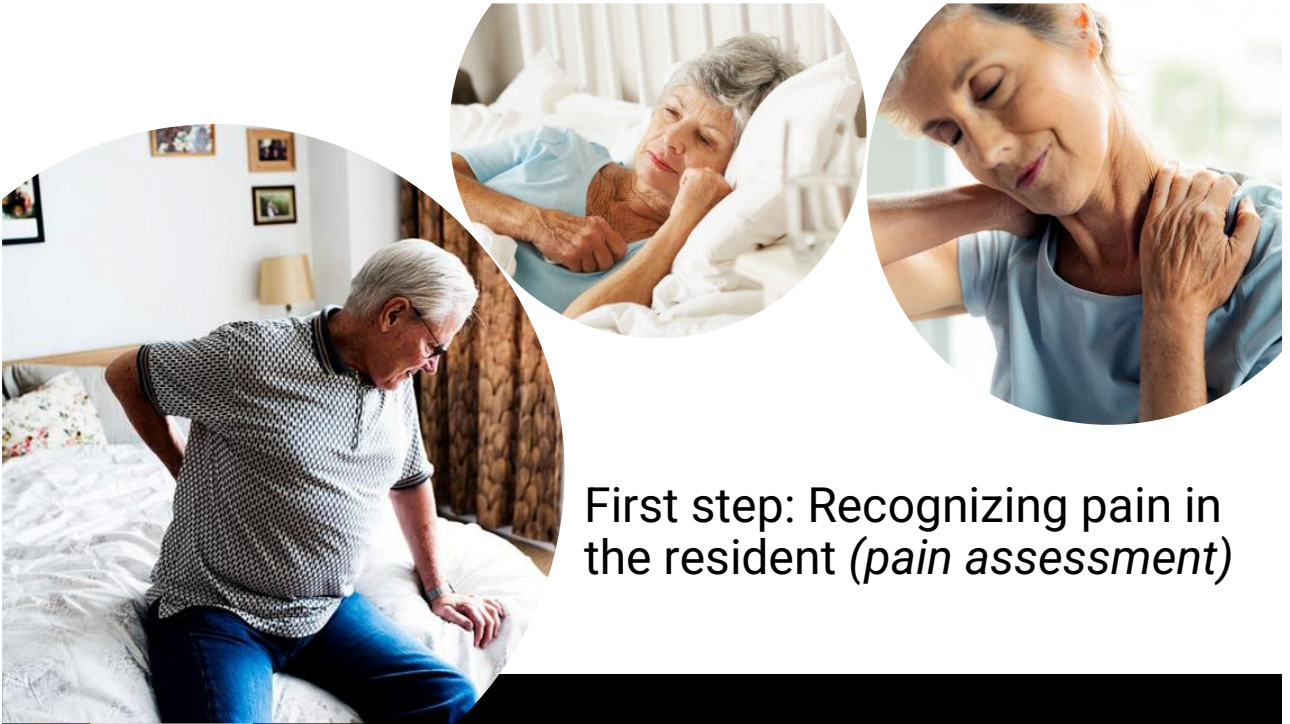


Salduker et al. 2019

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First step: Recognizing pain in the resident (*pain assessment*)

9

## Hierarchy of Pain Assessment Techniques

1. **Elicit self report.**
2. Identify potential causes of pain.
3. Assess for pain behaviors that may indicate pain.
4. Gather surrogate report and behavior change that may indicate pain.
5. Response to analgesic trial (or other treatment approaches).

## #1 – ASK about pain!

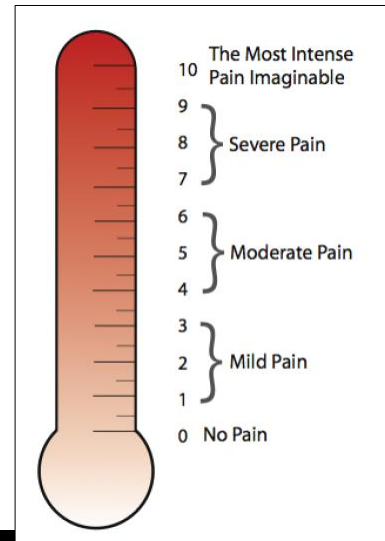
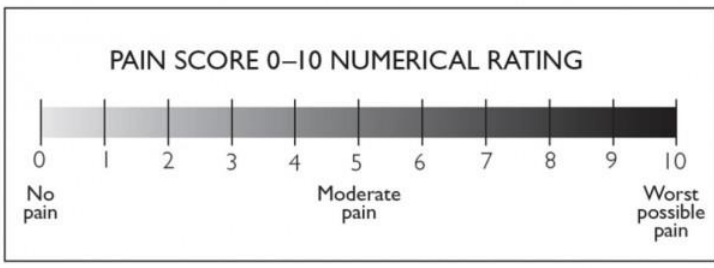
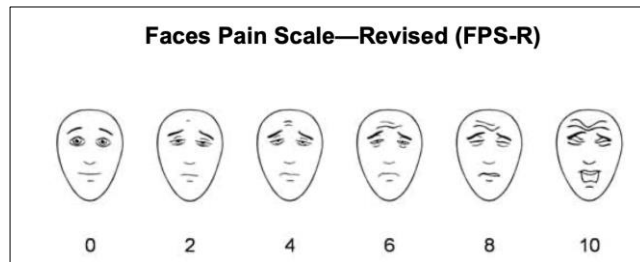
- “Self-report” = Ask!
- **Your words matter...**
  - Are you having *pain*? - no
  - *Soreness, hurting, aching, stiffness, cramping, discomfort* - yes

## Ways to ask

- 3 evidence-based pain questions:
  - Do you have aches or pains today?
  - Can you tell me about your pain, aches, soreness, or discomfort?
  - Would you say your pain was mild, moderate, or severe?

