

**The Palliative Care Education in Assisted Living
for Care Providers of Residents with Dementia
(PCEAL_RWD)**

**Facilitators' Training
Manual**



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Henderson, M. L., Hanson, L. C., & Reynolds, K. S. (2003). *Improving nursing home care of the dying: A training manual for nursing home staff*. Springer Publishing Company.

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Preface

The Palliative Care Education in Assisted Living (PCEAL) educational program was initially developed and pilot tested by Debra Dobbs and Dany Fanfan, with support from an internal grant from the University of South Florida, College of Behavioral and Community Sciences (CBCS) in 2016-18 (Dobbs, D., PI). This manual was developed in part based on the book written by Martha Henderson, Laura Hanson and Kimberly Reynolds entitled, “Improving Nursing Home Care of the Dying: A Training Manual for Nursing Home Staff” (Springer Publishing, 2003). This book was used as a resource in a quality improvement intervention study in nursing homes led by Dr. Hanson to improve the quality of end-of-life care and the knowledge of nursing home staff about how to provide palliative care. Results of this successful project have been reported elsewhere (Hanson, Reynolds, Henderson, & Pickard, 2015; Institute of Medicine, 2014).

In 2014-15, in a project supported by the USF Office of Community Engagement and Partnerships (Dobbs, D., PI), the PCEAL program adapted materials in Henderson, Hanson and Reynolds (2003) and those developed in the quality improvement project with the input of assisted living (AL) administrators, nurses, personal care aides and hospice nurses in Florida to include updated policies and practices specific to hospice, advance care planning and palliative care that would impact the care of AL residents. In 2016-18, an adapted version of the Hanson intervention (PCEAL) was pilot tested in two treatment and one control ALs, which consisted of all or mostly residents with advanced dementia. The CBCS funded pilot work (Dobbs, D., PI) tested feasibility of the methods, developed treatment fidelity protocols and curriculum materials including online modules, and manualized the intervention. The study results showed the PCEAL to be a feasible intervention among nursing staff in collaboration with local hospices. The present version is now referred to as the Palliative Care Education in Assisted Living for Residents with Dementia (PCEAL_RWD), and this manual was supported by a grant from Ed and Ethel Moore Alzheimer’s Disease Research Program with the goal of tailoring the program for AL residents with Alzheimer’s disease and other forms of dementia.

Community hospice nurses, referred to in the manual as Facilitators, will provide a structured training program for AL nurses, referred to in the manual as Nurse Interventionists. After completing training, these Nurse Interventionists are certified by the PCEAL_RWD team as having learned and demonstrating their ability to appropriately follow the structured intervention protocol. This manual presents four modules included in the PCEAL_RWD. The first module, How to Have a Good Death, is administered only face-to-face by trained Facilitators. The second module, Recognizing the Final Phase of Life can be administered face-to-face or via an optional online version. The third and fourth modules (Advance Care Planning and Hospice and Palliative Care Services and Pain Management) are administered only face-to-face by Facilitators. We hope that these materials will be useful in providing much needed improvement in end-of-life care for people with Alzheimer’s disease or related dementia (ADRD).

Training and Monitoring Requirement






We have developed a structured training and monitoring protocol to assure that the intervention is fully described (and thus replicable) so that Facilitators who train Nurse Interventionists and Nurse Interventionists who implement the program within ALs are both capable of faithfully following the protocol after training (assessed via role-plays after this structured training) and that the protocol is carefully followed during its delivery in ALs.

- Facilitator: Community hospice nurses who provide instruction about the protocol and observe the Nurse Interventionists during role-plays and actual clinical encounters, and monitor the extent to which Nurse Interventionists demonstrate treatment fidelity, or how closely they follow the protocol.
 - Qualifications for Facilitators include experience working as a registered nurse in a palliative and hospice care setting, expertise in palliative and hospice care, and successful completion of the PCEAL_RWD training provided by the study team.
- Nurse Interventionist: AL nurses who deliver the intervention in ALs.
 - Qualifications for Nurse Interventionists include working as a registered nurse or licensed practical nurse in an assisted living setting and completing the four-week PCEAL_RWD training program directed by the Facilitators.
- Fidelity Monitor: Study Co-Investigators who serve as secondary raters of treatment fidelity to maintain inter-rater reliability, assist with the training of Facilitators and conduct the observational assessment of Facilitators.

Although a structured protocol is provided, Facilitators can use their clinical judgment and the skills they have developed with experience to present the material required by the protocol in sensitive and culturally appropriate ways. The manual describes essential elements of the intervention but does not require a lock-step or robotic structure that would inhibit effective clinical care.

Facilitators will be required to attend a 4-hour workshop on how to use the materials in the PCEAL_RWD training program. At the end of this workshop, each trainer will role play the intervention protocols and be assessed on adherence to the protocol by one of the study's Co-Investigators trained to be a Fidelity Monitor. A 90% threshold for following protocol needs to be obtained on each of the three protocols before a Facilitator can go into the field. Ongoing monitoring of fidelity or following the program will be used to assure that Facilitators and Nurse Interventionists continue protocol and avoid drifting away from the standardized format. Training materials and protocol checklists are included in this manual.

General Instructions for Facilitator

-  At the beginning of each session, Facilitators will need to collect attendance and ensure that nurses input their nursing license number on the attendance sheet in order to appropriately administer CEUs at the end of the training.
-  Facilitators, please collect any homework due before going over new materials. Please inform Nurse Interventionists that an 80% HW completion rate is the desired goal in order to demonstrate mastery of assignment of the PCEAL_RWD program.
-  Each Facilitator will be provided with a USB drive with the content of the training materials and Nurse Interventionists will be provided with hard-copies of training materials (PCEAL_RWD Training folder).
-  COMMITMENT For face-to-face sessions, Nurse Interventionists will need to arrive on time and commit to the whole 90 minutes.
-  At the end of each session, Nurse Interventionists will also complete a checklist of topics that were presented to provide a quality check on the presentations completed by the Facilitators.

SESSION 1: PRE-TEST AND “ENVISIONING A GOOD DEATH” LECTURE

Length: Time estimate: 90 minutes

Class Materials

- Sign-in sheets
- Name tags
- Presentation slides
- Markers/pens
- Homework
- Laptop/Projector
- Facial Tissues



Goals

- Introduce the background and rationale for the PCEAL_RWD training program.
- To create a vision of what an ideal death would be like in an assisted living community and how death might differ if the person has any form of dementia.

Objectives

- Members of the study team will provide an overview of the PCEAL_RWD training program
- Nurse Interventionist will complete the palliative care knowledge pre-test and demographic questionnaire
- Nurse Interventionists should learn information about how to create a comforting and caring place for people to die.

- Among Nurse Interventionists, Facilitators should identify a Palliative Care champion who will host two meetings named booster sessions for Nurse Interventionists at their AL facility at 2- and 4-months post PCEAL_RWD training to reinforce what was learned in the training and assess barriers and challenges to implementation.

Outline

Welcome participants and hand out nametags, sign-in sheet, markers/pens and pencils (1min)

Introduce self (Facilitators, research study team members) (2min)



Overview of the PCEAL_RWD Training Program/Consent (15-20 min)

Instructions for Study Team and Facilitator:

- Distribute staff consent form to participants who have not already given their written consent to participate in the study.
- Distribute training material folders and accompanying book to each Nurse Interventionist.
- Take a few minutes to provide a brief overview of the PCEAL_RWD training program to Nurse Interventionists. You can utilize the information provided below as well as information from the staff consent form to inform study participants about the educational program, study activities, and expectations. Be ready to answer Nurse Interventionists' inquiries as they arise.
- Collect signed consent forms.
- **Note: A member of the research team e.g. the research assistant or principal investigator will facilitate the consent process and provide an overview of the PCEAL_RWD training.**

Key Information about PCEAL_RWD

- The PCEAL_RWD intervention will include four 1.5 hour sessions and be scheduled at a time determined by the assisted living administrator.
- The first session is focused on envisioning a good death and has to be attended in person. Session two covers the following topics: recognizing the final phase of life, emotional and spiritual care and grief and loss. Session two is the only session available online and face-to-face. Session three covers advance care planning and has to be attended in person. The fourth session covers pain management and hospice care services and has to be attended in person.
- Session two is available online if the Nurse Interventionist cannot attend in person. If they want to complete the online training sessions, they will be provided with access information for Canvas via email after completion of Session 1 homework.
- For face-to-face session, participants will need to arrive on time and commit to the whole 90 minutes.
- There will be homework due after each session. Homework will be turned in to the Facilitator at the beginning of each session, starting with Session 2. Exceptions: Session 4 homework will be submitted to the PC Champion and for those completing Session 2 online, they will submit Session 1 homework to the research team.



Palliative Care (PC) Champion

Instructions for Facilitator:

- Please ask who would like to volunteer to be the Palliative Care Champion for their respective site.
- Note: The PC Champion role is also discussed in the consent form.

- The PC Champion will need to be determined by the end of the first session. Be sure to collect contact information (name, phone #, email) and inform the research assistant or the principal investigator so that necessary follow-up can be completed.
 - Distribute the PC Champion folder or form to the Nurse Interventionist who volunteers for the role. The PC champion form is located in Appendix C of this manual.
- The principal investigator will contact each PC Champion by phone or email to discuss their role and review necessary tasks.

Key Information about the PC Champion Role

Each treatment facility will be required to designate one Nurse Interventionist as the PC Champion among all Nurse Interventionists completing the training sessions. The PC Champion facilitates booster sessions at 2- and 4-month post PCEAL_RWD with all who attended all four sessions. Booster sessions are 30 minute meetings with trained Nurse Interventionists to reinforce what was learned in the PCEAL_RWD (e.g., protocols for ACP discussions and pain screenings), to discuss the progress of ACP chart reviews, scheduling of ACP discussions, and completing of ACP discussion phone calls and to discuss challenges encountered while implementing the protocols. The PC Champion will document what was discussed in the PC Champion form provided at the beginning of the PCEAL_RWD program and the actionable plans on the form will be provided to the research team. The PC Champion will collect Session 4 homework from all Nurse Interventionists at their facility and submit this via email to the research team at carlynvogel@mail.usf.edu. The PC Champion will also monitor the ACP Calls Tracking/Log Sheet and email the completed form weekly to the research team.



Participant's Demographic Questionnaire and Palliative Care Knowledge Pre-test (10-15 min)

Instructions for Facilitator:

Each Nurse Interventionist will be provided with a questionnaire that consists of demographic information and a pre-test to measure the starting point or pre-existing knowledge that the Nurse Interventionists have regarding palliative care. The pre-test consists of several questions from a scenario about a resident with dementia in an assisted living facility.



Envisioning a good death presentation (50-60 min)

1. Prepare the classroom (2 min)
 - a. Instructions for Facilitator:
 - i. Dim the lights
 - ii. Create a comfortable environment
 - iii. Play soft instrumental music if desired
 - iv. Read the following statements and questions below slowly, pausing between each part to allow participants to reflect.



2. Envisioning a good death exercise (20 min)

This exercise is a validated intervention developed by Henderson, Hanson, and Reynolds (2003).

 - a. Instructions for Nurse Interventionists
 - i. Close your eyes. Relax. Take slow deep breaths.
 - ii. Connect with your heart. Recall memories of a good death that you have witnessed and what made it so. Or think about your dream of a good death for yourself or a loved one.
 - iii. Recall memories of a death that affected you strongly. Choose one person or one story to focus on. This could be someone from your past—a resident you've cared for, a family member, or a friend. Or create a vision of a good death you see in the future for someone you love.
 - iv. Imagine that person is dying in a room in an assisted living. If the person had a good death, think about what made it so. If not, think about how you wish it could have been.

- v. See the dying person's face. Who is this person to you? What is the expression on their face?
- vi. See where the person is in their room in the assisted living. What are their immediate surroundings like? What are the favorite things they want to have with them to comfort them?
- vii. What is the person listening to? What are their favorite sounds, music, and voices?
- viii. Who else is there? Who do they want with them during this time? How do you interact with them?
- ix. What does the person need now, as they are dying? What do they ask for? What do they need that they can't or won't ask for? How do you know what they need?

3. Discussion and review (25 min)

a. Instructions for Facilitator

- i. Ask the Nurse Interventionists to come back together as they take some deep breaths.
- ii. Tell them you will turn the lights back on.
- iii. Begin a discussion of people's visions. Ask participants to share their thoughts briefly, so that several people will have time to talk.

b. Instructions for Nurse Interventionists

i. Questions for discussion

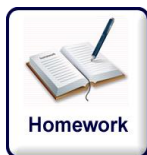
- 1. Would someone share their vision of a good death with the group?
- 2. What factors contributed to good deaths?
- 3. How can we meet all aspects of the resident's dying experience, including:
 - a. Physical needs: helping the resident be physically comfortable.
 - b. Emotional needs: listening for feelings.
 - c. Social needs: encouraging relationships with others.

d. Spiritual needs: supporting residents' beliefs and practices.

4. What factors should be considered for the resident with dementia during the dying experiences?

c. Instructions for Facilitator (5 min)

- i. Finish the session by reading aloud or asking a volunteer from the group to read aloud the conclusion.
- ii. Remind all Nurse Interventionists that Session 2 will be available both online via Canvas and face to face.
- iii. Explain to all Nurse Interventionists completing Session 2 online that they need to email Session 1 homework to Carly Vogel (carlynvogel@mail.usf.edu) within 7 days of receipt of Session 1 homework.
- iv. Nurse Interventionists will not have access to the online Session 2 in Canvas until homework for Session 1 is received within 7 days.
 1. Please determine the number of Nurse Interventionists who will be completing Session 2 online (A session 2 online sign-up sheet should be completed and emailed to the study team).
 2. If everyone will be completing Session 2 online, please inform the study team (principal investigator or research assistant).
- v. Hand out and explain the homework. Explain to the Nurse Interventionists not attending Session 2 in person that they will be required to submit Session 1 homework to Ms. Vogel as explained above before they complete Session 2.
 1. Please note that everyone will need to submit Session 2 homework at the beginning of Session 3 whether they completed Session 2 online or face-to-face.
- vi. Lastly, hand out the *Session One Fidelity Checklist* (see below) to all Nurse Interventionists present. Allot about 3 minutes for Nurse Interventionist to complete the checklist.



Homework

ENVISIONING A GOOD DEATH FOR ONE OF YOUR RESIDENTS

1. Pick one resident with dementia you believe is near the end of his/her life. Write a one paragraph (3-5 sentences) narrative describing the care and attention provided at your AL to meet the needs of this resident as he/she nears the end of life. Your narrative should address the following questions:
 - **Physical:** Is he/she getting the help he/she needs for pain, shortness of breath, mouth care, and personal cleanliness?
 - **Emotional:** Have you tried to understand his/her concerns, fears, and wishes?
 - **Social:** How can you support and nurture his/her connections with family, friends, and staff who care about him/her? How can we support his/her family during this difficult time?
 - **Spiritual:** What kind of religious or spiritual support does he/she want? Would he/she or his/her family like a visit from a minister? A prayer? A bible reading? Special music?



Please write your narrative (typed or handwritten) in a separate sheet of paper. Provide your responses to Question 2, 3, 4 on this form or type it separately. Be sure to submit responses to all questions together.

2. Identify 2-3 changes you could implement right now in your AL to address the unmet needs of the resident.
3. What steps or actions have you taken in the past that you have found to be most helpful in meeting the needs of residents near the end of life?
4. How did the resident's care plan change to meet these needs?

PCEAL_RWD Session One Fidelity Checklist for Nurse Interventionist

The objective of this checklist is to ascertain whether the learning objectives were met for Nurse Interventionists participating in the PCEAL_RWD Program. Please evaluate this session by checking the appropriate response for each of the following questions below:

Receipt of Curriculum

1. Did you understand the role of the PC Champion? ☐ Yes ☐ No
2. Did you envision what a good death experience should be like? ☐ Yes ☐ No
3. Did you identify factors that could be considered to promote good death? ☐ Yes ☐ No
4. Did you learn more information about how to create a comforting and caring place for people to die? ☐ Yes ☐ No

Delivery of Curriculum

1. Did the research team explain the PCEAL_RWD Training Program and your role/expectations as a Nurse Interventionist? ☐ Yes ☐ No
2. Did the Facilitator identify the PC Champion for your AL? ☐ Yes ☐ No
3. Did the Facilitator offer you an opportunity to ask questions, probe for clarity, and/or make connections to your practice? ☐ Yes ☐ No
4. Was the session well-paced and well-timed? ☐ Yes ☐ No
5. Did the Facilitator hand out and discuss the homework? ☐ Yes ☐ No

Overall, how would you rate this session? ☐ Poor ☐ Good ☐ Very Good ☐ Outstanding

Any other comments or suggestions?

SESSION 2: RECOGNIZING THE FINAL PHASE OF LIFE, GRIEF AND LOSS

Length: Time estimate: 90 minutes

Class Materials



Goals

- To better determine when residents with ADRD are nearing the final stages of life so that we can provide high-quality end-of-life care in an assisted living community.
- To provide knowledge you can use to help residents and family in their grieving processes.
- To understand the ways in which dying is much more than the death of a body.

Objectives

- To identify when a resident is nearing death.
- To discuss ways to predict death and recognize the signs of active dying.
- To discuss some of the physical and emotional symptoms that residents may exhibit as they prepare for their deaths.
- To discuss particular issues that should be considered and prioritized among residents with dementia when nearing the final stages of life.
- To discover how assisted living staff can be most helpful to residents' family members and friends when death is approaching.
- To discuss emotional and spiritual concerns that individuals experience as death draws near and develop strategies to help as caregivers.

Outline

Welcome Nurse Interventionists and hand out sign-in sheet (2 min)

Collect/Discuss homework from last session (5 min)



Handout PowerPoint (PPT) presentations that correspond with Session 2. Session 2 consists of materials and resources from Chapters 2, 3, and 7 from the book written by Henderson, Hanson and Reynolds (2003). Session 2 PPT slides can be found in Appendix F.