*Informal questioning lacks consistency and leads to underestimates of pain.*

## Tools



13

## Challenges with self-report

- Resident identification of pain
- Resident ability to communicate pain

### Hierarchy of Pain Assessment:

1. Elicit self report.
2. **Identify potential causes of pain. – assume pain present**
3. Assess for pain behaviors that may indicate pain.
4. Gather surrogate report and behavior change that may indicate pain.
5. Response to analgesic trial (or other treatment approaches).

14

## High reports of pain in residents with...

- ADL impairment (*immobility*)
- Depression
- Arthritis
- Sleep problems
- Falls
- Pressure ulcers

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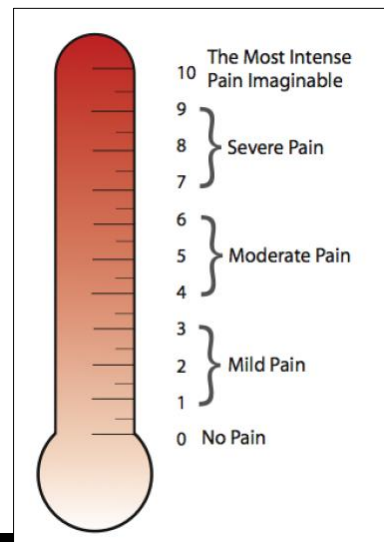
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## Challenges with self-report in dementia

### Hierarchy of Pain Assessment:

1. Elicit self report. – **Still #1**
2. Identify potential causes of pain.
3. **Assess for pain behaviors that may indicate pain.**
4. Gather surrogate report and behavior change that may indicate pain.
5. Response to analgesic trial (or other treatment approaches).



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Pain in dementia difficult to recognize, assess and measure

Many options for behavioral pain assessment tools for residents with dementia

**List of Nonverbal Pain Behavior Tools 2019**

A number of nonverbal pain behavior tools have been developed to identify pain in persons with dementia. Because tools vary on population focus, type of pain problem, setting of care, and characteristics evaluated, it is difficult to choose one tool that fits all cognitively impaired older adults.

The following group of tools includes those that have broad exposure beyond their country of origin and testing with a variety of cultures and settings and have the most extensive psychometric testing overall. They also have clinical utility based on time to train to use and to administer in the clinical setting.

- **ABBEY** (The Abbey Pain Scale): [Summary](#) | [Tool](#)
- **CNPI** (Checklist of Nonverbal Pain Indicators): [Summary](#) | [Tool](#)
- **Doloplus 2** (Doloplus-2 Scale, Behavioural Pain Assessment in the Elderly): [Summary](#) | [Website](#) (Contract information for Tool Developer)
- **MOBID-2** (Mobilization Observation Behavior Intensity Dementia Pain Scale - 2): [Summary](#) | [Tool](#)
- **PACSLAC** (The Pain Assessment Scale for Seniors with Severe Dementia): [Summary](#) | [Tool](#)
- **PACSLAC-II** (The Pain Assessment Scale for Seniors with Severe Dementia - II): [Summary](#) | [Tool](#)
- **PAINAD** (The Pain Assessment in Advanced Dementia Scale): [Summary](#) | [Tool](#)

**Other Tools**

The second set of tools are others that have at least moderate reliability and validity, although variable across tools. Several have recommendations for refinement and further testing.

- **Algoplus** (Algoplus Scale): [Summary](#) | [Website](#) (Contract information for Tool Developer)
- **CPAT** (Certified Nurse Assistant Pain Assessment Tool): [Summary](#) | [Tool](#)
- **Doloshort**: [Summary](#) | [Tool](#)
- **DS-DAT** (Discomfort Scale-Dementia of the Alzheimer's Type): [Summary](#) | [Tool](#)
- **EPCA-2** (Elderly Pain Caring Assessment): [Summary](#) | [Tool](#)
- **MPS** (Mahoney Pain Scale): [Summary](#) | [Article](#) (Contract information for Tool Developer)
- **NOPAIN** (The Non-Communicating Patient's Pain Assessment Instrument): [Summary](#) | [Tool](#)
- **PACI** (Pain Assessment in the Cognitively Impaired): [Summary](#) | [Tool](#)
- **PACSLAC-D** (The Pain Assessment Scale for Seniors with Severe Dementia - Dutch version): [Summary](#) | [Article](#) (Contract information for Tool Developer)
- **PADE** (Pain Assessment for the Dementing Elderly): [Summary](#) | [Article](#) (Contract information for Tool Developer)
- **PAINE** (Pain Assessment in Noncommunicative Elderly Persons): [Summary](#) | [Article](#) (Contract information for Tool Developer)
- **REPOS** (Rotterdam Elderly Pain Observation Scale): [Summary](#) | [Article](#) (Contract information for Tool Developer)

Two tools focus on synthesizing from existing behavior indicators in other tools and literature to identify a subset that may be most specific in identifying pain and/or determining its severity. These include the following

- **PAIC** (Pain Assessment in Impaired Cognition meta-tool): [Summary](#) | [Tool](#)
- **PIMD** (Pain Intensity Measure for Persons with Dementia): [Summary](#) | [Tool](#)

## Strong to moderate evidence for effectiveness of many tools...yet pain in dementia still an issue

European Geriatric Medicine  
<https://doi.org/10.1007/s41999-022-00655-z>

**REVIEW**

**Psychometric properties of pain measurements for people living with dementia: a COSMIN systematic review**

Toby O. Smith<sup>1,2</sup> · Karmen Harvey<sup>2</sup>

Received: 3 March 2022 / Accepted: 28 April 2022  
 © The Author(s) 2022

**Barriers to use:**

- Insufficient time 😞
- Access to finding tool 😊
- Uncertainty for using tools reliably 😊
- Perceived superiority of observational methods 😊

# Solution: Access to finding tools

<https://geriatricpain.org> – FREE!!!

The screenshot shows the GeriatricPain.org website. The navigation menu includes 'Clinicians', 'Older Adults', and 'Family Caregivers'. The main content area is titled 'Information for Clinicians' and features a 'Pain Assessment' section. This section includes three sub-sections: 'Cognitively Intact', 'Cognitively Impaired', and 'Pain Behavior Tool Critique'. The 'Pain Behavior Tool Critique' sub-section is circled in red. The Iowa College of Nursing logo is visible at the bottom left of the screenshot.

19

# Example: PAINAD

**Instructions:** Observe the older person both at rest and during activity/with movement. For each of the items included in the PAINAD, select the score (0, 1, or 2) that reflects the current state of the person's behavior. Add the score for each item to achieve a total score. Monitor changes in the total score over time and in response to treatment to determine changes in pain. Higher scores suggest greater pain severity.

**Note:** Behavior observation scores should be considered in conjunction with knowledge of existing painful conditions and report from an individual knowledgeable of the person and their pain behaviors.

**Note:**

- At rest *and* during activity
- Knowledgeable rater

geriatricpain.org Pain Assessment Tools

**Pain Assessment IN Advanced Dementia (PAINAD)**

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

\* Total scores range from 0 to 10 (based on a scale of 0 to 2 for five items), with a higher score indicating more severe pain (0="no pain" to 10="severe pain").

20



# Example: CNPI

geriatric Pain Assessment Tools  
pain.org

### Checklist of Nonverbal Pain Indicators (CNPI)

(Write a 0 if the behavior was not observed, and a 1 if the behavior occurred even briefly during activity or rest.)

	With Movement	Rest
1. Vocal Complaints: Non-verbal (Expression of pain, not in words, moans, groans, grunts, cries, gasps, sighs)	___	___
2. Facial Grimaces/Winces (Furrowed brow, narrowed eyes, tightened lips, jaw drop, clenched teeth, distorted expressions)	___	___
3. Bracing (Clutching or holding onto side rails, bed, tray table, or affected area during movement)	___	___
4. Restlessness (Constant or intermittent shifting of position, rocking, intermittent or constant hand motions, inability to keep still)	___	___
5. Rubbing: (Massaging affected area)	___	___
(In addition, record Verbal complaint)		
6. Vocal complaints: Verbal (Words expressing discomfort or pain, "ouch", "that hurts"; cursing during movement, or exclamations of protest: "stop", "that's enough".)	___	___
Subtotal Scores	___	___
Total Score	___	___

# Example: PIMD

geriatric Pain Assessment Tools  
pain.org

### Pain Intensity Measure for Persons with Dementia (PIMD)

Behavior, with description	Intensity of behavior				
	Absent	Mild	Moderate	Severe	Not Applicable
1. <b>Bracing:</b> Applying weight unevenly to relieve pressure from one body part by taking more weight onto another body part.	0	1	2	3	n/a
2. <b>Rigid or stiff body or body part</b> (include rigidity and stiffness related to contractures)	0	1	2	3	
3. <b>Sighing:</b> exaggerated exhale that you can hear; usually accompanied by shoulders rising and falling	0	1	2	3	
4. <b>Complaining:</b> Verbally express dissatisfaction, grumble	0	1	2	3	
5. <b>Grimacing:</b> Distressed or distorted appearance that involves: (1) furrowed brow and/or narrowed or closed eyes AND (2) one or more of the following: a) tightened lips b) corners of the mouth pulled back c) nose wrinkling d) cheeks raised.	0	1	2	3	
6. <b>Frowning:</b> Increased facial wrinkling in the forehead and/or eyebrows lowered/pulled together May also be present: downward turn of the corners of the mouth. Other mouth positions are not consistent with frown (e.g., smiling, grimacing)	0	1	2	3	
7. <b>Expressive eyes:</b> Eyes are open wide or bulging, eyebrows are lifted high, eyes are narrowed or squeezed shut	0	1	2	3	

## Example: PAIC15

Name of the patient: \_\_\_\_\_ Date: \_\_\_\_\_

### Pain Assessment in Impaired Cognition (PAIC 15)


Item	Meaning of Items	Not at all	Slight degree	Moderate degree	Great degree	Not scoreable
<b>FACIAL EXPRESSION</b>						
<b>Frowning</b>	lowering and drawing brows together	0	1	2	3	x
<b>Narrowing eyes</b>	narrowed eyes with tension around the eyes	0	1	2	3	x
<b>Raising upper lip</b>	upper lip raised, nose may be wrinkled	0	1	2	3	x
<b>Opening mouth</b>	the lips are parted, jaw is dropped	0	1	2	3	x
<b>Looking tense</b>	facial display of strain or worry	0	1	2	3	x
<b>BODY MOVEMENTS</b>						
<b>Freezing</b>	stiffening, avoiding movement, holding breath	0	1	2	3	x
<b>Guarding</b>	protecting affected area, holding body part, avoiding touch, moving away	0	1	2	3	x
<b>Resisting care</b>	resisting being moved or resisting care, being uncooperative	0	1	2	3	x
<b>Rubbing</b>	tugging or massaging affected area	0	1	2	3	x
<b>Restlessness</b>	fidgeting, wringing hands, rocking back and forth	0	1	2	3	x
<b>VOCALIZATION</b>						
<b>Using pain-related words</b>	using pain words, like "ouch", "ow", or "that hurts"	0	1	2	3	x
<b>Shouting</b>	using a loud voice to express words	0	1	2	3	x
<b>Groaning</b>	making a deep, inarticulate sound	0	1	2	3	x
<b>Mumbling</b>	uttering words and/or sounds indistinctly	0	1	2	3	x
<b>Complaining</b>	expressing being unhappy, sick, uncomfortable, and/or in pain	0	1	2	3	x
<b>SUM=</b>						

In which situation did you observe the person?