Recognizing the Final Phase of Life (30min)

Review class materials about “Recognizing the Final Phase of Life” Chapter

1. Instructions for Facilitator
 - a. Discuss the following topics with Nurse Interventionists, taking questions and comments as they arise (20 min)
 1. Identifying residents who are nearing death
 - a. See slide 4 in “Recognizing the Final Phase of Life” PPT.
For more details, see Chapter 2, pg. 5-6.
 2. How do we determine that someone is dying?
 - a. See slide 5 in “Recognizing the Final Phase of Life” PPT.
For more details, see Chapter 2, pg. 6.
 3. How do we recognize residents who are terminally ill or in the final phase of life?
 - a. See slide 6 in “Recognizing the Final Phase of Life” PPT.
For more details, see Chapter 2, pg. 7.
 - b. Additional resource: The Flacker Mortality index
 4. How do we communicate prognosis and begin a discussion of palliative care goals?
 - a. See slide 7 in “Recognizing the Final Phase of Life” PPT.
For more details, see Chapter 2, pg. 8-9.

5. How can hospice care benefit AL residents, their families, and the staff who care for them?
 - a. See slide 8 in “Recognizing the Final Phase of Life” PPT. For more details, see Chapter 2, pg. 9-10.
 6. What behaviors might AL residents exhibit in the weeks to months before death?
 - a. See slide 9 in “Recognizing the Final Phase of Life” PPT. For more details, see Chapter 2, pg. 10.
 7. Signs of actively dying and ways to offer comfort
 - a. See slide 10-12 in “Recognizing the Final Phase of Life” PPT. For more details, see Chapter 2, pg. 10-13.
 8. Comforting residents who are actively dying
 - a. See slide 13-14 in “Recognizing the Final Phase of Life” PPT. For more details, see Chapter 2, pg. 10-13.
 9. Conclusion
 - a. See slide 15 in “Recognizing the Final Phase of Life” PPT.
- b. Case Study/Group Discussion (8 min)
1. Instructions for Facilitator
 - a. Have someone in the group read the example (see below) and issues aloud, pausing for discussion along the way.
 - b. See case study example below and on slide 16.
 - c. Discuss the case study before continuing. How would you propose treating Mr. Jones and working with his son to resolve these issues?
 - d. See below for issues to consider and a potential action plan for this case study.



Case-Based Example: Mr. Jones

Mr. Jones was admitted to assisted living three months ago with lung cancer and emphysema in addition to mild dementia after receiving rehabilitative care in a nursing home. Mr. Jones' son is his surrogate decision maker. Mr. Jones' care needs became too great after a few days in assisted living and he was rehospitalized with respiratory distress and dehydration. He was readmitted back to the assisted living after a few days. After a month's time, the resident was weaker, had lost weight and his mild disorientation had worsened. The son

was angry about his father's failure to improve and he asked the staff to consider another hospital admission. Staff believes that Mr. Jones has had an adequate trial of rehabilitation and now think he is actively dying. They also think Mr. Jones understands this fact, although he hasn't said so. The son is hesitant to agree to a DNR order, and the physician, who has never met the son, does not want to become involved with an angry family member. The assisted living facility administrator asked the hospice team to do an evaluation, but the local hospice is uncomfortable about getting involved if the son refuses their services.

Issues to Consider

- The younger Mr. Jones does not agree that his father has a terminal illness. Mr. Jones needs education about the disease progression for his father.
 - Communication is needed to clarify that the failure of the rehabilitation is not due to staff incompetence but rather to the severity of the resident's progressive and terminal illness.
 - Assisted living staff wish to have a DNR order.
 - The hospice and the physician are not providing support or assistance to staff.
 - Facilitator: This is not an exhaustive list of issues to consider and what is discussed during the session will be based on the responses provided by Nurse Interventionists.
- c. Conclusion of Recognizing the Final Phase of Life (2 min)
1. Instruction for Facilitator
 - a. Conclude this section by reading through and discussing the action plan.

Action Plan for Mr. Jones

- Staff will talk with the physician to obtain a statement to confirm the patient's terminal prognosis, which they will then communicate directly to the son, invoking the physician's authority even though the doctor is unwilling to talk directly with the son. The staff person the son trusts the most will have this conversation.
- Staff will come up with alternative language to convey that the resident is dying and avoid using euphemistic language like "he is not doing well" or "he is having a bad day".

- Facilitator should empower Nurse Interventionist to use difficult verbiage about dying so that they become more comfortable communicating about death with family of their residents.
- Staff will not make a hospice referral unless the son requests it.
- Staff will develop their own palliative care plan to ensure the resident's comfort. This plan will include the positive actions for the resident's benefit—special foods, music, massage, and consideration of an appetite stimulant to improve his dehydration and resulting confusion.



Grief and Loss (25 min)

Review materials from the “Grief and Loss” Chapter

- a. Instructions for Facilitator
 - i. Discuss the following topics with Nurse Interventionists, taking questions and comments as they arise.
 1. What can we learn from studies of families who experience loss?
 - a. See slide 18 in “Grief and Loss” PPT. For more details, see Chapter 3, pg. 17-18.
 2. Why some residents do not achieve a good death
 - a. See slide 19 in “Grief and Loss” PPT. For more details, see Chapter 3, pg. 18.
 3. What Nurse Interventionists can offer grieving family members
 - a. See slide 20 in “Grief and Loss” PPT. For more details, see Chapter 3, pg. 19.
 4. Family stresses during the dying process
 - a. See slide 21 in “Grief and Loss” PPT. For more details, see Chapter 3, pg. 19.
 - b. Discussion questions after reviewing this section:
 - i. Tell about a time that you were able to be particularly helpful to a family member of one of your residents. What did you do? Why was this helpful to your resident's family?
 5. What can you do to help grieving family members?
 - a. See slide 22-23 in “Grief and Loss” PPT. For more details, see Chapter 3, pg. 19-20.

- ii. After going through the material above, move on to the case-based example.
 1. Ask for a volunteer from the group to read the example (see below and slide 24 on Session 2 PPT) and issues aloud, then pause for discussion and/or role-playing. See below for issues to consider and potential action plan for this case study.



Case-Based Example: Ms. Wilson

Ms. Wilson, age 60, seems to the staff to be actively dying. She is a long-term resident who has end-stage kidney disease on hemodialysis and advanced dementia. Her chronic illnesses have resulted in immobility and her food intake has drastically decreased. She has no advance directive and made no prior statements about her wishes for end-of-life care. Over the past several months she has had repeated episodes of low blood pressure, resulting in incomplete dialysis and repeated trips to the ER without improvement. In recent weeks, she has experienced episodes of pauses in her breathing. Her son wishes his mother to go on living and is resistant to any discussion that she might be terminally ill and that no treatments can reverse her decline. He is very attentive to her and has at times threatened to sue the AL when he feels her care is inadequate. He refuses a DNR order and wants “everything done” regarding treatment. Physicians at the hospital are frustrated by repeated ER visits by dying residents, have asked that the AL not send the resident back, and talk to the family member about signing a DNR.

When she is clean and comfortable in her own bed, Ms. Wilson seems at peace. However, she experiences discomfort when turned or moved and appears distressed each time she is sent to the ER. The AL staff acknowledge they do not know her wishes, but feel her present treatment is cruel and not in her best interest. They are deeply distressed about her being sent back and possibly dying in the ER.

Issues to Consider

- The staff feel they are at an impasse with the son, who is angry and grieving.
- Staff would like a way to authorize DNR and no further transfers to the hospital but feel helpless to change the present orders for her care.
- Ms. Wilson’s prognosis is clearly terminal, yet staff doubt that her son has accepted this situation.

- Pain management considerations and advance directives
 - Facilitator: This is not an exhaustive list of issues to consider and what is discussed during the session will be based on the responses provided by Nurse Interventionists.

iii. Conclusion of “Grief and Loss”

1. Conclude this section by reading through and discussing the action plan.

Action Plan for Ms. Wilson

- Staff plan to stop pushing the son for a DNR order, but instead work to acknowledge that son’s deep and loving commitment to his mother. Their discussions with him will have a different focus—on the shared goals of her physical comfort, hygiene, and psychological peace. They will discuss a DNR order again only if they feel that these other aspects of care are well managed and sense that he feels the same.
- The son is likely to know his mother’s prognosis, even if he is unable to admit it. Staff will stop saying “she is not doing well” and begin speaking directly about death by using the phrase “unfortunately, she seems to be dying.” They will acknowledge their own sorrow at this loss and ask the son how they can help him spend “special time” with his mother as she is dying.
- The physician will prescribe low-dose scheduled opioids to improve Ms. Wilson’s physical comfort.
- Staff will acknowledge the son’s grief and will provide support and emotional care.
- Staff will offer a referral to hospice and to a chaplain as a source of spiritual support for the son.



Emotional and Spiritual Care (28 min)

Review materials from Emotional and Spiritual Care Chapter

- a. Instructions to Facilitator
 - i. Lead assisted living staff through the following materials with time for questions and group discussions along the way (18 min).
 - ii. Remind participants that they can only work effectively with emotional and spiritual needs if they reflect on their own emotional state and religious beliefs and can distinguish between their needs and their

residents' needs. Note that a section of this module is relevant primarily to licensed nursing staff and medical prescribers.

2. Understanding emotional needs of dying persons
 - a. See slide 26 in "Emotional and Spiritual Care" PPT. For more details, see Chapter 7, pg. 62.
3. Long-term care residents and emotional and spiritual concerns
 - a. See slide 27 in "Emotional and Spiritual Care" PPT. For more details, see Chapter 7, pg. 63.
4. What are some of the emotional concerns of individuals near the end of life?
 - a. See slide 28 in "Emotional and Spiritual Care" PPT. For more details, see Chapter 7, pg. 61-62.
5. What are some of the spiritual concerns of individuals near the end of life?
 - a. See slide 29 in "Emotional and Spiritual Care" PPT. For more details, see Chapter 7, pg. 62.
6. What can you do to offer emotional support?
 - a. See slide 30-31 in "Emotional and Spiritual Care" PPT. For more details, see Chapter 7, pg. 63-64.
7. What can you do to offer spiritual support?
 - a. See slide 32-33 in "Emotional and Spiritual Care" PPT. For more details, see Chapter 7, pg. 64.
8. Issues to consider when helping residents with their emotional and spiritual needs
 - a. See slide 34-35 in "Emotional and Spiritual Care" PPT. For more details, see Chapter 7, pg. 65-66.
9. Things you should recognize as you work with dying residents
 - a. See slide 36-37 in "Emotional and Spiritual Care" PPT. For more details, see Chapter 7, pg. 66-67.
- iv. After going through the material above, move on to the case-based example.
 1. Ask for a volunteer from the group to read the example (see below and slide 38 on Session 2 PPT slides) and issues aloud, then pause for discussion and/or role-playing. During discussion, review issues to consider below.
 2. How would you recommend working with Ms. Barclay? Review action plan for Ms. Barclay (see below).



Case-Based Example: Ms. Barclay

Ms. Barclay, a 95-year old was forced to come to an assisted living several months ago because of chronic pain, falls and alcohol abuse.

She has chronic depression with mild dementia. She also has chronic constipation and bowel incontinence. She is fiercely independent and refuses help with toileting and personal care. She feels angry that, as she views it, her right to live independently has been violated. She refuses to accept psychiatric consultation and believes that everyone else residing in the AL has dementia. Her food and water intake are poor, and she remains in her room, refusing to interact with staff or other residents. Her family is supportive but feel their interactions with her are tense and not always helpful. The resident complains of pain under her right arm, and her nurse felt a mass in this area. Her physician ordered a mammogram and breast biopsy, which shows breast cancer with spread to the lymph nodes. The resident has not yet been told of this diagnosis. Medications include Nortriptyline 10 mg QhS, Vicodin 2 tablets q 6 hours, Percocet q 4 hours PRN, Sorbitol, Metamucil, Colace, and Ducolax. (See page 71 for issues to consider and action plan for Ms. Barclay)

Issues to Consider

- The resident is angry, depressed, refusing care, and in denial.
- Bowel incontinence and her unwillingness to accept help create problems for her skin, sanitations, and odor.
- Pain control is inadequate
- Ms. Barclay needs help with social isolation and poor quality of life
- She has so many needs it is hard to know how to begin. What is the first, best step that you as a team can take to improve care for this suffering resident?
 - Facilitator: This is not an exhaustive list of issues to consider and what is discussed during the session will be based on the responses provided by Nurse Interventionists.

iii. Conclusion of “Emotional and Spiritual Care” (12min)

3. Conclude the session by

- a. Reading through and discussing the action plan below (if time permits).

- b. Handing out Session 2 Quiz (no more than 7-10 min should be allotted for the quiz).
- c. Handing out the Session 2 homework (see below).
- d. Handing out the Session Two Fidelity Checklist (see below) to all Nurse Interventionist to complete (about 3 min should be allotted for this).

Action Plan for Ms. Barclay

First Steps:

- Establish a therapeutic relationship
 - Acknowledge that living in the assisted living is not how or where she wants to live, and that you know it is very hard for her.
 - Listen to what is most important to her, and promise to work with her to meet her needs.
- Treat her pain
 - Stop Vicodin and Percocet and begin a dose-equivalent, long acting opioid (e.g., MS Contin) plus a short-acting opioid to be increased as needed (e.g., morphine).

Next Steps

- A nurse who has a trusting relationship with Ms. Barclay asks her what she thinks is causing the pain under her arm and finds out how much she wants to know about her disease.
- CNAs acknowledge her need for independence and control by offering her meaningful choices in the daily care routine, such as when to bathe, what to wear, and where she will eat.
- The nurse practitioner orders an SSRI antidepressant to replace the Nortryptiline, which may be worsening her constipation and is not relieving her depression.
- Change medication for constipation after asking the resident what she thinks works for her and monitor results carefully. Offer a bedside commode to make toileting easier.

- Identify CNAs, nurses and other staff who have special relationship with resident. Create staffing patterns that make it easier for them to spend time with her.
- Know the resident as a person. She is dramatic and expressive, and you find out she used to do public poetry readings. Ask if she would like to hear poetry or do readings for other residents.
- Acknowledge the difficulty of her situation. Ask what has given her strength in the past and who has helped her when times were hard. Inquire about religious or spiritual beliefs.



PCEAL_RWD Session 2 Quiz

1. Which of the following is true about signs of actively dying?
 - A. Extremities are often warm to touch, mottled with a purplish color
 - B. Residents are alert and very communicative
 - C. Residents experience decreased appetite and thirst
 - D. Residents attempt to look their best

True or False

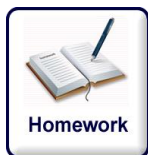
2. ____ Residents who have suffered for too long do achieve a good death
3. ____ Unresolved personal and spiritual conflicts do not help residents achieve a good death.
4. What is the first step toward good care at the end of life?
 - A. Encourage advance care planning
 - B. Educate residents about hospice and palliative care
 - C. Discuss treatment options
 - D. Effectively communicate about the resident's prognosis

True or False

5. ____ The ministry of presence is the most powerful comfort you can offer your residents and their family.
6. ____ While some residents with dementia are non-communicative, they can still respond to music, prayer, and touch.
7. How can you provide emotional and spiritual support to your residents? Select all that apply.
 - ☐ A. Help residents enjoy life and make the most of each day
 - ☐ B. Don't allow residents to be angry
 - ☐ C. Encourage them to reminisce
 - ☐ D. Allow residents choices in their care
 - ☐ E. Offer easy answers

Session 2 Quiz Answer Keys

1. C
2. False
3. True
4. D
5. True
6. True
7. A, C, D



Homework

RECOGNIZING AND RESPONDING TO THE FINAL PHASE OF LIFE

Identify one resident with dementia who is likely to die in the next few weeks or months and answer the following questions about the resident, thinking about ideal care for him/her during this time of preparation for dying.

1a. Please indicate one thing you could do to help the resident and family to make this time a special experience or to make the resident more comfortable.

1b. Take 5-10min to do the one thing you identified in 1a. How was the experience? What was the resident's response?

2. Based on what you know about the resident, indicate one change you could provide to meet an emotional or spiritual need and explain why you chose this for the resident. This might include:

- playing music that he/she prefers
- placing familiar objects with special meaning in his/her room
- inviting special visitors
- helping with a religious ceremony or ritual from the resident's own tradition
- offering a prayer or scripture reading
- sitting quietly or holding hands
- offering to organize a team of family and volunteers to sit with an actively dying resident who fears being alone
- offering to help him accomplish any last wishes
- Sharing memories
- Meals with family and friends

3. What steps or actions have you taken in the past that you have found to be most helpful in meeting the emotional and spiritual needs of residents that are actively dying?

4. How did the resident's care plan change to meet his/her emotional and spiritual needs?

PCEAL_RWD Session Two Fidelity Checklist for Nurse Interventionist

The objective of this checklist is to ascertain whether the learning objectives were met for Nurse Interventionists participating in the PCEAL_RWD Program. Please evaluate this session by checking the appropriate response for each of the following questions below:

Receipt of Curriculum

1. Did you learn to identify when a resident is nearing death? ☐ Yes ☐ No
2. Did you learn about the physical and emotional symptoms that Residents may exhibit as they prepare for their deaths? ☐ Yes ☐ No
3. Did you learn about issues that should be considered and prioritized among residents with dementia when nearing the final stages of life? ☐ Yes ☐ No
4. Did you discover how assisted living staff can be most helpful to residents' family members and friends when death is approaching? ☐ Yes ☐ No
5. Did you learn about strategies to employ to promote emotional and spiritual well-being with dying residents? ☐ Yes ☐ No

Delivery of Curriculum

1. Did the Facilitator collect and discuss Session 1 and 2 homework? ☐ Yes ☐ No
2. Did the Facilitator discuss ways to predict death and recognize the signs of active dying? ☐ Yes ☐ No
3. Did the Facilitator offer you an opportunity to ask questions, probe for clarity, and/or make connections to your practice? ☐ Yes ☐ No
4. Did the Facilitator discuss emotional and spiritual concerns that residents experience as death draws near? ☐ Yes ☐ No
5. Was the session well-paced and well-timed? ☐ Yes ☐ No

Overall, how would you rate this session? ☐ Poor ☐ Good ☐ Very Good ☐ Outstanding

Any other comments or suggestions?