At rest

During an activity of daily living (ADL), please describe: \_\_\_\_\_

During guided movement, please describe: \_\_\_\_\_

PAIC15 

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## Solutions: Uncertainty for using tools reliably and perceived superiority of observational methods.

- Research indicates that (observer) ratings are often less than self report.
- Review directions of tools – *don't assume you understand the definitions.*
- Understand interpretation – *common error pain at rest vs. movement.*
- Achieve reliability as a group.
- Try it out! – *Progress not perfection.*

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# Hierarchy of Pain Assessment Techniques

1. Elicit self report.
2. Identify potential causes of pain.
3. Assess for pain behaviors that may indicate pain.
4. **Gather surrogate report and behavior change that may indicate pain.**
5. Response to analgesic trial (or other treatment approaches).

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## Behavior Change

- Seeing higher responsive behaviors think **Pain!**

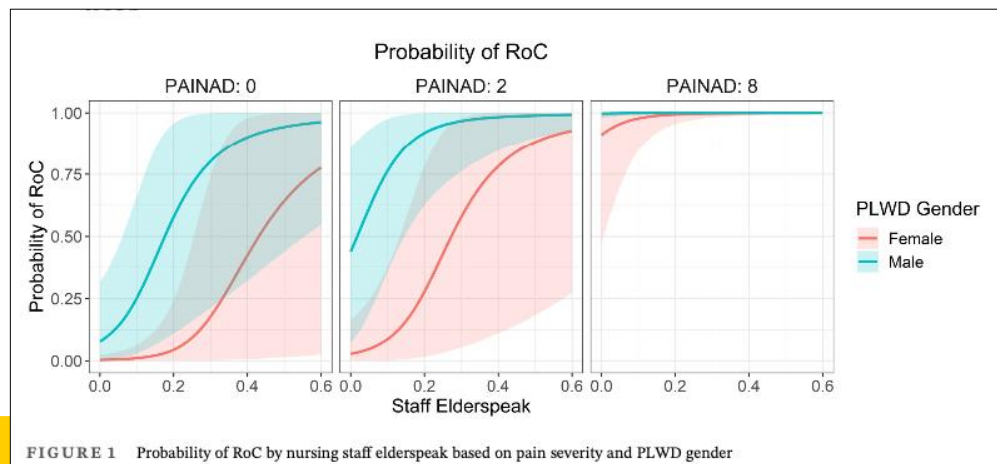


FIGURE 1 Probability of RoC by nursing staff elderspeak based on pain severity and PLWD gender

26

# Other pain behaviors

- Changes in interpersonal interactions
  - Not wanting to be touched, not allowing people near
  - Decreased social interactions and communications
  - Difficult to console or reassure
- Changes in activity patterns or routines
  - Sleep changes
  - Sudden cessation of common routines, activities

# Surrogate Report

**geriatric pain.org** Information for Family Caregivers

### Family Caregiver Pain Diary

A **Pain Diary** is a tool to record information on pain over time and collect data on things that possibly cause that pain. It is used to provide information for a healthcare provider to make best treatment decisions. Document your family member's pain experience on the attached page once per day or any time you see a change in pain or suspect a new or different pain problem. Bring the Pain Diary to the next appointment with your family member's healthcare provider.

- Use the [Pain Thermometer-Proxy](#) with your family member, if they are able to provide a self-report of their pain severity. See Pain Thermometer tool below.
- Use the [Pain Proxy](#) with your family member, if they are unable to provide a self-report of pain. If you need this tool, please click this link to access on GeriatricPain.org. [https://www.geriatricpain.org/painproxy](#)

**NOTE:** When a pain rating is requested, 0 is the lowest level and 10 is the highest level.  
**NOTE:** Where a pain rating is requested, 0 is the lowest level and 10 is the highest level.

Date/Time	Pain Location (Please only assess causing pain)	Self-Report Pain Rating (0-10)	PARAD to self-report (0-10)	What triggered the pain report or behavior?	Treatments Tried (specify drug and dose) non-drug treatment (e.g., heat, cool, exercise, massage, distraction, music, splinting)	Pain Rating for other treatment (0-10)	Additional Comments

Used with permission from Keela Herr, PhD, RN, and GeriatricPain.org  
 Revised January 2022  
 Resources and tools for quality pain care

**geriatric pain.org** Information for Family Caregivers

### Preparing for a Medical Appointment Tool

Healthcare Provider Name: \_\_\_\_\_

Appointment Date: \_\_\_\_\_

Is transportation arranged for the Appointment?  Yes  No

If no; how will I get to appointment? \_\_\_\_\_

Is someone going with patient to Appointment?  Yes  No; if yes; who: \_\_\_\_\_

**I plan to take the following items to the medical appointment**

Pain Diary  Medication List  Other: \_\_\_\_\_

Completed "Preparing for a Medical Appointment Tool"

**I want to remember to ask the Healthcare Provider the following questions:**

- 
- 

**I want to remember to share the following information with the Healthcare Provider:**

- Major concern(s):
- Major Changes happening in my life (i.e. divorce, death of a loved one, etc.):
- Other information:

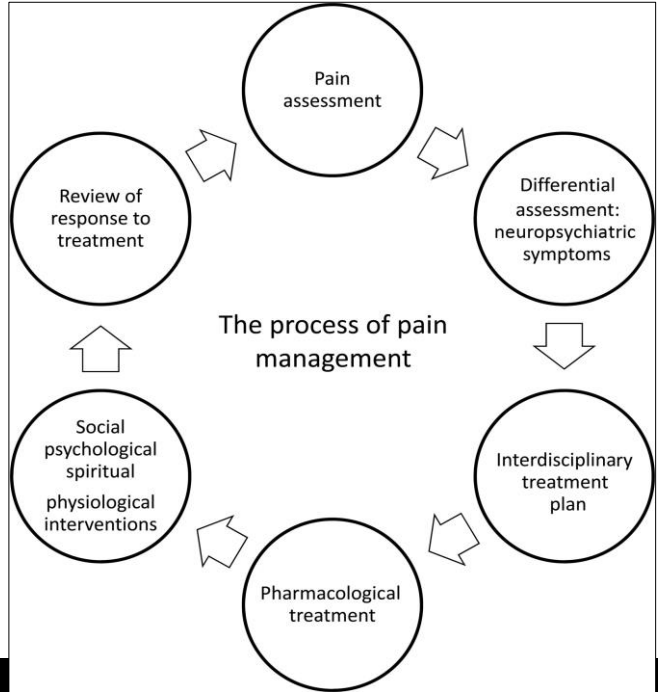
Date/Time of next appointment: \_\_\_\_\_

Resources and tools for quality pain care

## Hierarchy of Pain Assessment Techniques

1. Elicit self report.
2. Identify potential causes of pain.
3. Assess for pain behaviors that may indicate pain.
4. Gather surrogate report and behavior change that may indicate pain.
5. **Response to analgesic trial (or other treatment approaches).**

Corbett et al., 2014



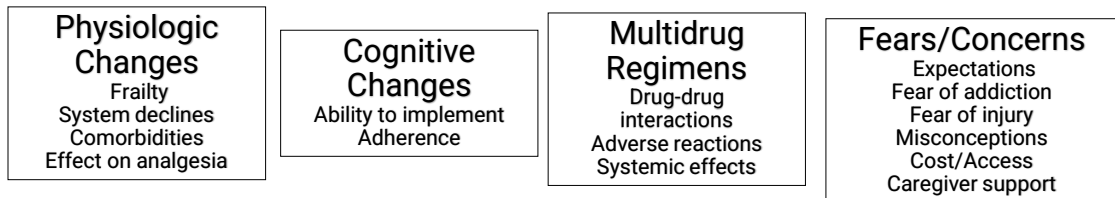
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## Pain management

- 1/3 of patients with substantial pain are not receiving any treatments.
- Use of treatments decline with cognitive impairments.
- Pain management is challenging in older adults.



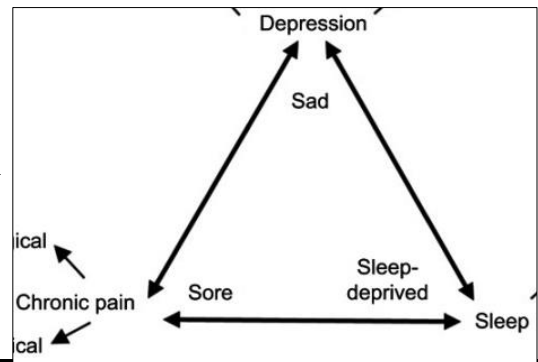
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## Pain Management

- Evaluate underlying diseases that are known to be painful in older persons – *acute vs. chronic*
- Acute: treat problem **and treat pain!**
- Chronic or persistent: complex



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## Emphasize resident goals with treatment plan

- Emphasis on impact/tolerability/satisfaction with treatment plan.
- Think about pain interference and resident goals.
- Addressing misconceptions/misbeliefs.
- Support communication between resident, caregiver, and health care provider team

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# Functional Pain Scale

Journal of the American Medical Directors Association (JAMDA) 2001 May-Jun; 2(3): 110-4.

## The *Functional Pain Scale*: Reliability, Validity, and Responsiveness in an Elderly Population

F.M. Gloth, III, MD, CMD, A.A. Sclafani, MS, RN, CCM, SCL, BC, Sclafani, CL, J. J. Rizzo, BS

### Functional Pain Scale

(0)	(2)	(4)	(6)	(8)	(10)
No Pain	Doesn't interfere with activities	Interferes with some active activities	Interferes with active, but not passive activities	Interferes with even passive activities	Intolerable. Incapacitated, by pain

Active activities : usual activities or those requiring effort (turning, walking, etc)  
Passive activities: talking on phone, watching TV, reading

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## Treatment Considerations

- Interdisciplinary!
  - Quality assessments
  - Monitor & document outcomes
  - Optimize non-pharmacologic approaches
- Complimentary therapies: acupuncture, TENS/PENS, massage, reflexology, aromatherapy

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## Other Non-Pharm

### Back to basics!

Exercise  
 Assistive devices  
 Repositioning  
 Cognitive impairment: basic needs  
 Treat cause

### Mind matters!

Cognitive and behavioral therapies  
 Acceptance and commitment therapy  
 Distraction  
 Education and goal setting

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## Who does what?

- EVERYONE can do something!
- Nurses & therapists: assess, document, manage
- Prescribers: assess, prescribe, supervise
- CNAs: observe, screen, report
- **Social work: observe, report, advocate - *Brainstorm***
- **Family: observe, report, advocate**

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## Resident's thoughts on pain:

- Pain is natural part of aging
- 68% think it should be tolerated
- 27% reporting to staff

Be the advocate!