SESSION 3: ADVANCE CARE PLANNING

Length: Time estimate: 90 minutes

Class Materials



Goals

- To describe and communicate the general aim or focus of advance care planning.
- To describe principles involved in advance care planning for residents with ADRD.

Objectives

- To provide nursing staff with knowledge and skills they can use to talk with residents and their families about goals of care and treatment choices.
- To understand the differences between aggressive treatment and comfort care; the family's role in the decision-making process for residents with dementia and cultural issues related to advance care planning.
- To provide nursing staff with tools that are specific to residents with dementia living in Florida.
- To train nurses about the advance care planning chart review protocol.
- To train nurses on the protocol for having the advance care planning discussion.

Outline



Prior to this session, Facilitator should prepare by learning the laws in your state on Living Wills, Health Care Powers of Attorney, and other end-of-life treatment decisions. Bring copies of advance care directives that are legal in your state. Know the policies and procedures for documenting these things in the AL facility itself. See Appendix D for Florida specific information and advance directive documents.

1. Welcome participants and hand out name tags, sign-in sheet, and pens/pencils (3min)
2. Collect/Discuss homework from last session (5min)



3. Handout PowerPoint presentations that correspond with session 3 (2min).
Session 3 consists of materials and resources from Chapter 4 from the book written by Henderson, Hanson and Reynolds (2003). Session 3 PPT slides can be found in Appendix F.



Advance Care Planning (75 min)

4. Review class materials about “Advance Care Planning” Chapter
 - a. Instructions to Facilitator
 - i. Discuss the following topics with Nurse Interventionists, taking questions and comments as they arise (40 min).
 1. What is advance care planning (ACP)?
 - a. See slide 4-5 in “Advance Care Planning” PPT. For more details, see Chapter 4, pg. 26.
 2. Advance care planning documents
 - a. See slide 6-8 in “Advance Care Planning” PPT.
 3. Who decides—resident or family?
 - a. See slide 9 in “Advance Care Planning” PPT. For more details, see Chapter 4, pg. 27.
 4. When do you start talking about advance care planning?
 - a. See slide 10 in “Advance Care Planning” PPT. For more details, see Chapter 4, pg. 28.
 5. Considerations with ACP and ADRD
 - a. See slide 11 in “Advance Care Planning” PPT.
 6. How ADRD changes the ACP process
 - a. See slide 12-13 in “Advance Care Planning” PPT.
 7. Importance of ACP discussions
 - a. See slide 14 in “Advance Care Planning” PPT.
 8. What can you say to residents and family members in your first discussion?

- a. See slide 15 in “Advance Care Planning” PPT. For more details, see Chapter 4, pg. 28-29.
- 9. End of life medical decisions
 - a. See slide 16-17 in “Advance Care Planning” PPT. For more details, see Chapter 4, pg. 30-31.
- 10. ADRD living will
 - a. See slide 18 in “Advance Care Planning” PPT.
 - b. Review content of the Dementia Living Will form (a copy is added in the session folder under resources).
 - c. Link: <https://empathhealth.org/wp-content/uploads/2018/05/Dementia-extension-FINAL.pdf>
- 11. ACP Video- (10 min)
 - a. See slide 19 in “Advance Care Planning” PPT.
 - b. Link: <http://www.bc.edu/centers/iaa/videos.html>
- 12. Physician’s Order for Life Sustaining Treatment
 - a. See slide 20 in “Advance Care Planning” PPT.
 - b. Link: <https://www.youtube.com/watch?v=zlqQgCBChn0&feature=youtu.be>
<https://polstfl.org/wp-content/uploads/2017/12/POLST-Form-July-10-2015.pdf>
- 13. Advance directives chart review and ACP discussion protocol checklist (25 min)
 - a. See slide 21-27 in “Advance Care Planning” PPT.
 - b. Copy of protocol checklists for Nurse Interventionist can be found in Appendix A.



Please stop to review Protocol Checklists and do the Mock Chart Activity (25 min)

Overview of Mock Chart Activity



There will be four mock chart case scenarios. The Facilitator will give each Nurse Interventionist one mock chart and a blank Chart Review of Advance Directives Protocol Checklist for Nurse Interventionist.

- 1) If there are more than four Nurse Interventionists in the session, have two nurses pair up, but both nurses in the pair have to fill out the protocol checklist and submit it to the Facilitator.
- 2) The Facilitator will monitor the activity and rate each Nurse Interventionist using the ACP Chart Review Answers and Checklist for Facilitators.



- 3) Large group discussion with the Facilitator reviewing the correct answers and discussion about incorrect answers on each Nurse Interventionist's Protocol Checklist for Chart Review of Advance Directives.
- 4) Role Play Activity for Nurse Interventionists to complete the Advance Directives and ACP Discussions Protocol Checklist for Nurse Interventionist.



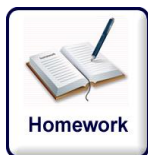
- 5) Have each nurse use the results based on the mock chart review for advance directives activity above to make ACP discussion phone calls for this role-play activity. The Nurse Interventionists will be in pairs and one Nurse Interventionist will play the part of the family member. The other nurse will play the role of the Nurse Interventionist. If there is an odd number of nurses, have the extra nurse join a pair of nurses and repeat the role play with the Nurse Interventionist to play the part of the family member or Nurse Interventionist. All Nurse Interventionists will be required to submit a completed Advance Directives and ACP Discussions Protocol checklist.
- 6) The Facilitator will monitor the activity and rate each Nurse Interventionist using the Checklist for Advance Directives and ACP Discussions.
 - a. A Chart Review Answer Key and Checklist to help guide Facilitators when rating the performance of each Nurse Interventionist will accompany each mock chart.



- 7) Large group discussion with the Facilitator about Nurse Interventionists' Protocol Checklist for Advance Directives and ACP Discussions.

Advance care planning presentation continues

14. Resources for ADRD residents
 - a. See slide 28 in “Advance Care Planning” PPT.
15. Additional resources
 - a. See slides 29 in “Advance Care Planning” PPT.
- ii. Conclusion of “Advance Care Planning” (5min)
 1. Finish the session with further discussion about working with residents and their families to establish advance care plans.
 2. Hand out the homework (see below).
 3. Handing out the Session Three Fidelity Checklist (see below) to all Nurse Interventionists to complete (about 3 min should be allotted for this).



Homework

ADVANCE CARE PLANNING

1. For this assignment, complete the Protocol Checklist Items for Chart Review of Advance Directives to identify at least one resident who needs updated advance directives.



For this activity, you will need to coordinate with the other Nurse Interventionists who attended Session 3 and refer to the current resident roster developed for this study in coordination with the PC Champion, in order to avoid duplication of resident chart reviews.

Remember that you will want to audio-record any ACP discussions, (refer to Do Not Call List for Study if family has explicitly said not to call) (see script and protocol for more details).

2. Complete the Protocol Checklist for Advance Directives and ACP Discussions for the person identified in Question 1.



Among the nurses who attended Session 3, each nurse should try to complete one ACP discussion by Session 4.

Copies of the protocols are located in your folder and additional copies can be obtained from your AL administrator.

PCEAL_RWD Session Three Fidelity Checklist for Nurse Interventionist

The objective of this checklist is to ascertain whether the learning objectives were met for Nurse Interventionists participating in the PCEAL_RWD Program. Please evaluate this session by checking the appropriate response for each of the following questions below:

Receipt of Curriculum

1. Did you learn how to communicate with residents and their families about goals of care and treatment choices? ☐ Yes ☐ No
2. Did you learn about the differences between aggressive treatment and comfort care? ☐ Yes ☐ No
3. Did you learn about the family's role in the decision-making process for residents with dementia and cultural issues related to advance care planning? ☐ Yes ☐ No
4. When the session ended, did you feel confident in your ability to implement the advance care planning chart review and discussion protocols? ☐ Yes ☐ No

Delivery of Curriculum

1. Did the Facilitator collect Session 2 and hand-out Session 3 homework? ☐ Yes ☐ No
2. Did the Facilitator communicate the general aim or focus of advance care planning? ☐ Yes ☐ No
3. Did the Facilitator discuss advance care planning consideration specific to dementia residents? ☐ Yes ☐ No
4. Did the Facilitator discuss tools/documents that are specific to residents with dementia living in Florida? ☐ Yes ☐ No
5. Did the Facilitator train you on the advance care planning chart review protocol/checklist? ☐ Yes ☐ No
6. Did the Facilitator train you on the protocol for having the advance care planning discussion/ phone call? ☐ Yes ☐ No
7. Was the session well-paced and well-timed? ☐ Yes ☐ No

Overall, how would you rate this session? ☐ Poor ☐ Good ☐ Very Good ☐ Outstanding

Any other comments or suggestions?

SESSION 4: HOSPICE, PALLIATIVE CARE SERVICES AND PAIN MANAGEMENT

Length: Time estimate: 90 minutes

Class Materials



Goals

- To educate participants about the services provided by hospice and the structure of hospice.
- To educate participants about approaches to pain screening and identification of screening tools.

Objectives

- To recognize when residents with dementia are experiencing pain and how to screen for pain and respond appropriately until a resident is comfortable.
- To educate about the differences in hospice care and eligibility criteria for patient with or without dementia.
- To recognize hospice as a vital resource for residents who are in need of pain and symptom management beyond what the assisted living staff can provide.
- To train nursing staff on the pain screening protocol.
- To complete case studies to help nurses determine best approach for pain screening with dementia patients.
- To understand the role of Palliative Care Champion at booster sessions and treatment fidelity checklist post intervention.

Outline

1. Welcome participants and hand out name tags, sign-in sheet, and pens/pencils (2min)
2. Collect/Discuss homework from last session (5min)



3. Handout PowerPoint presentations that correspond with session 4 (1min). Session 4 consists of materials and resources from Chapter 6 from the book written by Henderson, Hanson and Reynolds (2003). Session 4 PPT slides can be found in Appendix F.



Pain Management (10 min)

4. Review class materials about “Pain Management” Chapter
 - a. Instructions to Facilitator
 - i. Discuss the following topics with Nurse Interventionists, taking questions and comments as they arise.
 1. What are the barriers to treating pain?
 - a. See slide 4 in “Pain Management and the Role of Palliative and Hospice Care” PPT. For more details, see Chapter 6, pg. 47.
 2. Successful Pain Management
 - a. See slide 5-6 in “Pain Management and the Role of Palliative and Hospice Care” PPT. For more details, see Chapter 6, pg. 55-56.
 3. How can you assess pain in residents with dementia?
 - a. See slide 7 in “Pain Management and the Role of Palliative and Hospice Care” PPT. For more details, see Chapter 6, pg. 49-50.
 - b. For additional resources including pain scales see pg. 49-50 and Appendix E.

Nurses and Pain Management (40 min)

- a. Instructions to Facilitator
 - ii. Discuss the following topics with Nurse Interventionists, taking questions and comments as they arise.
 - 1. What are different types of pain and their causes?
 - a. See slide 9 in “Pain Management and the Role of Palliative and Hospice Care” PPT. For more details, see Chapter 6, pg. 51.
 - 2. Pain assessment with Dementia
 - a. See slide 10 in “Pain Management and the Role of Palliative and Hospice Care” PPT.
 - b. Please spend a few minutes to introduce the PAIN-AD (see Appendix E of this manual for pain scales).
 - 3. What are elements of a complete pain assessment
 - a. See slide 11 in “Pain Management and the Role of Palliative and Hospice Care” PPT. For more details, see Chapter 6, pg. 51-52.
 - 4. What are important issues in medication use?
 - a. See slide 12 in “Pain Management and the Role of Palliative and Hospice Care” PPT. For more details, see Chapter 6, pg. 52-53.
 - 5. Talking with Providers
 - a. See slide 13 in “Pain Management and the Role of Palliative and Hospice Care” PPT. For more details, see Chapter 6, pg. 52-53.



CNAs are often the people most likely to notice when a resident is acting differently or showing subtle signs of pain, since these extremely valuable staff members are the ones most often at the bedside. CNAs, therefore, play a crucial role in pain identification and relief. CNAs should take an active approach to helping residents with pain, reporting their observations to the Nurse Interventionists regularly and providing comfort measures to residents as often as possible.

- 6. Working with CNAs
 - a. See slide 14 in “Pain Management and the Role of Palliative and Hospice Care” PPT. For more details, see Chapter 6, pg. 53-54.

7. What comfort measures can CNAs provide?
 - a. See slide 15 in “Pain Management and the Role of Palliative and Hospice Care” PPT. For more details, see Chapter 6, pg. 53-54.
8. Helping residents with pain management
 - a. See slide 16 in “Pain Management and the Role of Palliative and Hospice Care” PPT. For more details, see Chapter 6, pg. 54-55, under “Remember the special role CNAs play in pain relief.”
9. Protocol Checklist for Pain Screening (5-10 min)
 - a. See slide 17-19 in “Pain Management and the Role of Palliative and Hospice Care” PPT. For a copy of the protocol checklist for pain screening used by Nurse Interventionists, see Appendix A.



Please stop to review Protocol Checklist for Pain Screening and do the Mock Chart Activity (25 min)

Overview of Mock Chart Activity



For the pain screening mock chart activity, use the same four mock chart case scenarios from Session 3. The Facilitator will give each Nurse Interventionist one mock chart and a blank Protocol Checklist for Pain Screening for Nurse Interventionist.

- 1) If there are more than four Nurse Interventionists in the session, have two nurses pair up, but both nurses in the pair have to fill out the protocol checklist and submit it the Facilitator.
- 2) Role Play Activity for Nurse Interventionists to complete the Protocol Checklist for Pain Screening for Nurse Interventionist.



- 3) Have each nurse use the results from Step 1, Chart Review for Identification of Pain Observation to conduct the pain screening for this role-play activity. The Nurse

Interventionists will be in pairs and one Nurse Interventionist will play the part of the resident. The other nurse will play the role of the Nurse Interventionist. If there is an odd number of nurses, have the extra nurse join a pair of nurses and repeat the role play with the Nurse Interventionist to play the part of the resident or Nurse Interventionist. All Nurse Interventionists will be required to submit a completed Protocol Checklist for Pain Screening for Nurse Interventionist.

- 4) The Facilitator will monitor the activity and rate each Nurse Interventionist using the Pain Chart Review Answers and Pain Screening Checklist for Facilitators.
 - a. A Chart Review Answer Key and Checklist to help guide Facilitators when rating the performance of each Nurse Interventionist will accompany each mock chart.



- 5) Large group discussion with the Facilitator reviewing the correct answers and discussion about incorrect answers on each Nurse Interventionists' Protocol Checklist for Pain Screening.

iii. Case Studies/Group Discussion (10 min)

1. Instructions for Facilitator

- a. Have someone in the group read the example and issues aloud, pausing for discussion along the way.
- b. See case study example (Slide 20), issues to consider and potential action plan below.



Case-Based Example: Ms. Miller

An elderly woman, Ms. Miller has been diagnosed with lung cancer. After some time, her disease spreads to her neck, which causes difficulty swallowing. She has mild dementia but can make her own care decisions. She also suffers from chronic pain, which has now become more severe. Facility staff have known her for years. She loves classical music and is deeply religious. She had an abusive marriage and tends to not talk about her own needs and avoids disturbing others. Staff describes her personality as very passive. Ms. Miller never says she is in pain and avoids answering a direct question such as 'Are you feeling any pain now?' Nurses who know Ms. Miller observe she is less physically active than in the past months. She is less willing to move from her bed to a chair and appears tired and withdrawn when they try to talk with her. Aides have reported

she grimaces during bathing but responds with gentle touch. These observations lead staff to agree that she is experiencing daily physical pain.

She has a DNR order, and the hospice team is providing additional palliative care and spiritual and emotional support. She has taken Percocet for back pain in the past but has recently received long-acting oxycodone 30mg PO BID plus oxycodone 10mg every 4 hours for breakthrough pain. This still does not seem to be enough.



Discuss and design a care plan for the team to treat Ms. Miller's pain.

Issues to Consider

- How can staff screen for pain, given that the resident does not like to complain and that she has mild dementia?
- What behaviors and expressions make CNAs and other staff think that Ms. Miller is in pain?
- Pain management needs to be improved and staff would like to change all medication to non-oral forms because of her difficulty swallowing.
- What comfort measures can staff use to help relieve Ms. Miller's pain?
- How will staff know when Ms. Miller's pain is relieved?
 - Facilitator: This is not an exhaustive list of issues to consider and what is discussed during the session will be based on the responses provided by Nurse Interventionists.

Action Plan for Ms. Miller

- A primary nurse is assigned who has won the trust of this resident. She tests several pain scales. A visual color-coded scale appears to work best, because it allows Ms. Miller to point and to avoid using the word "pain." All other staff agree to use this scale.
- The primary nurse contacts the physician and discusses her need for non-oral pain medication. She reports that Ms. Miller uses a total of 120mg of oxycodone per day, equivalent to 180mg of morphine. They discuss other options, and the physician tapers oral oxycodone and orders fentanyl 75mcg patch q72 hours with concentrated liquid morphine 10mg q2 hours as needed for breakthrough pain.

- Nurses let the CNAs know that they all are working together to relieve Ms. Miller's pain.
- Family members and assisted living volunteers agree to spend extra time with Ms. Miller to talk and play tapes of her favorite hymns.
- CNAs on every shift clean Ms. Miller's dry mouth with swabs moistened with water and apply moisturizer on her lips.
- CNAs offer to read the Bible or pray with her if they feel comfortable.
- After obtaining Ms. Miller's permission, the social worker notifies the resident's pastor about her condition and he visits. Ms. Miller also continues to receive supportive visits from the hospice chaplain.
- When CNAs go off shift, they pass on information to the new staff members about comfortable repositioning and the gentle touch that seems to help Ms. Miller.



Hospice and Palliative Care (30 minutes)

The following section on hospice care is not in the book; therefore, the PowerPoint will serve as your sole guide.