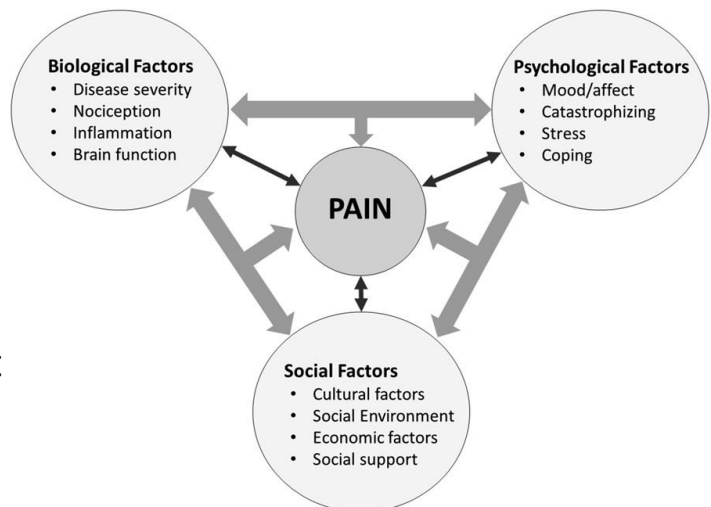
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## Takeaways!

- Best indicator of pain is self-report
- Interdisciplinary approach to assess, manage, treat
- Collaborate with resident to establish comfort and function goals



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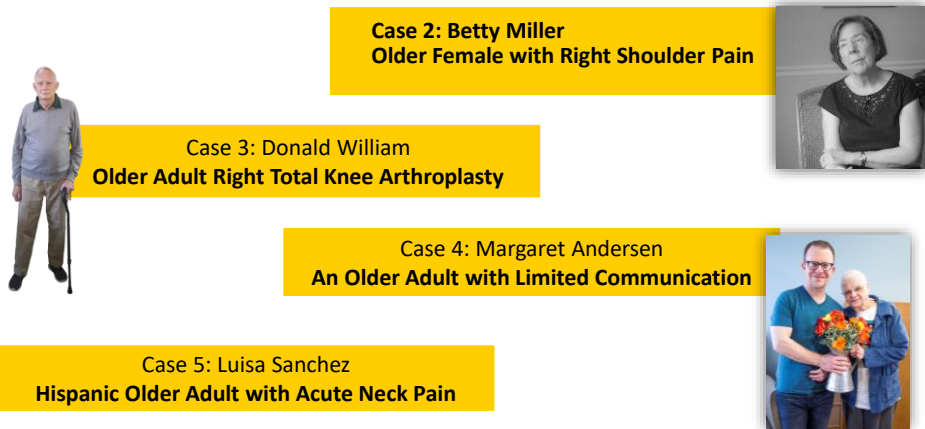
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# Free Resources

39

## University of Iowa COEPE Older Adult Cases



**Case 2: Betty Miller**  
Older Female with Right Shoulder Pain

**Case 3: Donald William**  
Older Adult Right Total Knee Arthroplasty

**Case 4: Margaret Andersen**  
An Older Adult with Limited Communication

**Case 5: Luisa Sanchez**  
Hispanic Older Adult with Acute Neck Pain

<https://uiowa.edu/coepe/ui-coepe-case-module-series>



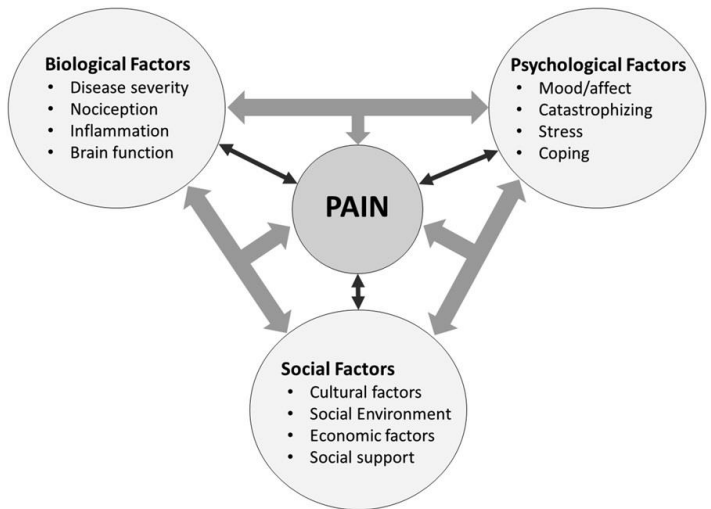
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40

41

## Questions?!

- Best indicator of pain is self-report
- Interdisciplinary approach to assess, manage, treat
- Collaborate with resident to establish comfort and function goals



42

# Opportunities!

## Currently Recruiting

We are currently recruiting nursing homes to participate in a national NIA-funded research study testing the Changing Talk: Online Training (CHATO).

There is no cost, direct-care staff can earn 3 contact hours, and all staff get a Certificate of Completion for their file.

Benefits to you, your staff, and your residents include:

- A person-centered approach.
- Education about elderspeak and better communication strategies.
- Reduction in resistiveness to care and other behavioral symptoms in residents with dementia.
- Reduction in the need for psychotropic medication.
- Convenient, online educational format for busy nursing homes.
- Qualifies for CMS dementia care training hours requirements.
- A free, nonpharmacological, evidence-based intervention is an excellent addition to a Quality Improvement Plan



If you are interested in taking the training and participating in the research, please enter your name and email address below or contact Carissa Coleman at ccoleman3@kumc.edu for more information.

### Changing Talk: Online Training (CHATO) interest form.

Name \*

First Name

Last Name

Email \*

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## Education on communication best-practices while wearing PPE

The University of Iowa College of Nursing and University of Kansas School of Nursing are pleased to offer a new educational program on best practices for communicating with residents while wearing PPE. This web-based education takes only 30-minutes to complete and you will be compensated for your time.

You will receive \$15 for completing the training and an additional \$25 for a post-education interview with a member of our research team. All staff (including non-care staff) are eligible regardless of role.

Visit [kumc.edu/chato-ppe](https://kumc.edu/chato-ppe) to enroll



Questions: contact [clarissa-shaw@uiowa.edu](mailto:clarissa-shaw@uiowa.edu)

# IOWA

**Supporting Those Who Are Grieving**

Long Term Care Social Workers of Iowa  
 April 5, 2024  
 Chris Klug, MA, MDiv.  
 Grief Counselor, Educator and Consultant  
[cklug7284@yahoo.com](mailto:cklug7284@yahoo.com)  
 Iowa City, IA

*Feeling deeply,  
 Seeing clearly,  
 Responding wisely*

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1

**Loss**

- Universal human experience, part of the fabric of human existence
- **Not** only death related (see the *Loss Inventory Handout*)
- What is my relationship with the experiences of loss in my life, and why is that important?

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- Assumption: **Relationship shapes experience**
- **Acknowledging** loss as a part of the fabric of human existence,
  - as something that is unavoidable
  - And mostly not out fault
  - Rather than as something we **should** be able to avoid,
  - Frees us from the “piling on” suffering that happens when we believe we should be able to arrange our lives so that significant loss doesn’t happen

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## Grieving

- Is the human person's often difficult and painful, normal, healthy, dynamic response to the experience of **loss**.
- This process involves integrating the loss event into the wholeness of who I (the griever) am today.

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## Grieving, (cont.)

- What is my relationship to my experiences of grieving, and why is that important?
- Grieving as something right with me rather than something wrong with me
- As "What's supposed to Happen"
- Rather than as something wrong with me that I need to "get over," "put behind me," "recover from," "get passed," "bring closure to," so that I can "get back to normal"
- It is an **integrative process** and a living into a "new normal"

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*"Grieving is as natural as crying when you are hurt, sleeping when you are tired, eating when you are hungry, or sneezing when your nose itches. It is nature's way of healing a (wounded) heart."*

Doug Manning

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## Pain

- Part of the grieving process
- What is my relationship with the pain of grieving in my life?
  - Acknowledging as part of a healing process
  - As something that is right with me
  - Rather than something that is wrong with me
  - Moving toward the pain
  - At my own pace

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*Refuge in Grief* YouTube Video  
*How to Help a Grieving Friend*

[How to help a grieving friend: the animation](#)

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## How to Be With Those Who Are Grieving

- **Relationship:** being a **Companion**
- Creating a safe environment
- Giving "Permission to Grieve"
- Listen, Listen, Listen: attempting to enter into the griever's experience
- Allowing the Griever to teach you about their experience

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**Listen**

*When I ask you to listen to me and you start giving advice you have not done what I asked.*

*When I ask you to listen to me and you begin to tell me why I shouldn't feel that way, you are trampling on my feelings.*

*When I ask you to listen to me and you feel you have to do something to solve my problems, you have failed me, strange as that may seem.*

*Listen! All I ask is that you listen. Not talk or do – just hear me.*

*Advice is cheap: 50 cents will get you both Dorothy Dix and Dr Spock in the same newspaper.*

*And I can DO for myself; I'm not helpless.*

*Maybe discouraged and faltering, but not helpless.*

*When you do something for me that I can and need to do for myself, you contribute to my fear and weakness.*

*But when you accept as a simple fact that I do feel what I feel, no matter how irrational, then I quit trying to convince you and can get about the business of understanding what's behind this irrational feeling.*

*And when that's clear, the answers are obvious and I don't need advice.*

*So, please listen and just hear me, and if you want to talk, wait a minute for your turn; and I'll listen to you.*

- Anonymous

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10

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**Acknowledging  
and  
Validating  
the Griever's Experience**

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**"To be able to say, 'this hurts,' without being talked out of it. That's what helps. Being heard, helps. It seems too simple to be of use, but acknowledgement can be the best medicine we have. It makes things better even when they can't be made right."**

From the *Refuge in Grief* YouTube Video

12

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“The human soul doesn’t want to be advised, or fixed or saved. It simply wants to be witnessed, exactly as it is.”

Parker Palmer

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### Normalizing the Griever’s Experience

- Familiarity with “Common Characteristics of Grieving” (See handout)
- People who are grieving describe their experience and mention things that don’t “feel normal” to them.
- These are **characteristics** of grieving, not **symptoms**.
- **Normalizing** involves affirming the commonality of these experiences for those who are in similar situations. “That’s very common for someone who is going through what you’re going through.”
- It does not mean telling the griever this should feel normal for them.

14

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### Normalizing (cont.)

- Characteristics are not permanent, they are experienced most intensely during the acute time of grieving
- They then diminish and fall away\*
- Only to often recur for many years at birthday, holidays, anniversaries and other unpredictable times
- **\*Sometimes they become chronic**

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## Reminiscing and Memory Work

- Healthy grieving is about staying connected, not disconnecting
- The primary way humans stay connected to loss events and what has been lost is by remembering, also through persons, places and things (connecting objects)
- Remembering and Reminiscing nurture the relationships that are available to the griever.