- a. Instructions to Facilitator
 1. Discuss the following topics with Nurse Interventionists, taking questions and comments as they arise.
 - c. Hospice Care
 - i. See slide 21 in "Pain Management and the Role of Palliative and Hospice Care" PPT.
 - d. History of Hospice and Palliative Care in the U.S.
 - i. See slide 22 in "Pain Management and the Role of Palliative and Hospice Care" PPT.
 - e. Palliative Care
 - i. See slide 23-24 in "Pain Management and the Role of Palliative and Hospice Care" PPT.
 - f. Interdisciplinary team
 - i. See slide 25 in "Pain Management and the Role of Palliative and Hospice Care" PPT.
 - g. Settings of Hospice and Palliative Care

- i. See slide 26 in “Pain Management and the Role of Palliative and Hospice Care” PPT.
- h. Levels of Hospice Care
 - i. See slide 27 in “Pain Management and the Role of Palliative and Hospice Care” PPT.
- i. Location of Deaths
 - i. See slide 28 in “Pain Management and the Role of Palliative and Hospice Care” PPT.
- j. When to refer to Hospice
 - i. See slide 29 in “Pain Management and the Role of Palliative and Hospice Care” PPT.
- k. Hospice Functional Assessment Staging Tool (FAST), criteria for end stage dementia
 - i. See slide 30-31 in “Pain Management and the Role of Palliative and Hospice Care” PPT.
- l. Review of Hospice care statistics
 - i. See slide 32-34 in “Pain Management and the Role of Palliative and Hospice Care” PPT.
- m. Benefits of Hospice among Dementia patients
 - i. See slide 35 in “Pain Management and the Role of Palliative and Hospice Care” PPT.
- n. Who pays?
 - i. See slide 36 in “Pain Management and the Role of Palliative and Hospice Care” PPT.
- o. Features and Benefits
 - i. See slide 37 in “Pain Management and the Role of Palliative and Hospice Care” PPT.
- p. Working with Patients
 - i. See slide 38 in “Pain Management and the Role of Palliative and Hospice Care” PPT.
- q. Working with Caregivers
 - i. See slide 39 in “Pain Management and the Role of Palliative and Hospice Care” PPT.
- r. Pain and Symptoms Management
 - i. See slide 40 in “Pain Management and the Role of Palliative and Hospice Care” PPT.
- s. Resources

- i. See slide 41 in “Pain Management and the Role of Palliative and Hospice Care” PPT.
- t. Post Intervention Procedures
 - i. See slide 42-44 in “Pain Management and the Role of Palliative and Hospice Care” PPT.
 - ii. Additional information is provided below.



Please stop to review Post-PCEAL_RWD Intervention Procedures

Post- PCEAL_RWD Intervention Procedures

Instructions for Nurse Interventionists

1. Nurses will need to use the three protocol checklists (advance directive chart review, advance directive and ACP discussions, pain screening) when providing care to their residents after the PCEAL_RWD training.
2. The Nurse Interventionists will audio-record (recorder provided by study team) all ACP discussions with LAR's verbal permission and pain screening protocols will be video-taped with LAR's verbal permission by a member of the study team.
 - a. Your AL administrator will have a list of residents whose LARs expressed they do not want their resident video-taped for the study. For those residents who have been identified as needing a pain screening who are not in the study, verbal consent of the resident's LAR will be obtained by the Nurse Interventionist for video-taping and documented in nurse's progress notes.
3. The Nurse Interventionists will need to monitor and record ACP calls completed on the weekly ACP calls tracking sheet/log. This form should be emailed to the research team.



Please note that timely completion of the tracking/log sheet will enable the study team to make swift changes about the audio-recording and the need to have more frequent site visits to observe ACP discussions/calls in real time.

4. Email your videos and audio-recordings on the same day they are completed to the research team at carlynvogel@mail.usf.edu. Your videos and audio-recordings will be reviewed by a Facilitator weekly and you will receive feedback from the Facilitator by phone within one week from submission date.
5. Protocol fidelity checks will continue throughout the study period to avoid interventionists drifting away from protocol.
6. Nurse Interventionists will need to attend booster sessions facilitated by the PC Champion at 2- and 4-month post PCEAL_RWD intervention in order to reinforce what was learned in the training program.
 - *Facilitator:* Please ensure that the PC Champion has the PC Champion informational form. Please provide a timeframe (suggested dates) for each booster session meeting.
7. **Location of Study Forms.** Each facility will need to designate a location where all forms from the PCEAL program will be stored. Study forms can be stored in resident charts, electronic health records, specified study binder and more. The study team will need to be informed of the location so that they can review needed documents during site visits.

Instructions for Facilitator

Treatment Fidelity

1. The Facilitator will score the ACP checklist for 10% of audio-recorded ACP discussions. So, for any deviations from the protocol the Facilitator will be able to discuss proper protocol and correct the interventionists.



A 90% threshold of adherence to protocol will need to be obtained by the Nurse Interventionist when rating their performance. The audio and video recordings will be checked by one additional independent rater from the study team.

2. Along with the study team, Facilitators will review weekly tracking sheet of ACP calls (Facilitators will receive completed forms via email from the research team).
3. All treatment fidelity data will be shared at regular biweekly project meetings between investigators and the Facilitator so that investigators can get feedback about how the intervention is going and modify protocols if necessary.
4. The Facilitator will closely monitor the Nurse Interventionists during treatment fidelity of 10% of residents for the protocol for pain screenings. The Facilitator will be evaluating the video-recording to assess adherence to protocol. A member of the study team will email video-recordings to the Facilitator.

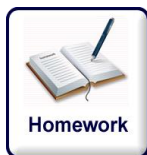
iv. Conclusion of “Pain Management and the Role of Palliative and Hospice Care” (2-5min)

1. After going through the material above, conclude the session with further discussion about pain management, palliative and hospice care.
2. Hand out the homework (see below).
 - a. Please inform Nurse Interventionists that they will need to hand in Session 4 homework to their designated PC Champion. Once homework is received, CEUs will be released.
3. Hand out the Post-test



Please don't forget to administer the ***Palliative Care Knowledge Post-test (10min)***. A member of the study team (principal investigator, research assistant) should be on site to help facilitate this. You will be informed in advance if a member of the research team cannot be present and will be provided with copies of the post-test prior to Session 4.

4. Hand out the Session Four Fidelity Checklist (see below) to all Nurse Interventionist to complete (about 3 min should be allotted for this).



Homework

PAIN MANAGEMENT: NURSES

Identify *one* resident who has not had a pain screening in the last 30 days and complete the Protocol Checklist for ***pain observation***.



For this activity, you will need to coordinate with your AL administrator/ or other nurses from the PCEAL_RWD to ensure that several nurses are not screening for pain on the same resident.

Remember, that you will want to video-record any pain screening, if LAR provides permission. Check with your AL administrator to determine which residents' LARs have given permission to be video-taped.



This homework will be the only homework turned in to the Palliative Care Champion at your facility.

Remember: Routine screening of all residents is important to find those who are in pain and to plan treatment.

PCEAL_RWD Session Four Fidelity Checklist for Nurse Interventionist

The objective of this checklist is to ascertain whether the learning objectives were met for Nurse Interventionists participating in the PCEAL_RWD Program. Please evaluate this session by checking the appropriate response for each of the following questions below:

Receipt of Curriculum

1. Did you learn to recognize when residents with dementia are experiencing pain and barriers to pain management? ☐ Yes ☐ No
2. Did you learn how to screen pain and respond appropriately until a resident is comfortable? ☐ Yes ☐ No
3. Did the Facilitator educate you about approaches to pain screening and identification of pain screening tools? ☐ Yes ☐ No
4. Did the Facilitator train you on the pain assessment protocol? ☐ Yes ☐ No
5. When the session ended, did you feel confident in your ability to implement the pain screening protocol? ☐ Yes ☐ No
6. Did you learn about the services provided by hospice and the structure of hospice? ☐ Yes ☐ No
7. Did you learn about the differences in hospice care and eligibility criteria for patient with or without dementia? ☐ Yes ☐ No
8. Did you learn about the benefits hospice can provide to residents? ☐ Yes ☐ No
9. Do you have a clear understanding of post-training activities and requirements? ☐ Yes ☐ No

Delivery of Curriculum

1. Did the Facilitator collect Session 3 and hand-out Session 4 homework? ☐ Yes ☐ No
2. Did the Facilitator discuss the role of the CNA in pain identification and relief? ☐ Yes ☐ No
3. Did the Facilitator discuss using hospice as a resource for residents who are in need of pain and symptom management beyond what the assisted living staff can provide? ☐ Yes ☐ No
4. Did the Facilitator discuss your role in implementing the protocols (advance care planning chart review, advance care planning discussion/phone call, and pain screening) after the end training program? ☐ Yes ☐ No
5. Did the Facilitator discuss the role of the 2-month and 4-month booster sessions completed with the palliative care champion at your AL? ☐ Yes ☐ No
6. Was the session well-paced and well-timed? ☐ Yes ☐ No

Overall, how would you rate this session? ☐ Poor ☐ Good ☐ Very Good ☐ Outstanding

Any other comments or suggestions?

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Appendix A: Protocol Checklists for Nurse Interventionists

School of Aging Studies

Palliative Care Education in Assisted Living for Care Providers of Residents with Dementia

Chart Review of Advance Directives Protocol Checklist for Nurse Interventionist

Facility ID:					Staff ID:						
Resident ID:					Date:						
						M	M	D	D	Y	Y

Name of Nurse Interventionist completing checklist _____
 Resident Name for Chart Review (if no ID): Last _____ First _____



School of Aging Studies, University of South Florida, 13301 Bruce B Downs Blvd., MHC 1300,
 Tampa, FL 33612
 Phone: (813) 974-2414 -- Fax: (813) 974-975

Instructions: This protocol is designed to assist the interventionist in identification of the appropriate person with whom to have an advance care planning conversation, either the actual resident if they are their own decision maker or a family member (e.g., durable health care proxy and if not, a designated primary caregiver). In addition, the protocol assists in triggering the interventionist to schedule an ACP conversation if the following conditions apply:

- A need to confirm current decisions made in advance directives (durable power of attorney, health care proxy, living will, Do Not Resuscitate, Do Not Hospitalize) if it has been more than two years.
- A need to complete new, or obtain existing, copies of any missing advance directives that should be in the chart.
- To schedule and have these ACP conversations within a timely manner (2-3 weeks) if triggered to be needed.

Check if completed	Protocol Checklist Items:
<input data-bbox="342 968 391 1003" type="checkbox"/>	<p>1. Identified from chart records who the legally authorized representative or next of kin is for medical decisions and (only one name should be listed below): Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Resident name and Room _____</p> <p>Legally authorized representative or next of kin's name and phone number _____</p>
<input data-bbox="342 1304 391 1339" type="checkbox"/>	<p>2. Records in chart indicate who health care surrogate is. Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>a. If yes, List name of health care proxy _____</p>
<input data-bbox="342 1514 391 1549" type="checkbox"/>	<p>3. Records in chart indicate who durable power of attorney is. Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>a. If yes, List name of durable power of attorney _____</p>

<input data-bbox="324 216 376 254" type="checkbox"/>	<p>4. Do Not Resuscitate and Living will located in the chart (not just indicated as "on file"). Living Will Yes <input type="checkbox"/> No <input type="checkbox"/> DNR Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>a. Date last completed _____</p>
<input data-bbox="324 426 376 464" type="checkbox"/>	<p>5. Were any of the above advance directives signed and completed in a state other than Florida. Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<input data-bbox="321 594 373 632" type="checkbox"/>	<p>6. Contact the legally authorized representative listed in #1 above in protocol checklist within 2 weeks if</p> <p>a. Questions #2, #3 or #4 above are no.</p> <p>b. any advance directives are more than two years since completion.</p> <p>c. Question #5 is yes.</p> <p>Please refer to the Treatment Fidelity Checklist for Advance Directives and ACP Discussions.</p>
	<p>7. Indicated the date of the meeting and if it was: In person <input type="checkbox"/> Phone call <input type="checkbox"/></p>

School of Aging Studies

Palliative Care Education in Assisted Living for Care Providers of Residents with Dementia

Advance Directives and ACP Discussions Protocol Checklist for Nurse Interventionist

Facility ID:

--	--	--

Staff ID:

--	--	--

Resident ID:

--	--	--

Date:

M	M	D	D	Y	Y

Name of Nurse Interventionist completing checklist: _____

Resident Name (if no ID): Last _____ First _____



School of Aging Studies, University of South Florida, 13301 Bruce B Downs Blvd., MHC 1300,
Tampa, FL 33612
Phone: (813) 974-2414 -- Fax: (813) 974-9754

Instructions: This checklist is designed to assess the adherence of ACP discussions and discuss advance directives with the person who is determined in the resident chart to be the durable power of attorney for healthcare or the legally authorized representative of the resident by the Nurse Interventionist. In addition, this checklist will enable the Nurse Interventionist to confirm that information on current advance directives documents are accurate and to update if needed. The interventionist will receive feedback on the adherence to the protocol and will be required to make adjustments if adherence is less than 90%.

Check if completed	Checklist Items:
<input type="checkbox"/>	1. Introduce self, inform resident's legally authorized representative about purpose of call, and obtain permission to audio record conversation. Purpose: Confirm they are the durable power of attorney and to learn about any changes to advance directives they may want to make for the resident.
<input type="checkbox"/>	2. Reassure residents' legally authorized representative that nothing is wrong. We try to have this conversation with residents' families on a regular basis. Clarify any initial questions families may have about purpose of call and advance directives.
<input type="checkbox"/>	3. Determine whether the intervention nurse explained the current status of the resident's living will and other advance care directives. a. Living Will Yes <input type="checkbox"/> No <input type="checkbox"/> – if no, recommend the POLST in item 4. b. Health Care Surrogate Yes <input type="checkbox"/> No <input type="checkbox"/> c. Durable Power of Attorney Yes <input type="checkbox"/> No <input type="checkbox"/> d. Do Not Resuscitate Yes <input type="checkbox"/> No <input type="checkbox"/> e. Do Not Hospitalize order Yes <input type="checkbox"/> No <input type="checkbox"/> f. Other (e.g., POLST) Yes <input type="checkbox"/> No <input type="checkbox"/>
<input type="checkbox"/>	4. Clarify if the legally authorized representative thinks the resident is able to be involved in the decision-making process. Yes <input type="checkbox"/> No <input type="checkbox"/> a. If yes, an in-person meeting was scheduled with the resident and LAR in the next 1-2 weeks to discuss completion of the living will. b. If no, ask if they would like to have more information about the POLST form. If yes to 4b, or would like to know more, set up a time to come in to meet. If not local, the conversation occurred on the phone and facilitation of copies of the advance directive documents were sent to review and follow-up meeting scheduled within one week.

<input type="checkbox"/>	<p>5. Determine if any of the above advance directives were signed and completed in a state other than Florida. Yes <input type="checkbox"/> No <input type="checkbox"/> If yes, recommend completing a Florida living will form.</p>																																							
<input type="checkbox"/>	<p>6. During any needed follow-up meeting in 1-2 weeks, review advance directives and indicate which advance directives document/decisions were updated if any:</p> <table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 60%;">a. Living Will</td> <td style="width: 20%;">Yes <input type="checkbox"/></td> <td style="width: 20%;">No <input type="checkbox"/></td> </tr> <tr> <td>b. Health Care Surrogate</td> <td>Yes <input type="checkbox"/></td> <td>No <input type="checkbox"/></td> </tr> <tr> <td>c. Durable Power of Attorney</td> <td>Yes <input type="checkbox"/></td> <td>No <input type="checkbox"/></td> </tr> <tr> <td>d. Do Not Resuscitate</td> <td>Yes <input type="checkbox"/></td> <td>No <input type="checkbox"/></td> </tr> <tr> <td>e. Do Not Hospitalize order</td> <td>Yes <input type="checkbox"/></td> <td>No <input type="checkbox"/></td> </tr> </table> <table style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 60%;"></th> <th style="width: 20%; text-align: center;"><u>Done</u></th> <th style="width: 20%; text-align: center;"><u>Under Discussion</u></th> <th style="width: 20%; text-align: center;"><u>Discussed/ Declined</u></th> </tr> </thead> <tbody> <tr> <td>a. Living Will</td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td>b. Health Care Surrogate</td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td>c. Durable Power of Attorney</td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td>d. Do Not Resuscitate</td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td>e. Do Not Hospitalize order</td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> </tbody> </table>	a. Living Will	Yes <input type="checkbox"/>	No <input type="checkbox"/>	b. Health Care Surrogate	Yes <input type="checkbox"/>	No <input type="checkbox"/>	c. Durable Power of Attorney	Yes <input type="checkbox"/>	No <input type="checkbox"/>	d. Do Not Resuscitate	Yes <input type="checkbox"/>	No <input type="checkbox"/>	e. Do Not Hospitalize order	Yes <input type="checkbox"/>	No <input type="checkbox"/>		<u>Done</u>	<u>Under Discussion</u>	<u>Discussed/ Declined</u>	a. Living Will	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	b. Health Care Surrogate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	c. Durable Power of Attorney	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	d. Do Not Resuscitate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	e. Do Not Hospitalize order	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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<input type="checkbox"/>	7. If under discussion, set up another follow-up meeting within two weeks.																																							
<input type="checkbox"/>	8. Clarify any updates and address concerns.																																							
<input type="checkbox"/>	9. Document in resident's chart phone conversation and outcomes and make copies of any changes for the legally authorized representative.																																							
<input type="checkbox"/>	10. During any follow-up meetings, document conversation and outcomes and make copies of any documents that were updated for the legally authorized representative.																																							

Script (for items necessary)

Checklist item #1: Hello, this is (Nurse Interventionist's name) at (AL's name) and I am calling about (resident's name) for who you are listed as the legally authorized representative (LAR) or next of kin in (his/her) chart. Is that correct? I want you to know that nothing is wrong with (resident's name), I am calling to see if I can discuss a project we are doing with the University of South Florida and part of the project is to discuss advance directives of residents with their legally authorized representatives. I anticipate it to take at least 10-15 minutes. Do you have time?

(If no, identify when would be a good time to contact this week).

(If yes, proceed) As part of this project, we would like to audio-record this conversation so that the project team can improve the way that we discuss issues related to advance directives with the legal representatives of AL residents. You may or may not have already consented to be audio-recorded. If you give your permission to be recorded, the recording will be used for research purposes only by the research team. Do you consent to being audio-recorded?

(If no, inform the representative that you respect their decision and will proceed with the conversation without audio-recording.)

❖ Start audio-recording here before proceeding with the script.

As I mentioned, I would like to discuss the current status of (resident's name) advance directives in his/her chart.

Checklist item #2: We want to assure you again that nothing is wrong, this is a conversation we try to have with all residents legally authorized representatives. We want to make sure that you are aware of all medical decisions made based on the information in (resident's name) advance directives, examples of these include the living will, health care surrogate and durable power of attorney. **(Have on hand brief description of each from slide 5, Session 3 power point, in the event a family member asks for clarification of what any of these advance directives are).**

Checklist item #3: We have on file a copy of (list/summarize advance directives on file and the dates completed and who signed the documents). We do not have a copy of (list/summarize the advance directives that are not file). Of those we do not have, are there originals that you are aware of that we could obtain?

Checklist item #4: What is your perception about the ability of (resident's name) to be involved in decisions about their medical care? Could (resident's name) be able to review a dementia specific living will under any circumstances (give examples of times of day he/she may be more alert and communicative; could they be with certain people present in the family)?

If yes, one of our hospice partners with Choices for Care of Empath Health in Clearwater, have developed a Dementia Living Will extension that we would recommend you review.

Link to Dementia Living Will:

<https://empathhealth.org/wp-content/uploads/2018/05/Dementia-extension-FINAL.pdf>

a. (determine if LAR is local and if so, use this script) If you would like to come in and meet with me to discuss it, we can review it together.

b. (If not local) I can send you the website address to download the document for free if you provide me with your email address.

If not, and you believe their preferences for care are not reflected accurately in the living will based on any discussions you may have had with (resident's name) in the past, there is a form in Florida that the patient's physician can complete with the health care surrogate known as the physician's order for life sustaining treatment or POLST, if you are interested to learn more.

Link to the Florida POLST:

<https://polstfl.org/wp-content/uploads/2017/12/POLST-Form-July-10-2015.pdf>

- a. (determine if LAR is local and if so, use this script) If you would like to come in and meet with me to discuss it, we can review it together.
- b. (If not local) I can send you the website address to download the document for free if you provide me with your email address.

Checklist item #5: In some cases advance directives from other states may not be valid and meet the requirements for Florida. We recommend (resident's name) have a Florida authorized living will on file with us.

- a. (determine if LAR is local and if so, use this script) If you would like to come in and meet with me to discuss it, we can review it together.
- b. (If not local) I can send you the website address to download the document for free if you provide me with your email address.

Checklist item #6: Are there any clarifications in (resident's name) chart that you would like to make about the decisions made in the living will? Or updates that you as the legally authorized representative/durable power of attorney feel need to be made to the documents?

Checklist item #9: In summary, today you decided to update the following advance directives (list/summarize any request made by the legally authorized representative), is that correct? Thank you for taking the time to talk with me about (resident's name) wishes and advance directives today. Do you have any other concerns or questions? (Please answer any questions or concerns they may have, and be sure to thank them at the end of the phone conversation, provide them with your number and email address, get their email address, so you can send an email reminder about any follow-up ACP meeting).

School of Aging Studies

Palliative Care Education in Assisted Living for Care Providers of Residents with Dementia

Pain Screening Protocol Checklist for Nurse Interventionist

Facility ID:		<table border="1" style="border-collapse: collapse; width: 100px; height: 40px;"> <tr> <td style="width: 33%; height: 30px;"></td> <td style="width: 33%; height: 30px;"></td> <td style="width: 33%; height: 30px;"></td> </tr> </table>					Staff ID:		<table border="1" style="border-collapse: collapse; width: 100px; height: 40px;"> <tr> <td style="width: 33%; height: 30px;"></td> <td style="width: 33%; height: 30px;"></td> <td style="width: 33%; height: 30px;"></td> </tr> </table>												
Resident ID:		<table border="1" style="border-collapse: collapse; width: 100px; height: 40px;"> <tr> <td style="width: 33%; height: 30px;"></td> <td style="width: 33%; height: 30px;"></td> <td style="width: 33%; height: 30px;"></td> </tr> </table>					Date:		<table border="1" style="border-collapse: collapse; width: 200px; height: 40px;"> <tr> <td style="width: 16.6%; height: 30px;"></td> <td style="width: 16.6%; height: 30px;"></td> <td style="width: 16.6%; height: 30px;"></td> <td style="width: 16.6%; height: 30px;"></td> <td style="width: 16.6%; height: 30px;"></td> <td style="width: 16.6%; height: 30px;"></td> </tr> <tr> <td style="text-align: center;">M</td> <td style="text-align: center;">M</td> <td style="text-align: center;">D</td> <td style="text-align: center;">D</td> <td style="text-align: center;">Y</td> <td style="text-align: center;">Y</td> </tr> </table>							M	M	D	D	Y	Y
M	M	D	D	Y	Y																

Name of Nurse Interventionist completing checklist: _____

Resident Name (if no ID): Last _____ First _____



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Appendix B: Fidelity Checklist for Facilitator and Fidelity Monitor

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Palliative Care Education in Assisted Living for Care Providers of Residents with Dementia

Chart Review of Advance Directives Scoring Sheet for Facilitator and Fidelity Monitor

Facility ID:					Staff ID:						
Resident ID:					Date:						
						M	M	D	D	Y	Y

Name of Fidelity Monitor/Facilitator completing checklist: _____

Resident Name for Chart Review (if no ID): Last _____ First _____



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Phone: (813) 974-2414 -- Fax: (813) 974-975

Instructions: This protocol is designed to assist the interventionist in identification of the appropriate person with whom to have an advance care planning conversation, either the actual resident if they are their own decision maker or a family member (e.g., durable health care proxy and if not, a designated primary caregiver). In addition, the protocol assists in triggering the interventionist to schedule an ACP conversation if the following conditions apply:

- A need to confirm current decisions made in advance directives (durable power of attorney, health care proxy, living will, Do Not Resuscitate, Do Not Hospitalize) if it has been more than two years.
- A need to complete new, or obtain existing, copies of any missing advance directives that should be in the chart.
- To schedule and have these ACP conversations within a timely manner (2-3 weeks) if triggered to be needed.

RATING: 1= no deviation from protocol
0 = deviation from protocol

Rating	Protocol Checklist Items:
<input type="checkbox"/>	<p>1. Identified from chart records who the legally authorized representative or next of kin is for medical decisions and (only one name should be listed below): Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Resident name and Room _____</p> <p>Legally authorized representative or next of kin's name and phone number _____</p>
<input type="checkbox"/>	<p>2. Records in chart indicate who health care surrogate is. Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>b. If yes, List name of health care proxy _____</p>
<input type="checkbox"/>	<p>3. Records in chart indicate who durable power of attorney is. Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>b. If yes, List name of durable power of attorney _____</p>

<input data-bbox="326 218 375 254" type="checkbox"/>	<p>4. Do Not Resuscitate and Living will located in the chart (not just indicated as "on file"). Living Will Yes <input type="checkbox"/> No <input type="checkbox"/> DNR Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>b. Date last completed _____</p>
<input data-bbox="326 428 375 464" type="checkbox"/>	<p>5. Were any of the above advance directives signed and completed in a state other than Florida. Yes <input type="checkbox"/> No <input type="checkbox"/></p>
<input data-bbox="326 596 375 632" type="checkbox"/>	<p>6. Contact the legally authorized representative listed in #1 above in protocol checklist within 2 weeks if</p> <p>a. Questions #2, #3 or #4 above are no.</p> <p>b. any advance directives are more than two years since completion.</p> <p>c. Questions #5 is yes.</p> <p>Please refer to the Treatment Fidelity Checklist for Advance Directives and ACP Discussions.</p>
	<p>7. Indicated the date of the meeting and if it was: In person <input type="checkbox"/> Phone call <input type="checkbox"/></p>
<p>Final Score: /7</p>	

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Palliative Care Education in Assisted Living for Care Providers of Residents with Dementia

Advance Directives and ACP Discussions Scoring Sheet for Facilitator and Fidelity Monitor

Facility ID:

--	--	--

Staff ID:

--	--	--

Resident ID:

--	--	--

Date:

M	M	D	D	Y	Y

Name of Fidelity Monitor/Facilitator completing checklist: _____

Resident Name (if no ID): Last _____ First _____



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Phone: (813) 974-2414 -- Fax: (813) 974-9754

Instructions: This checklist is designed to assess the adherence of ACP discussions and discuss advance directives with the person who is determined in the resident chart to be the durable power of attorney for healthcare or the legally authorized representative of the resident by the Nurse Interventionist. In addition, this checklist will enable the Nurse Interventionist to confirm that information on current advance directives documents are accurate and to update if needed. The interventionist will receive feedback on the adherence to the protocol and will be required to make adjustments if adherence is less than 90%.

RATING: 1= no deviation from protocol
0 = deviation from protocol

Rating	Checklist Items:
	1. Introduce self, inform resident's legally authorized representative about purpose of call, and obtain permission to audio record conversation. Purpose: Confirm they are the durable power of attorney and to learn about any changes in choices for medical care, hospice/palliative care, advance directives they may want to make for the resident.
	2. Reassure residents' legally authorized representative that nothing is wrong. We try to have this conversation with residents' families on a regular basis. Clarify any initial questions families may have about purpose of call and advance directives.
	3. Determine whether the intervention nurse explained the current status of the resident's living will and other advance care directives. <ul style="list-style-type: none"> a. Living Will Yes <input type="checkbox"/> No <input type="checkbox"/> – if no, recommend the POLST in item 4. b. Health Care Surrogate Yes <input type="checkbox"/> No <input type="checkbox"/> c. Durable Power of Attorney Yes <input type="checkbox"/> No <input type="checkbox"/> Do Not Resuscitate Yes <input type="checkbox"/> No <input type="checkbox"/> d. Do Not Hospitalize order Yes <input type="checkbox"/> No <input type="checkbox"/> e. Other (e.g., POLST) Yes <input type="checkbox"/> No <input type="checkbox"/>
	4. Clarified if the legally authorized representative thinks the resident is still able to be involved in the decision-making process. Yes <input type="checkbox"/> No <input type="checkbox"/> <ul style="list-style-type: none"> a. If yes, an in-person meeting was scheduled with the resident and LAR in the next 1-2 weeks to discuss completion of the living will. b. If no, ask if they would like to have more information about the POLST form. If yes to 4b, or would like to know more, set up a time to come in to meet. If not local, the conversation occurred on the phone and facilitation of copies of the advance directive documents were sent to review and follow-up meeting scheduled within one week.
	5. Determine if any of the above advance directives were signed and completed in a state other than Florida. Yes <input type="checkbox"/> No <input type="checkbox"/> If yes, recommend completing Florida living will form.

	6. During any needed follow-up meeting in 1-2 weeks, review advance directives and indicate which advance directives document/decisions were updated if any:																								
	<table> <tr> <td>a. Living Will</td><td>Yes <input type="checkbox"/> No <input type="checkbox"/></td></tr> <tr> <td>b. Health Care Surrogate</td><td>Yes <input type="checkbox"/> No <input type="checkbox"/></td></tr> <tr> <td>c. Durable Power of Attorney</td><td>Yes <input type="checkbox"/> No <input type="checkbox"/></td></tr> <tr> <td>d. Do Not Resuscitate</td><td>Yes <input type="checkbox"/> No <input type="checkbox"/></td></tr> <tr> <td>e. Do Not Hospitalize order</td><td>Yes <input type="checkbox"/> No <input type="checkbox"/></td></tr> </table>	a. Living Will	Yes <input type="checkbox"/> No <input type="checkbox"/>	b. Health Care Surrogate	Yes <input type="checkbox"/> No <input type="checkbox"/>	c. Durable Power of Attorney	Yes <input type="checkbox"/> No <input type="checkbox"/>	d. Do Not Resuscitate	Yes <input type="checkbox"/> No <input type="checkbox"/>	e. Do Not Hospitalize order	Yes <input type="checkbox"/> No <input type="checkbox"/>														
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j. Do Not Hospitalize order	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>																						
	7. If under discussion, set up another follow-up meeting within two weeks																								
	8. Clarify any updates and address concerns.																								
	9. Document in resident's chart phone conversation and outcomes and make copies of any changes for the legally authorized representative.																								
	10. During any follow-up meetings, document conversation and outcomes and make copies of any documents that were updated for the legally authorized representative.																								
Final Score: / 10																									

Script (for items necessary)

Checklist item #1: Hello, this is (Nurse Interventionist's name) at (AL's name) and I am calling about (resident's name) for who you are listed as the legally authorized representative (LAR) or next of kin in (his/her) chart. Is that correct? I want you to know that nothing is wrong with (resident's name), I am calling to see if I can discuss a project we are doing with the University of South Florida and part of the project is to discuss advance directives of residents with their legally authorized representatives. I anticipate it to take at least 10-15 minutes. Do you have time?

(If no, identify when would be a good time to contact this week).

(If yes, proceed) As part of this project, we would like to audio-record this conversation so that the project team can improve the way that we discuss issues related to advance directives with the legal representatives of AL residents. You may or may not have already consented to be audio-recorded. If you give your permission to be recorded, the recording will be used for research purposes only by the research team. Do you consent to being audio-recorded?

(If no, inform the representative that you respect their decision and will proceed with the conversation without audio-recording.)

❖ Start audio-recording here before proceeding with the script.

As I mentioned, I would like to discuss the current status of (resident's name) advance directives in his/her chart.

Checklist item #2: We want to assure you again that nothing is wrong, this is a conversation we try to have with all residents legally authorized representatives. We want to make sure that you are aware of all medical decisions made based on the information in (resident's name) advance directives, examples of these include the living will, health care surrogate and durable power of attorney. **(Have on hand brief description of each from slide 5, Session 3 power point, in the event a family member asks for clarification of what any of these advance directives are).**

Checklist item #3: We have on file a copy of (list/summarize advance directives on file and the dates completed and who signed the documents). We do not have a copy of (list/summarize the advance directives that are not file). Of those we do not have, are there originals that you are aware of that we could obtain?

Checklist item #4: What is your perception about the ability of (resident's name) to be involved in decisions about their medical care? Could (resident's name) be able to review a dementia specific living will under any circumstances (give examples of times of day he/she may be more alert and communicative; could they be with certain people present in the family)?

If yes, one of our hospice partners with Choices for Care of Empath Health in Clearwater, have developed a Dementia Living Will extension that we would recommend you review.

Link to Dementia Living Will:

<https://empathhealth.org/wp-content/uploads/2018/05/Dementia-extension-FINAL.pdf>

a. (determine if LAR is local and if so, use this script) If you would like to come in and meet with me to discuss it, we can review it together.

b. (If not local) I can send you the website address to download the document for free if you provide me with your email address.

If not, and you believe their preferences for care are not reflected accurately in the living will based on any discussions you may have had with (resident's name) in the past, there is a form in Florida that the patient's physician can complete with the health care surrogate known as the physician's order for life sustaining treatment or POLST, if you are interested to learn more.

Link to the Florida POLST:

<https://polstfl.org/wp-content/uploads/2017/12/POLST-Form-July-10-2015.pdf>

a. (determine if LAR is local and if so, use this script) If you would like to come in and meet with me to discuss it, we can review it together.

b. (If not local) I can send you the website address to download the document for free if you provide me with your email address.

Checklist item #5: In some cases advance directives from other states may not be valid and meet the requirements for Florida. We recommend (resident's name) have a Florida authorized living will on file with us.

- a. (determine if LAR is local and if so, use this script) If you would like to come in and meet with me to discuss it, we can review it together.
- b. (If not local) I can send you the website address to download the document for free if you provide me with your email address.

Checklist item #6: Are there any clarifications in (resident's name) chart that you would like to make about the decisions made in the living will? Or updates that you as the legally authorized representative/durable power of attorney feel need to be made to the documents?

Checklist item #9: In summary, today you decided to update the following advance directives (list/summarize any request made by the legally authorized representative), is that correct? Thank you for taking the time to talk with me about (resident's name) wishes and advance directives today. Do you have any other concerns or questions? (Please answer any questions or concerns they may have, and be sure to thank them at the end of the phone conversation, provide them with your number and email address, get their email address, so you can send an email reminder about any follow-up ACP meeting).

School of Aging Studies

Palliative Care Education in Assisted Living for Care Providers of Residents with Dementia

Pain Screening Treatment Fidelity Scoring Sheet for Facilitator and Fidelity Monitor

Facility ID:

--	--	--

Staff ID:

--	--	--

Resident ID:

--	--	--

Date:

M	M	D	D	Y	Y

Name of Fidelity Monitor/Facilitator completing checklist: _____

Resident Name (if no ID): Last _____ First _____



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Phone: (813) 974-2414 -- Fax: (813) 974-9754

Instructions: This checklist is designed to determine adherence to the pain screening protocol.