16

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- Making Referrals When Appropriate
- **Reading:** It's OK That You're Not OK: Meeting Grief and Loss in a Culture That Doesn't Understand, by Megan Devine
- Megan Devine Website: <https://refugeingrief.com>
- Companioning the Dying, by Greg Yoder

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We think we get over things.  
 We don't get over things.  
 Or say, we get over the measles  
 but not a broken heart.  
 We need to make that distinction.  
 The things that become part of  
 our experience  
 never become less a part of our  
 experience.  
 How can I say it?  
 The way to "get over" a life is to  
 die.  
 Short of that, you move with it,  
 let the pain be pain,  
 not in the hope that it will vanish  
 but in the faith that it will fit in,  
 find its place in the shape of  
 things

and be then not any less pain but  
 true to form.  
 Because anything natural has an  
 inherent shape  
 and will flow towards it.  
 And a life is as natural as a leaf.  
 That's what we're looking for:  
 not the end of a thing but the  
 shape of it.  
 Wisdom is seeing the shape of  
 your life  
 without obliterating (getting over)  
 a single

instant of it.

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# Loss Inventory

Prepared by: Chris Klug  
Grief Counselor, Educator and Consultant 319-471-0832  
[cklug.7384@yahoo.com](mailto:cklug.7384@yahoo.com)

Please **check** which losses you have experienced in the past 18 months to 2 years and **circle** the losses the patients and families whom you serve may be experiencing.

- Loss of some aspect of self
  - Physical loss, e.g., amputation, eyesight, bladder control
  - Mental loss, e.g., memory,
  - Loss of self-esteem, loss of identity, e.g., mid-life crisis
- Age related Losses
  - Loss of teeth, hair, eyesight, hearing
  - Loss of youth and/or beauty
  - “Empty Nest” syndrome
  - Retirement
- Financial Loss
- Loss through change in relationships
  - Divorce
  - Separation
  - Children leaving home, e.g., graduation, marriage
  - Becoming caregivers for parents
  - Loss of caregiving role with regard to children
  - Leaving groups or clubs or communities, e.g., faith community
- Symbolic Losses
  - Dreams not being realized
  - Loss of the future
  - Loss of status
  - Loss of identity
- Loss through death: family member, friend, pet, someone you’ve admired, a teacher, etc.
- Loss of a treasured objects, e.g., home, car, jewelry, pictures, etc.
- Spiritual loss, e.g., previous beliefs not longer adequate to the new situation.
- Work related losses
  - Death of a patient or co-worker
  - Loss of income or benefits
  - Loss of a co-worker by their leaving the agency/hospital
  - Loss of support or validation
  - Loss of physical environment, e.g., office space, etc.
  - Change in job description and/or duties
- Geographic Losses: leaving one part of the country, or city, or neighborhood and moving to another
- Loss due to change of seasons and/or weather
- Limbo-state Losses, e.g., awaiting the outcome of medical tests, person in a non-responsive state, person declining approaching death, dementia, Alzheimer’s, person or pet missing, uncertainty in relationship following a conflict or an argument
- Other losses: \_\_\_\_\_
- *\*Please contact the author for permission to reprint or share electronically.*

## **\*Common Characteristics of Grieving**

*Prepared by: Chris Klug,  
Grief Counselor, Educator and Consultant  
319-471-0832 [cklug.7384@yahoo.com](mailto:cklug.7384@yahoo.com)*

**Grieving:** the word most commonly used to describe the constellation of emotional, mental, physical, and spiritual experiences that naturally follow the experience of loss.

When actively grieving, a person may experience many of the following characteristics of grief. These characteristics are not permanent, are most intense during active grieving, and may reappear later at such times as anniversaries, birthdays, holidays, etc. Though these don't feel normal to the griever, they are normal given the context of having experienced a significant loss.

### **Characteristics of Grieving** (partial lists)

**Physical:** deep sighing; weakness and fatigue; rapid heartbeat; increased blood pressure; increase in activity; decrease in activity; muscular tension; decreased resistance to illness; neglect of self-care; increase in self-care; heaviness or tightness in the chest; nausea; dizziness; feeling flushed or feverish; cold or clammy hand; nervousness or trembling; shortness of breath; headaches; constipation or diarrhea; dry mouth, tightness or "lump" in the throat; aches and pains in muscles and joints; change in appetite; change in sleep pattern; tears at unexpected times and places.

**Emotional:** shock and disbelief; panic; sadness; crying; emptiness; longing/pining/yearning; despair; hopelessness; helplessness; nervousness; restlessness; worthlessness; anxiety; mood changes; emotional outbursts; denial; anger; irritability; rage; guilt; shame; fear; frustration; impatience; emotional exhaustion; sorrow; feelings of being lost; loneliness; relief; peace; comforted; bitterness; vengefulness; blameful.

**Mental:** loss of short term memory; confusion; denial; disbelief; disorganization; difficulty in performing/completing tasks or chores; difficulty concentrating; dreaming; intense preoccupation with the past; difficulty in communication; sense of the presence of the deceased; searching for the deceased; difficulty making decisions and problem solving; difficulty making plans and keeping commitments; difficulty in coping with significant dates; anniversaries, and holidays; struggles in coping with changes in relationships; remembering.

**Spiritual:** trying to have the loss "make sense" by searching into one's belief system; questioning the meaning and purpose of life/death; finding comfort in religious belief and rituals; finding religious beliefs and rituals empty/meaningless; anger toward God/Creator/ Universe; feeling the presence of the deceased; searching for the presence of the deceased; feeling punished/rewarded because of the loss event; questioning the trustworthiness of the higher power

*\*Please contact the author for permission to reprint or share electronically.*