RATING: 1= no deviation from protocol
0 = deviation from protocol

Rating	Item
	Step 1. Chart Review for Identification of Pain Observation
<input type="checkbox"/>	1. Verified in the chart that the last recorded pain screening entered was more than 30 days?
<input type="checkbox"/>	2. Confirm with administrator if resident has a consent form to be video-taped and review list of eligible residents for pain chart review to make sure that it was not already completed for the resident.
<input type="checkbox"/>	3. If yes to video-taped consent, schedule a time with research team to do a video-taped pain screening within 48 hours.
<input type="checkbox"/>	4. If no, continue to conduct the pain observation by the end of your shift.
	Step 2. Pain Observation
<input type="checkbox"/>	1. Ask about discomfort and observe pain behaviors to determine whether pain is present.
<input type="checkbox"/>	2. For verbal residents, administer the visual pain scale informing the resident that zero is no pain and 10 meaning the worst possible pain.
<input type="checkbox"/>	3. For nonverbal residents, observe the resident for 5min and score the behaviors using the PAINAD.
<input type="checkbox"/>	4. Document the pain screening in the chart.
<input type="checkbox"/>	5. Determine whether the resident is currently taking medication to treat pain.
<input type="checkbox"/>	6. Communicate the resident's pain to the physician or other staff members (esp. if new onset).
<input type="checkbox"/>	7. Document what pain intervention was provided
<input type="checkbox"/>	8. Recommend alternative/nonpharmacological treatment and did they document this.
<input type="checkbox"/>	9. Update the resident's chart, if necessary.
<input type="checkbox"/>	10. Communicate any changes to pain management or care plan to the family.
<input type="checkbox"/>	11. Evaluate the resident's pain after treatment was provided to determine whether the resident reached their goal of pain relief.
Final Score /15	

Appendix C: Palliative Care Champion Form

School of Aging Studies

Palliative Care Education in Assisted Living for Care Providers of Residents with Dementia

Palliative Care (PC) Champion Form

Facility ID:

--	--	--

Staff ID:

--	--	--

Date:

M	M	D	D	Y	Y

Name of Nurse Interventionist completing form: _____



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The Role of the Palliative Care Champion and the PCEAL_RWD Study.

Thank you for agreeing to serve as your AL community Palliative Care Champion for the PCEAL_RWD Study in collaboration with the School of Aging Studies, USF, Tampa. Your role is very important for the study to document ways that the knowledge learned in the PCEAL educational sessions is applied.

For the study, you will coordinate a 30-minute 2 and 4-month follow-up with PCEAL_RWD trained staff members to discuss palliative care for your residents specific to: 1) ACP chart review; 2) ACP discussions and advance directives (updates to existing or newly completed) and 3) pain screening. You will need to reinforce the protocol. You will want to prompt the group to discuss challenges they have had in implementing the protocols.

For ACP discussions, the PC Champion will ask about the progress of ACP chart reviews, scheduling of ACP discussions, and completing of ACP discussion phone call using the ACP protocol checklists and how care practices have changed.

For pain screening, the PC Champion will ask about the use of the pain screening protocol, what tools they have been using to detect pain based on the PCEAL_RWD training and have they changed care practice behaviors? If so, in what ways? As PC Champion you will want to remind them to use the pain screening protocol when screening for pain in addition to what should be documented in the nurses notes.

For hospice, the PC Champion will ask if in the course of conducting ACP discussions and pain screenings, have they identified any residents who could benefit from a palliative care consult for pain and symptom management or a referral to hospice.

Please indicate your AL Facility Name _____

Please Indicate which follow-up post training this meeting is ____ 2 month follow-up ____ 4 month follow-up

Below is a checklist and space for you to document accomplishable tasks related to the above palliative care related outcomes.

1) Documentation of advance care planning discussions and advance directives:

Have staff had any ACP discussions post-PCEAL training using the protocol checklist? Have these discussions been documented? Are there challenges to using the two ACP protocol checklists? Identify a staff member (including yourself) to follow up with any gaps in care related to ACP discussions and documentation.

2) Detection and reporting of resident pain:

Have you been using the pain screening protocol? Are there challenges to using the pain screening protocol? Were different approaches taken related to detection and reporting of pain? What pain screening tools have you used? Identify a staff member (including yourself) to follow up with any gaps in care related to pain.

3) Referrals and admissions to palliative care and hospice.

Have any residents been identified as someone who would benefit from hospice care?
If so, has a referral been made? Identify a staff member (including yourself) to follow up with any gaps in care related to palliative care and hospice referral.

4) Any additional palliative care practices based on the PCEAL training that has occurred (e.g., bereavement care, spiritual and emotional support, social support)? Document in this section. Identify a staff member(s) (including yourself) to follow up with any gaps in care related to these additional areas of palliative needs.

Scan and return this form by email to ddobbs@usf.edu OR leave with your administrator to submit to Dr. Dobbs.

Thank you, PCEAL_RWD Research Team

Appendix D: Florida Advance Directive Information and Forms

Sample Advance Care Planning Discussion Guide

Case-Based Example: Mr. Garrett



Mr. Garrett, 65 years old, is admitted to the assisted living with severe emphysema. His “responsible party” is a great-niece who cares for him but has not provided direct personal care during his illness. He suffers from mild to moderate dementia, and although he can talk, his ability to make decisions is unclear. CPR was discussed with Mr. Garrett on admission, and he seemed unable to understand or make a consistent choice. He has since had several acute illnesses and during one episode he asked the staff not to send him to the hospital. At present he is a full code and is sent to the hospital every time he is acutely ill. In the past two weeks Mr. Garrett has stopped eating and drinking and complains that he feels too tired and too short of breath to eat. He does not complain of any other discomfort but talks about heaven and has said goodbye to several favorite staff members. Staff would like to ensure that Mr. Garrett has a peaceful death but fear that they will have to do CPR if he stops breathing. They believe hospice might be helpful.

Issues to Consider

- What treatment decisions need to be discussed and clarified?
- How do you determine whether or not someone who has dementia can make decisions? What role does his great-niece have in medical treatment decisions? What can staff tell about his wishes from the statements he has made?
- Can hospice be called in, or can assisted living staff develop a comfort care plan?



Do one or more advance care planning role-play based on this case. For example, ask one staff member to pretend she is Mr. Garrett, one to pretend she is the great-niece, and one to be the nurse who begins a discussion of advance care planning, using some of the ideas from the section “What can you say ...” Ask the participants to play their roles based on the ideal ways that residents, family members, and staff can discuss these hard issues. Alternatively, the script below can be used for the role-play:

Scene 1

Prior to entering Mr. Garrett's room, the nurse and the niece have a brief discussion about the dementia specific living will as a recommended form to use if they decide to update Mr. Garrett's advance directive.

Nurse: Thank you Linda for coming in today to discuss your uncle Joe. As mentioned during our previous phone call, the goals of today's discussion with your uncle will be to learn more about his medical preferences and how they may have changed since a recent hospitalization. I hope you have had a chance to review a copy of the Dementia Living Will form that I mentioned to you during our last conversation.

Two scenarios to consider from Linda's response:

Scenario One:

Linda: Yes. I've had a chance to review the living will.

Nurse: Do you have any questions or concerns at this time that you would like to discuss before we go see Mr. Garrett?

Linda: Not at this time.

Scenario Two:

Linda: No. I have not had a chance to review the living will.

Nurse: Would you like me to print a copy for you now and review the form with you?

Linda: Yes

Scene 2

The nurse and the niece Linda have reviewed the dementia living will and they are now in Mr. Garrett's room.

Nurse: I want to thank you for coming today to discuss Mr. Garrett's plan of care. Mr. Garrett, let's first have you explain if there are any concerns about your care.

Mr. Garrett: Well, I have been tired and I haven't felt like eating lately. I know I don't want to go to the hospital anymore. That place is not for me. They can't fix what is wrong with me. I am just coming to the end.

Niece: (to her uncle), You can't mean that Uncle Joe, if something is wrong with you, and the nurses and aides here can't help you, then the hospital is going to be the best place for you, what if something is wrong with your heart or you can't breathe or if you get out of bed in the middle of the night and have a fall?

Nurse: Mr. Garrett, we want to pay attention to what you want for your care. Are there certain medical treatments you do not want?

Mr. Garrett: I don't want to go to the hospital under any circumstances.

Nurse (to both Mr. Garrett and Niece): Just to clarify your wishes Mr. Garrett, that if something happened to you medically, you would want what we refer to as comfort measures only.

Mr. Garrett: That sounds about right, but can you tell me what that means.

Nurse: I have a form here that is the dementia specific living will, which can help explain what comfort measures only means, especially related to hospital care.

Mr. Garrett: Okay.

{Nurse proceeds to review the form and the section on the definition of comfort measures only and level of hospital care pg. 9}.

Nurse: I noticed that currently Mr. Garrett, you do not have an advance directive on file in your chart that reflects your preferences to not go to the hospital. You do not have what is known as a living will. You do have a health care surrogate, the person who makes healthcare decisions for you when you can't make them for yourself. That health care surrogate is your niece, Linda Jones. Ms. Jones, do you know Mr. Garrett's wishes in case he cannot speak for himself?

Niece: Well, I thought I did, but after this discussion, it is clear to me that the dementia specific living will can help document what Uncle Joe has indicated today, that he would want comfort measures only. If I hadn't heard him say it just now, I would have told you to send him to the hospital again, so I think we should have him complete the form now so that his wishes are clear when making future medical decisions.

Nurse: Mr. Garrett, when you first were admitted here a few months ago you were not interested in completing a living will. As your niece stated, now may be a good time to fill out the dementia specific living will form. Is this something you would like to do now?

Mr. Garrett and Niece: Yes, that is probably a good idea.

Nurse: Okay, I have brought a copy of the Dementia Living Will.

Health Care Advance Directives

The Patient's Right to Decide

Every competent adult has the right to make decisions concerning his or her own health, including the right to choose or refuse medical treatment.

When a person becomes unable to make decisions due to a physical or mental change, such as being in a coma or developing dementia (like Alzheimer's disease), they are considered incapacitated. To make sure that an incapacitated person's decisions about health care will still be respected, the Florida legislature enacted legislation pertaining to health care advance directives (Chapter 765, Florida Statutes). The law recognizes the right of a competent adult to make an advance directive instructing his or her physician to provide, withhold, or withdraw life-prolonging procedures; to designate another individual to make treatment decisions if the person becomes unable to make his or her own decisions; and/or to indicate the desire to make an anatomical donation after death.

By law hospitals, nursing homes, home health agencies, hospices, and health maintenance organizations (HMOs) are required to provide their patients with written information, such as this pamphlet, concerning health care advance directives. The state rules that require this include 58A-2.0232, 59A-3.254, 59A-4.106, 59A-8.0245, and 59A-12.013, Florida Administrative Code.

Questions About Health Care Advance Directives

What is an advance directive?

It is a written or oral statement about how you want medical decisions made should you not be able to make them yourself and/or it can express your wish to make an anatomical donation after death. Some people make advance directives when they are diagnosed with a life-threatening illness. Others put their wishes into writing while they are healthy, often as part of their estate planning.

Three types of advance directives are:

- A Living Will
- A Health Care Surrogate Designation
- An Anatomical Donation

You might choose to complete one, two, or all three of these forms. This pamphlet provides information to help you decide what will best serve your needs.

What is a living will?

It is a written or oral statement of the kind of medical care you want or do not want if you become unable to make your own decisions. It is called a living will because it takes effect while you are still living. You may wish to speak to your health care provider or attorney to be certain you have completed the living will in a way that your wishes will be understood.

What is a health care surrogate designation?

It is a document naming another person as your representative to make medical decisions for you if you are unable to make them yourself. You can include instructions about any treatment you want or do not

want, similar to a living will. You can also designate an alternate surrogate.

Which is best?

Depending on your individual needs you may wish to complete any one or a combination of the three types of advance directives.

What is an anatomical donation?

It is a document that indicates your wish to donate, at death, all or part of your body. This can be an organ and tissue donation to persons in need, or donation of your body for training of health care workers. You can indicate your choice to be an organ donor by designating it on your driver's license or state identification card (at your nearest driver's license office), signing a uniform donor form (seen elsewhere in this pamphlet), or expressing your wish in a living will.

Am I required to have an advance directive under Florida law?

No, there is no legal requirement to complete an advance directive. However, if you have not made an advance directive, decisions about your health care or an anatomical donation may be made for you by a court-appointed guardian, your wife or husband, your adult child, your parent, your adult sibling, an adult relative, or a close friend.

The person making decisions for you may or may not be aware of your wishes. When you make an advance directive, and discuss it with the significant people in your life, it will better assure that your wishes will be carried out the way you want.

Must an attorney prepare the advance directive?

No, the procedures are simple and do not require an attorney, though you may choose to consult one. However, an advance directive, whether it is a written document or an oral statement, needs to be witnessed by two individuals. At least one of the witnesses cannot be a spouse or a blood relative.

Where can I find advance directive forms?

Florida law provides a sample of each of the following forms: a living will, a health care surrogate, and an anatomical donation. Elsewhere in this pamphlet we have included sample forms as well as resources where you can find more information and other types of advance directive forms.

Can I change my mind after I write an advance directive?

Yes, you may change or cancel an advance directive at any time. Any changes should be written, signed and dated. However, you can also change an advance directive by oral statement; physical destruction of the advance directive; or by writing a new advance directive.

If your driver's license or state identification card indicates you are an organ donor, but you no longer want this designation, contact the nearest driver's license office to cancel the donor designation and a new license or card will be issued to you.

What if I have filled out an advance directive in another state and need treatment in Florida?

An advance directive completed in another state, as described in that state's law, can be honored in Florida.

What should I do with my advance directive if I choose to have one?

- If you designate a health care surrogate and an alternate surrogate be sure to ask them if they agree to take this responsibility, discuss how you would like matters handled, and give them a copy of the document.

- Make sure that your health care provider, attorney, and the significant persons in your life know that you have an advance directive and where it is located. You also may want to give them a copy.
- Set up a file where you can keep a copy of your advance directive (and other important paperwork). Some people keep original papers in a bank safety deposit box. If you do, you may want to keep copies at your house or information concerning the location of your safety deposit box.
- Keep a card or note in your purse or wallet that states that you have an advance directive and where it is located.
- If you change your advance directive, make sure your health care provider, attorney and the significant persons in your life have the latest copy.

If you have questions about your advance directive you may want to discuss these with your health care provider, attorney, or the significant persons in your life.

More Information On Health Care Advance Directives

Before making a decision about advance directives you might want to consider additional options and other sources of information, including the following:

- As an alternative to a health care surrogate, or in addition to, you might want to designate a durable power of attorney. Through a written document you can name another person to act on your behalf. It is similar to a health care surrogate, but the person can be designated to perform a variety of activities (financial, legal, medical, etc.). You can consult an attorney for further information or read Chapter 709, Florida Statutes.

If you choose someone as your durable power of attorney be sure to ask the person if he or she will agree to take this responsibility, discuss how you would like matters handled, and give the person a copy of the document.

- If you are terminally ill (or if you have a loved one who is in a persistent vegetative state) you may want to consider having a pre-hospital Do Not Resuscitate Order (DNRO). A DNRO identifies people who do not wish to be resuscitated from respiratory or cardiac arrest. The pre-hospital DNRO is a specific yellow form available from the Florida Department of Health (DOH). Your attorney, health care provider, or an ambulance service may also have copies available for your use. You, or your legal representative, and your physician sign the DNRO form. More information is available on the DOH website, www.doh.state.fl.us or www.MyFlorida.com (type DNRO in these website search engines) or call (850) 245-4440.

When you are admitted to a hospital the pre-hospital DNRO may be used during your hospital stay or the hospital may have its own form and procedure for documenting a Do Not Resuscitate Order.

- If a person chooses to donate, after death, his or her body for medical training and research the donation will be coordinated by the Anatomical Board of the State of Florida. You, or your survivors, must arrange with a local funeral home, and pay, for a preliminary embalming and transportation of the body to the Anatomical Board located in Gainesville, Florida. After being used for medical education or research, the body will ordinarily be cremated. The cremains will be returned to the loved ones, if requested at the time of donation, or the Anatomical Board will spread the cremains over the Gulf of Mexico. For further information contact the Anatomical Board of the State of Florida at (800) 628-2594 or www.med.ufl.edu/anatbd.
- If you would like to read more about organ and tissue donation to persons in need you can view the Agency for Health Care Administration's website <http://ahca.MyFlorida.com> (Click on "Site Map" then scroll down to "Organ Donors") or the federal government site www.OrganDonor.gov. If you have further questions you may want to talk with your health care provider.
- Various organizations also make advance directive forms available. One such document is "Five Wishes" that includes a living will and a health care surrogate designation. "Five Wishes" gives you the opportunity to specify if you want tube feeding, assistance with breathing, pain medication, and other details that might bring you comfort such as what kind of music you might like to hear, among other things. You can find out more at:

Aging with Dignity
www.AgingWithDignity.org
 (888) 594-7437

Other resources include:

American Association of Retired Persons (AARP)
www.aarp.org
 (Type "advance directives" in the website's search engine)

Your local hospital, nursing home, hospice, home health agency, and your attorney or health care provider may be able to assist you with forms or further information.

Brochure: End of Life Issues
www.FloridaHealthStat.com (Under Reports and Guides)
 (888) 419-3456

Florida Living Will

Declaration made this _____ day of _____, 2____, I, _____, willfully and voluntarily make known my desire that my dying not be artificially prolonged under the circumstances set forth below, and I do hereby declare that, if at any time I am mentally or physically incapacitated and

_____(initial) I have a terminal condition,
 or _____(initial) I have an end-stage condition,
 or _____(initial) I am in a persistent vegetative state,

and if my attending or treating physician and another consulting physician have determined that there is no reasonable medical probability of my recovery from such condition, I direct that life-prolonging procedures be withheld or withdrawn when the application of such procedures would serve only to prolong artificially the process of dying, and that I be permitted to die naturally with only the administration of medication or the performance of any medical procedure deemed necessary to provide me with comfort care or to alleviate pain.

I do ____, I do not ____ desire that nutrition and hydration (food and water) be withheld or withdrawn when the application of such procedures would serve only to prolong artificially the process of dying.

It is my intention that this declaration be honored by my family and physician as the final expression of my legal right to refuse medical or surgical treatment and to accept the consequences for such refusal.

In the event I have been determined to be unable to provide express and informed consent regarding the withholding, withdrawal, or continuation of life-prolonging procedures, I wish to designate, as my surrogate to carry out the provisions of this declaration:

Name _____
 Street Address _____
 City _____ State _____ Phone _____

I understand the full import of this declaration, and I am emotionally and mentally competent to make this declaration.

Additional Instructions (optional): _____

(Signed) _____

Witness _____	Witness _____
Street Address _____	Street Address _____
City _____ State _____	City _____ State _____
Phone _____	Phone _____

At least one witness must not be a husband or wife or a blood relative of the principal.

Definitions for terms on the Living Will form:

“End-stage condition” means an irreversible condition that is caused by injury, disease, or illness which has resulted in progressively severe and permanent deterioration, and which, to a reasonable degree of medical probability, treatment of the condition would be ineffective.

“Persistent vegetative state” means a permanent and irreversible condition of unconsciousness in which there is: The absence of voluntary action or cognitive behavior of any kind and an inability to communicate or interact purposefully with the environment.

“Terminal condition” means a condition caused by injury, disease, or illness from which there is no reasonable medical probability of recovery and which, without treatment, can be expected to cause death.

These definitions come from section 765.101 of the Florida Statutes. The Statutes can be found in your local library or online at www.leg.state.fl.us.

Florida Designation of Health Care Surrogate

Name: _____

In the event that I have been determined to be incapacitated to provide informed consent for medical treatment and surgical and diagnostic procedures, I wish to designate as my surrogate for health care decisions:

Name _____
 Street Address _____
 City _____ State _____ Phone _____
 Phone: _____

If my surrogate is unwilling or unable to perform his or her duties, I wish to designate as my alternate surrogate:

Name _____
 Street Address _____
 City _____ State _____ Phone _____

I fully understand that this designation will permit my designee to make health care decisions and to provide, withhold, or withdraw consent on my behalf; or apply for public benefits to defray the cost of health care; and to authorize my admission to or transfer from a health care facility.

Additional instructions (optional):

I further affirm that this designation is not being made as a condition of treatment or admission to a health care facility. I will notify and send a copy of this document to the following persons other than my surrogate, so they may know who my surrogate is.

Name _____

Name _____

Signed _____

Date _____

Witnesses 1. _____

2. _____

At least one witness must not be a husband or wife or a blood relative of the principal.

FLORIDA DURABLE POWER OF ATTORNEY

State of Florida

County of _____

KNOW ALL MEN BY THESE PRESENTS, that I, _____ (name), of
_____ (county) Florida, as authorized by Florida law, do hereby appoint,
_____ (name)

To manage and conduct my affairs. This power of attorney shall be non-delegable except as otherwise provided in Florida Statutes, and shall be valid and effective from date hereof until such time as I shall die or revoke the power. This durable power of attorney is not affected by subsequent incapacity of the principal except as provided in Florida Statutes.

The property subject to this durable power of attorney shall include all real and personal property owned by me, my interest in al property held in joint tenancy, my interest in all non-homestead property held in tenancy by the entirety, and all property over which I hold power of appointment and shall also include authority to sell, mortgage or convey my homestead property.

Without limiting the broad powers intended to be conferred by the preceding provisions, I expressly authorize my attorney acting hereunder in a fiduciary capacity to do and execute all or any of the following acts, deeds, and things for my benefit and on my behalf.

1. **COLLECTION POWERS:** To ask, demand, sue for, recover, collect, receive all sums of money, bank deposits, chattels and other real or personal property, tangible or intangible, of whatsoever nature or description that may be due, owing, payable or belonging to me, and to execute and deliver receipts, releases, cancellations or discharges.
2. **PAYMENT POWERS:** To settle any account or reckoning whatsoever wherein I now am or at any time hereafter shall be in any way interested or concerned with any person whomsoever, and to pay or receive the balance thereof as the case may require.
3. **SAFE DEPOSIT BOXES:** To enter any safe deposit or other place of safekeeping standing in my name with full authority to remove any and all the contents thereof and to make additions, substitutions and replacements, specifically including any safe deposit box in my name jointly with my spouse or any other person.
4. **BANKING POWERS:**
 - (a) To borrow any sum or sums of money on such terms and with such security, whether real or personal property belonging to me, as my attorney may think fit, and to execute any and all notes, mortgages and other instruments which my attorney may deem necessary or desirable.
 - (b) To draw, accept, make, endorse or otherwise deal with any checks, promissory notes, bills of exchange or other commercial or mercantile instruments, specifically including the right to make withdrawals from any savings account or building or loan deposits.

(c) To redeem or cash in any/or all bonds issued by the United States Government or any of its agencies, any other bonds and any certificates of deposit or other similar assets or securities belonging to me.

(d) To sell all or any bonds, shares of stock, warrants, debentures, or other securities belonging to me, and to execute all assignments and other instruments necessary or proper for transferring the same to the purchaser or purchasers thereof, and to give good receipts and discharges for all monies payable in respect thereof.

(e) To invest the proceeds of any redemptions or sales aforesaid, and any other of my monies, in such, bonds, shares of stock and other securities as my attorney shall think fit, and from time to time to vary the said investments or any of them.

5. MANAGEMENT POWERS: To vote at all meetings of stockholders of any company or corporation, and otherwise to act as my attorney or proxy in respect of my shares of stock or other securities or investments which now or hereafter shall belong to me, and to appoint substitutes or proxies with respect to any such shares of stock.

6. TAX POWERS: To sign and execute in my behalf any tax return, state or federal relating to income, gift, ad valorem, intangible or other taxes, state or federal, and to act for me in any examinations, audits, hearings, conferences or litigation relating to any such taxes, including authority to file and prosecute refund claims, and to enter into an effect any settlements.

7. TRUST POWERS:

(a) To execute a revocable or irrevocable trust which provides that all income and principal shall be paid to me or the guardian of my estate, or applied for my benefit in such manner as I or my attorney hereunder shall request or as the trustee shall determine, and that on my death any remaining assets, including income, shall pass according to my will or intestate succession if I have no will.

(b) To make additions of funds and assets, real and personal, to any trust established by me.

8. BUSINESS INTERESTS:

(a) To sell, rent, lease for any term, or exchange, any real estate or interests therein, for such considerations and upon such terms and conditions as my attorney may see fit; specifically including the power and authority to execute acknowledge and deliver deeds, mortgages, leases and other instruments conveying or encumbering title to property owned by me and my spouse jointly.

(b) To commence, prosecute, discontinue or defend all actions or other legal proceedings touching my estate or any part thereof, or touching any matter in which I or my estate may be in any way concerned.

(c) The powers herein conferred upon my attorney shall extend to and include all of my right, title and interest in and to any real and personal property, tangible or intangible, in which I may have an estate by the entirety, joint tenancy, tenancy in common, as trustee or beneficiary of any trust, or in any other manner.

9. PERSONAL INTERESTS:

(a) To make gifts, outright or in trust, in an amount not greater than \$10,000.00 per donee per year or the amounts allowed without gift tax consequences under

the appropriate Internal Revenue code provisions (including my attorney hereunder appointed).

(b) To arrange for my entrance to and care at any hospital, nursing home, health center, convalescent home, retirement home or similar institution.

(c) To renounce or disclaim any interest acquired by testate or intestate succession or by inter vivos transfer.

10. HEALTH CARE POWERS:

(a) To authorize, arrange for, consent to, waive and terminate any and all medical and surgical procedures on my behalf (including any election or election and agreement under the Life-Prolonging Procedures Act of Florida with request to providing, withholding or withdrawing life-prolonging procedures should I fail to make a declaration hereunder) and to pay or arrange compensation for my care.

(b) To make health care decisions for me and to provide informed consent if I am incapable of making health care decisions or providing informed consent.

(i) To be the final authority to act for me and to make health care decisions for me in matters regarding my health care during any period in which I have the incapacity to consent.

(ii) To expeditiously consult with appropriate health care providers to provide informed consent in my best interest and make health care decisions for me which my said Surrogate believes I would have made under the circumstances if I were capable of making such decisions.

(iii) To give any consent in writing using the appropriate consent form.

(iv) To have access to appropriate clinical records regarding me and have authority to authorize the release of information and clinical records to appropriate persons to insure the continuity of my health care.

(v) To apply for public benefits, where necessary, such as Medicare and Medicaid, for me and have access to information regarding my income and assets to the extent required to make such application if necessary.

(vi) To make all health care decisions on my behalf including but not limited to those set forth in F.S. Chapter 765.

11. GENERAL POWERS:

(a) In general to do all other acts, deeds, matters and things whatsoever in or about my estate, property and affairs, or to concur with persons jointly interested with me therein in doing all acts, deeds, matters and things herein particularly or generally described, as fully and effectually to all intents and purposes as I could do myself.

(b) This instrument is executed by me in the State of Florida but it is my intention that the powers and authority herein conferred upon my attorney as authorized by the laws of Florida now or hereafter in force and effect shall be exercisable in any other state or jurisdiction where I may have any property or assets.

I hereby ratify and confirm, and promise at all times to ratify and confirm all and whatsoever my duly authorized attorney hereunder shall lawfully do or cause to be done by virtue of these presents, including anything which shall be done between the revocation of this instrument by my death or in any other manner and notice of such revocation reaching my attorney; and I hereby declare that as against me and all persons claiming under me everything which my said attorney shall do or cause to be done in pursuance hereof after such revocation as aforesaid shall be valid and effectual in favor of any persons claiming the benefit thereof who, before the doing thereof, shall not have had notice of such revocation.

IN WITNESS WHEREOF, I have executed this Durable Power of Attorney.

Witness Signature Date

Signature Date

Witness Signature Date

Print Name

State of Florida
County of _____

Before me, the undersigned authority, duly authorized to take acknowledgements and administer oaths, personally appeared _____, personally known to me to be the person described above, who being by me first duly sworn states that (His or Her) is the person who executed the foregoing instrument for the reasons expressed therein.

Dated this _____ day of _____.

NOTARY PUBLIC _____

My Commission Expires: _____

The card below may be used as a convenient method to inform others of your health care advance directives. Complete the card and cut it out. Place in your wallet or purse. You can also make copies and place another one on your refrigerator, in your car glove compartment, or other easy to find place.

<h2 style="text-align: center;">Health Care Advance Directives</h2> <p>I, _____ have created the following Advance Directives:</p> <p>___ Living Will</p> <p>___ Health Care Surrogate Designation</p> <p>___ Anatomical Donation</p> <p>___ Other (specify) _____</p> <p style="text-align: center;">----- FOLD -----</p> <p>Contact:</p> <p>Name _____</p> <p>Address _____ _____ _____</p> <p>Phone _____</p> <p>Signature _____ Date _____</p>	
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Appendix E: Pain Scales

Pain Assessment in Advanced Dementia Scale (PAINAD)

Instructions: Observe the patient for five minutes before scoring his or her behaviors. Score the behaviors according to the following chart. Definitions of each item are provided on the following page. The patient can be observed under different conditions (e.g., at rest, during a pleasant activity, during caregiving, after the administration of pain medication).

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

(Warden et al., 2003)

Scoring:

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

Source:

Warden V, Hurley AC, Volicer L. Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *J Am Med Dir Assoc.* 2003;4(1):9-15.

PAINAD Item Definitions

(Warden et al., 2003)

Breathing

1. *Normal breathing* is characterized by effortless, quiet, rhythmic (smooth) respirations.
2. *Occasional labored breathing* is characterized by episodic bursts of harsh, difficult, or wearing respirations.
3. *Short period of hyperventilation* is characterized by intervals of rapid, deep breaths lasting a short period of time.
4. *Noisy labored breathing* is characterized by negative-sounding respirations on inspiration or expiration. They may be loud, gurgling, wheezing. They appear strenuous or wearing.
5. *Long period of hyperventilation* is characterized by an excessive rate and depth of respirations lasting a considerable time.
6. *Cheyne-Stokes respirations* are characterized by rhythmic waxing and waning of breathing from very deep to shallow respirations with periods of apnea (cessation of breathing).

Negative Vocalization

1. *None* is characterized by speech or vocalization that has a neutral or pleasant quality.
2. *Occasional moan or groan* is characterized by mournful or murmuring sounds, wails, or laments. Groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
3. *Low level speech with a negative or disapproving quality* is characterized by muttering, mumbling, whining, grumbling, or swearing in a low volume with a complaining, sarcastic, or caustic tone.
4. *Repeated troubled calling out* is characterized by phrases or words being used over and over in a tone that suggests anxiety, uneasiness, or distress.
5. *Loud moaning or groaning* is characterized by mournful or murmuring sounds, wails, or laments in much louder than usual volume. Loud groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
6. *Crying* is characterized by an utterance of emotion accompanied by tears. There may be sobbing or quiet weeping.

Facial Expression

1. *Smiling or inexpressive*. Smiling is characterized by upturned corners of the mouth, brightening of the eyes, and a look of pleasure or contentment. Inexpressive refers to a neutral, at ease, relaxed, or blank look.
2. *Sad* is characterized by an unhappy, lonesome, sorrowful, or dejected look. There may be tears in the eyes.
3. *Frightened* is characterized by a look of fear, alarm, or heightened anxiety. Eyes appear wide open.
4. *Frown* is characterized by a downward turn of the corners of the mouth. Increased facial wrinkling in the forehead and around the mouth may appear.
5. *Facial grimacing* is characterized by a distorted, distressed look. The brow is more wrinkled, as is the area around the mouth. Eyes may be squeezed shut.

Body Language

1. *Relaxed* is characterized by a calm, restful, mellow appearance. The person seems to be taking it easy.
2. *Tense* is characterized by a strained, apprehensive, or worried appearance. The jaw may be clenched. (Exclude any contractures.)
3. *Distressed pacing* is characterized by activity that seems unsettled. There may be a fearful, worried, or disturbed element present. The rate may be faster or slower.
4. *Fidgeting* is characterized by restless movement. Squirming about or wiggling in the chair may occur. The person might be hitching a chair across the room. Repetitive touching, tugging, or rubbing body parts can also be observed.
5. *Rigid* is characterized by stiffening of the body. The arms and/or legs are tight and inflexible. The trunk may appear straight and unyielding. (Exclude any contractures.)
6. *Fists clenched* is characterized by tightly closed hands. They may be opened and closed repeatedly or held tightly shut.
7. *Knees pulled up* is characterized by flexing the legs and drawing the knees up toward the chest. An overall troubled appearance. (Exclude any contractures.)
8. *Pulling or pushing away* is characterized by resistiveness upon approach or to care. The person is trying to escape by yanking or wrenching him- or herself free or shoving you away.
9. *Striking out* is characterized by hitting, kicking, grabbing, punching, biting, or other form of personal assault.

Consolability

1. *No need to console* is characterized by a sense of well-being. The person appears content.
2. *Distracted or reassured by voice or touch* is characterized by a disruption in the behavior when the person is spoken to or touched. The behavior stops during the period of interaction, with no indication that the person is at all distressed.
3. *Unable to console, distract, or reassure* is characterized by the inability to soothe the person or stop a behavior with words or actions. No amount of comforting, verbal or physical, will alleviate the behavior.

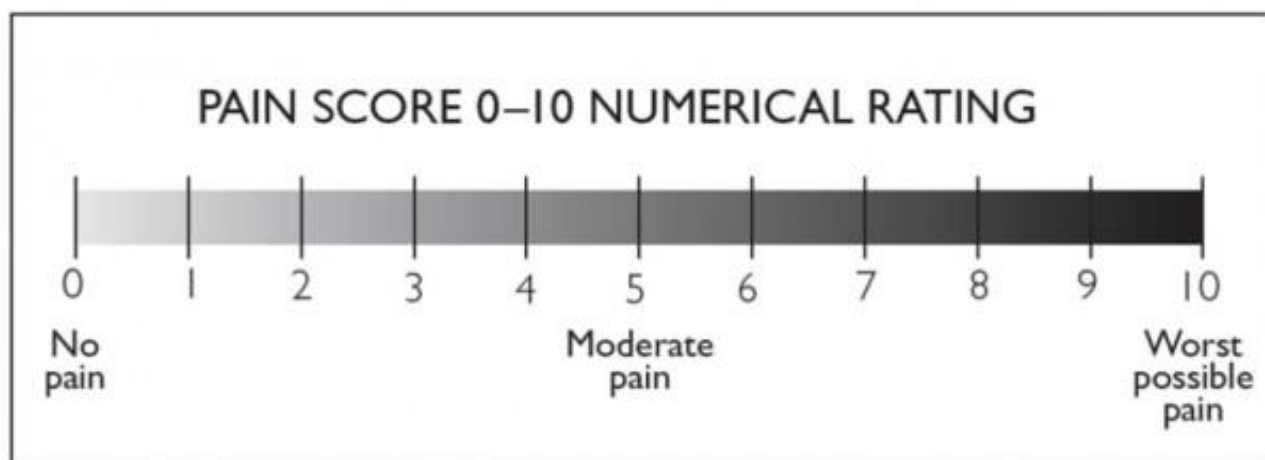
The Numeric Pain Rating Scale

Purpose

The Numeric Pain Rating Scale (NPRS) is a unidimensional measure of pain intensity in adults.

Content

The NPRS requires resident to select a whole number (0–10) that reflects the intensity of his/her pain. The 11-point numeric scale ranges from '0' representing one pain extreme (e.g. “no pain”) to '10' representing the other pain extreme (e.g. “worst pain imaginable”).



Appendix F: Session PPT Slides

Session 2 PPT

Recognizing the Final Phase of Life

Session Goals

- To better determine when residents with Alzheimer's disease or related dementia (ARD) are nearing the final stages of life so that we can provide high-quality end-of-life care in an assisted living community.
- To provide you with practical tools you can use to help people in their grieving processes.
- To understand the ways in which dying is much more than the death of a body.

Specific Objectives

- To identify when a resident is nearing death.
- To discuss ways to predict death and recognize the signs of active dying.
- To discuss some of the physical and emotional symptoms that residents may exhibit as they prepare for their deaths.
- Discover how assisted living staff can be most helpful to residents' family members and friends when death is approaching.
- To discuss emotional and spiritual concerns that individuals experience as death draws near

Who needs a comfort care plan?

- Residents with life expectancy of less than 6 months
- Residents about whom you can say, "I wouldn't be surprised if she died within the next year."
- Residents with an incurable, progressive disease
- Anyone who want a comfort care approach

How do we determine that someone is dying

- Identifying when current illness have become terminal
- With progressive decline, resident may recognize he is dying and begin to prepare for it.
- Recognizing the physical signs of actively dying

Signs death might be near

- Needs more assistance with ADL's
- Weight loss
- Shortness of breath
- Swallowing problems
- Congestive heart failure
- Advanced Alzheimer's with hip fracture or pneumonia

Communicating prognosis and palliative care goals

- Effective communication of prognosis is the first step toward good care at the end of life.
 - Start by asking for their concerns and fears
 - Provide the best estimate of prognosis
 - Provide information on what to expect as the illness unfolds
 - Let resident and family know that you sympathize with their grief and fear
 - Discuss treatment, care, and what is most important to the resident
 - Encourage them to do advance care planning
 - Offer hope in the form of palliative treatments and comforts

Benefits of Hospice

- Hospice provides specialized care to residents who meet criteria for terminal illness
- Provides expert pain and symptom management, emotional and spiritual care and supportive care after death
- Studies show that hospice can:
 - Improve family satisfaction with end-of-life care
 - Improve pain control
 - Decrease use of hospital transfers and physical restraint

Behaviors in the weeks to months before death

- Social withdrawal, less communication
or
- Desire to address old conflicts
- Increased sleep; decreased intake of food and water
- Postponing death until a special event occurs
- Saying good-bye

Signs of Actively Dying and Ways to Offer Comfort

- Coolness – extremities cool to touch, mottled, purplish color
- Less alert – drowsy, sleepy, hard to awaken, eyes open but not focused.
 - always assume the resident can hear, smell and feel.
 - Talk and touch gently, respectfully
 - Don't talk in the room as if the resident is absent.
- Terminal alertness – a spurt of energy and mental clarity shortly before dying.
 - Educate family about this possibility
 - Encourage family to take this time for good-byes

Signs of Actively Dying and Ways to Offer Comfort cont.

- Disorientation and delirium – confusion, possible hallucination
 - Reassure; offer orienting information if that is calming or go along with the resident's reality if that is more helpful
 - If very distressed, consider antipsychotic medication
- Restlessness – picking, pulling, turning
 - Use gentle massage, reassuring talk, music
 - Distinguish from delirium, pain or inadequate oxygen.
- Decreased intake – diminished appetite, thirst, ability to take food.
 - Offer sips, ice chips, provide good mouth care
 - If unable to swallow, give mouth care only.
 - This is only natural and usually does not cause suffering
- Incontinence, decreased urine output.
 - Use incontinence pads

Signs of Actively Dying and Ways to Offer Comfort cont.

- Distressing physical appearance or odor
 - Increase intensity of personal care for cleanliness
 - Provide daily hair and facial care to create more familiar appearance
 - Use oil of wintergreen in room for odor control
 - Bandage or cover distorted areas of the body
- Vital signs - blood pressure will drop, pulse, respirations and temperature will fluctuate.
- Breathing pattern may change

Comforting residents who are actively dying

- Provide warm blankets or clothing
- Always assume resident's sense of hearing and touch are intact
- Take advantage of all opportunities to communicate and love
- Offer reassuring talk
- Give good mouth care
- Help with personal cleanliness (being careful not to cause pain)

Comforting residents who are actively dying (continued)

- Breathing pattern – labored, irregular, cyclical, or shallow breathing may occur.
 - Treat for shortness of breath as needed
 - Give oxygen
 - Give low-dose morphine
 - Elevate head

Conclusion

- Predicting death is difficult.
- Work together as a team with the resident's physician/medical director to try to estimate and communicate to the family resident's prognosis.
- A hospice or palliative care referral can help clarify a terminal prognosis and create effective care plans for good end-of-life care.
- Know your facility's policy about dead body removal

Mr. Jones Case Study

Mr. Jones was admitted to assisted living three months ago with lung cancer and emphysema in addition to mild dementia after receiving rehabilitative care in a nursing home.

Mr. Jones' son is his surrogate decision-maker. Mr. Jones' care needs became too great after a few days in assisted living and he was rehospitalized with respiratory distress and dehydration. He was readmitted back to the assisted living after a few days. After a month's time, the resident was weaker, had lost weight and his mild disorientation has worsened. The son was angry about his father's failure to improve and asked the staff to consider another hospital admission.

Staff believed that Mr. Jones has had an adequate trial of rehabilitation and now think he is actively dying. They also think Mr. Jones understands this fact, although he hasn't said so. The son is hesitant to agree to a DNR order, and the physician, who has never met the son, does not want to become involved with an angry family member. The assisted living facility administrator asked the hospice team to do an evaluation, but the local hospice is uncomfortable about getting involved if the son refuses their services.

Grief and Loss:

Understanding and
Supporting Families

What do families want for their dying loved ones?

- Presence and support of staff
- Spiritual support
- Personal cleanliness/attention to details of their loved one's care
- Freedom from pain and discomfort
- Communication with staff

Why Some Residents Do Not Achieve a Good Death

- Too much suffering for too long
- Unresolved personal and spiritual conflicts
- No one to make decisions for them
- Lots of trouble breathing
- Tremendous pain

What can you offer grieving family members

- Be there
- Listen
- Offer your presence and concern
- Remember, for you a resident's death is somewhat common while for them it is a crisis.
- Encourage the saying of good-byes

What are some family stresses during the dying process?

- Feelings of sadness, anger, or guilt
- Difficulty balancing a dying person's needs with other demands
- Changing of family roles
- Practical issues such as finances and funeral arrangements
- Old family conflicts that can surface during times of crisis
- Concerns about quality of care

What can you do to help grieving family members

- Show family members how to touch or provide personal care for their loved ones
- Allow family members to give special, personalized care
- Listen to family members when they share their concerns or grief with you

What can you do to help grieving family members (continued)

- Recognize your own feelings
- Let family members know that you will provide the best care possible
- Attend funerals or other memorial services if possible
- Have memorial services at your facility; invite family members to attend

Case Study – Ms. Wilson

Ms. Wilson, age 60, seems to the staff to be actively dying. She is a long-term resident who has end-stage kidney disease on hemodialysis and advanced dementia. Her chronic illnesses have resulted in immobility and her food intake has drastically decreased. She has no advance directive and made no prior statements about her wishes for end-of-life care. Over the past several months she has had repeated episodes of low blood pressure, resulting in incomplete dialysis and repeated trips to the ER without improvement. In recent weeks she has experienced episodes of pauses in her breathing. Her son wishes his mother to go on living and is resistant to any discussion that she might be terminally ill and that no treatments can reverse her decline. He is very attentive to her and has at times threatened to sue the AL when he feels her care is inadequate. He refuses a DNR order and wants “everything done” regarding treatment. Physicians at the hospital are frustrated by repeated ER visits by dying residents and have asked that the AL not send the resident back and talk to the family member about signing a DNR.

When she is clean and comfortable in her own bed Ms. Wilson seems at peace. However, she experiences discomfort when turned or moved and appears distressed each time she is sent to the ER. The AL staff acknowledge they do not know her wishes, but feel her present treatment is cruel and not in her best interest. They are deeply distressed about her being sent back and possibly dying in the ER.

Emotional and Spiritual Care

Understanding Emotional Needs of Dying Persons

Kubler-Ross' Emotional Stages of Dying:

1. Denial – Resident cannot accept he/she is dying
2. Anger – can also be expressed as fear, resentment, frustration and a struggle with emotional and spiritual questions related to death.
3. Bargaining – trying to make a deal with God in order to avoid death or suffering
4. Depression – grief over past losses, disappointments and unfulfilled dreams, preparation for death; expressed as withdrawal, detachment. Not necessarily clinical depression.
5. Acceptance – can lead to a time of calm and peacefulness

Long Term Care Residents and Emotional and Spiritual Concerns

- Living-Dying Interval - Many residents have a long period of time between the knowledge they will die from their chronic illnesses and the experience of active dying.
- Focus on day-to-day living – Time becomes precious near death. Quality of life needs to be enhanced moment by moment. Want to focus on every day pleasures without a constant focus on dying.
- Racial and cultural differences – African Americans sometimes receive less pain control and poorer comfort care. Minority residents may require special attention to improve their care.

Some emotional concerns at the end of life

- How will I die?
- Will it be painful?
- Will I be taken care of?
- Will I be alone?
- What will happen to my family after I die?
- Are there things I want to do or say before I die?

Some spiritual concerns at the end of life

- Why am I dying?
- Where will I go after death?
- What has been meaningful about my life?
- How can I find meaning in my death?
- How can I be spiritually ready for my death?

How can you offer emotional support?

- Be with the resident and family – the ministry of presence is the most powerful comfort you can offer
- Reflect on your own emotional and spiritual response to the resident's situations and to dying in general.
- Listen with full attention and be sympathetic.
- Accept them, wherever they are, understanding that this is a difficult time for them

How can you offer emotional support? (continued)

- Help them enjoy life and make the most of each remaining day
- Allow them choices in routines and care
- Support special relationships the dying person has with staff, family, or friends

How can you offer spiritual support?

- Listen for spiritual language and concerns
- Don't offer "easy answers"
 - To hard questions – "What do you think?" "what feels right to you?"
- Allow questions and anger without judgment
- Offer prayers, sacraments, religious music, etc., that are special to the resident

How can you offer spiritual support? (continued)

- Offer to contact the resident's preferred clergy member or a hospice chaplain
- Encourage the resident and family to reminisce
- Assure the resident that she or he will not be abandoned or forgotten, and that they will be missed

Issues to consider

- Are you meeting the resident's physical needs?
 - Residents who are in pain, uncomfortable, or dirty will be less able to cope with their emotional and spiritual concerns
- Does the resident want to talk about his or her approaching death?
- What is the resident's cultural or religious background?

Issues to consider (continued)

- What is the resident's emotional and spiritual state?
- What are the resident's spiritual resources and inner strengths?
- Who are the resident's social supports?

As you work with dying residents, remember

- Even people who cannot talk about spiritual concerns (for example, someone with advanced dementia) can respond to music, prayer, or touch
- Residents who are angry or in denial are defending themselves from emotional pain; try to respect and support them, wherever they may be

As you work with dying residents, remember (continued)

- Each death is unique – think about what is individual about this resident's experience.
- Distinguish between your beliefs and the beliefs and needs of the resident
- Acknowledge—to residents, families, and yourself—the emotional and spiritual intensity of dying
- Excellent emotional and spiritual care creates good memories and promotes healing for family and staff

Case Study- Ms. Barclay

Ms. Barclay, a 95-year old was forced to come to an assisted living several months ago because of chronic pain, falls and alcohol abuse. She has chronic depression with mild dementia. She also has chronic constipation and bowel incontinence. She is fiercely independent and refuses help with toileting and personal care. She feels angry that, as she views it, her right to live independently has been violated. She refuses to accept psychiatric consultation and believes that everyone else residing in the AL has dementia. Her food and water intake is poor, and she remains in her room, refusing to interact with staff or other residents. Her family is supportive but feel their interactions with her are tense and not always helpful.

The residents complains of pain under her right arm, and her nurse felt a mass in this areas. Her physician ordered a mammogram and breast biopsy, which shows breast cancer with spread to the lymph nodes. The resident has not yet been told of this diagnosis. Medications include Nortriptyline 10 mg QhS, Vicodin 2 tablets q 6 hours, Percocet q 4 hours PRN, Sorbitol, Metamucil, Colace, and Dulcolax.

Session 3 PPT

Session 3: Advance Care Planning

Session Goals

- To describe and communicate the general aim or focus of advance care planning
- To describe principles involved in advance care planning for residents with Alzheimer's disease or related dementia (ADRD).

Objectives

- To provide nursing staff with knowledge and skills they can use to talk with residents and their families about goals of care and treatment choices.
- To understand the differences between aggressive treatment and comfort care; the family's role in the decision-making process for residents with dementia and cultural issues related to advance care planning.
- To provide nursing staff with tools that are specific to residents with dementia living in Florida.
- To train nurses about advance care planning chart review protocol
- To train nurses on the protocol for having the advance care planning discussion

What is Advance Care Planning (ACP)?

- Process of planning one's final phase of life
- Should be done *before* a health crisis occurs
- Includes thinking and discussing, looking at values and priorities
- Involves deciding what treatments one would want
- Involves documentation of treatment preferences in the event they become incapacitated and cannot make their own decisions.

ACP should result in a plan of care to:

- Make clear what treatments a resident wants or does not want (for example, CPR, hospitalization, tube feeding)
- Improve the resident's quality of life (for example, providing things the resident enjoys, offering comfort care, helping the resident to make the most of each and every day)
- Treatment preferences are usually expressed in Advance Directives
 - Living Wills - includes preferences about
 - Resuscitation
 - Ventilators
 - Nutrition and Hydration
 - Hospitalization
 - Antibiotic use
 - Durable Power of Attorney for financial matters
 - Durable Health Care Power of Attorney

Advance Directive

- Florida Statue Chapter 765 Definition
 - A witnessed written document or oral statement in which instructions are given by a principal or in which the principal's desires are expressed concerning any aspect of the principal's health care, and includes, but is not limited to, the designation of a health care surrogate, a living will, or an anatomical gift
 - Can be changed at anytime
 - Not the same as a physician order

Living Will

- A witnessed document in writing or a witnessed oral statement expressing instructions concerning providing, withholding, or withdrawing life prolonging procedures (CPR, mechanical ventilation, artificial nutrition/hydration, etc.) when the person has a terminal condition, an end stage condition, or is in a persistent vegetative state.
- Signed by the principal with two witnesses, one is neither a spouse nor a blood relative.
- May not reciprocate legally in different state or location (applies to all ACP documents)
 - AL nurse can help facilitate when necessary
 - May need to update or complete new documents

Health Care Surrogate (HCS)

- A written document designating a surrogate to make health care decisions and/or receive health information on behalf of a principal.
- Signed in the presence of two adult witnesses, one is not a blood relative, spouse, nor the HCS.
- May designate an alternative surrogate.
- If neither available, a proxy may be appointed.
- The surrogate may act upon determination of incapacity or immediately, as chosen by the principal.

Who decides—resident or family?

- Try to include both resident and family
- Even residents with dementia can express preferences and participate with family in discussions
- A Durable Health Care Power of Attorney or close family member can serve as a surrogate if residents cannot speak for themselves

When do you start talking about ACP

- Talk to new residents when he or she is admitted
 - The Patient Self-Determination Act of 1991 is a federal law requiring:
 - that all residents be asked on admission if they have:
 - a living will
 - A health care surrogate
 - Any kind of advance directive
 - That the answer to these questions be documented in medical records and communicated to health care staff
 - That all residents be offered information on their right to make decisions concerning medical care and their right to create an advance directive

Questions to consider with ACP and ADRD

- Is the patient with dementia excluded from the possibility of exercising the freedom of choice of his/her treatments?
- At what point should the living will be proposed to him/her so that s/he can fully express his/her wishes?
- Advance directives can be an option to minimize the prospective loss of autonomy.

How does ADRD change the ACP process?

- The person with ADRD may
 - Not be aware of their condition
 - Not understand the disease or how it progresses
 - Forget what you discussed or change their mind often; surprise you with new ideas or values
 - Tell different people different things
 - Become distrustful
 - Refuse to talk about their health . . . let alone dying
 - Refuse to sign anything
 - Agree with anything anyone tells them

How (else) does ADRD change the ACP process?

- Someone will likely have to be part of the support and decision-making process much earlier and much more actively
- Why? Possibly to:
 - Deal with the pharmacy & oversee medications
 - Observe and get treatment for things that the person with dementia has a hard time identifying or denies
 - Oversee doctor visits and hospital stays
 - Make decisions about what to treat, and how
 - Steer the person to get diagnosed in the first place
 - Deal with many non-medical issues that come up, such as . . .

Importance of ACP Discussions

- Gives a sense of control
- Patient's values/preferences vary and can be honored
- Can be used if unable to express decisions
- Can happen to anyone at any age
- Discuss before crisis occurs
- Encourage dialogue, discussion, and communication of values and choices
- Enables patient to consider end of life choices
- Allows one to introduce option for hospice if appropriate
- Most patients are comfortable talking about this topic
- Best if written

(Webster & Fedna, 2018)

What can you say?

- First time discussion --- “We ask all residents if they have a living will or a health care power of attorney. Do you have these? “
 - If yes, ask them to bring in the forms, when the last time they were updated, and what is her/his phone number.
 - If no, offer information and provide forms and notary service for facilitate completion of written advance directives.
- If resident is uncomfortable completing legal forms, ask “Can you identify a person you would trust to make health care choices for you if you become unable to do this for yourself?”
- Ask resident about her values, priorities, and goals of care
- Reassure residents and families: let them know that you will respect their decisions and that you will always provide the best comfort care possible

Discussing end-of-life medical decisions

- For discussion about medical treatments you can approach in the following manner, “When death is approaching, there are some treatment choices. If you prefer a “natural death” you should express this wish and ask that treatments be used only to assure your comfort. Or you may want to try to live as long as possible with the use of medical technology to prolong your life.”
- CPR is an attempt to restart heart and breathing. Is usually unsuccessful/ If resident survives, it offers no guarantee of recovering previous level of functioning.
- Ventilators

Discussing end-of-life medical decisions (continued)

- IV fluids and tube feedings provide nourishment when a person can no longer eat or drink.
- Useful when resident will recover from current illness or when waiting for a special event
- For a terminally ill resident, may prolong death and make resident less comfortable
- Dying people generally want very little to eat or drink. This is not painful and they are not hungry or thirsty.

ADRD Living Will

- Dementia Living Will
 - <https://empathhealth.org/wp-content/uploads/2018/05/Dementia-extension-FINAL.pdf>

Planning for End of Life

<http://www.bc.edu/centers/ioa/videos/end-of-life-plannin.html>

Physician's Order for Life Sustaining Treatment

- <https://www.youtube.com/watch?v=zlqQgCBChn0&feature=youtu.be>
- Review Florida Specific POLST
 - <https://polstfl.org/wp-content/uploads/2017/12/POLST-Form-July-10-2015.pdf>

Protocol Checklist

- Protocols are used to improve the process for nurses to identify who the primary care decision makers are, ascertain residents' ACP needs, and discuss necessary updates with family and residents.
- Two ACP Protocol Checklists
 - Protocol Checklist Items for Chart Review of Advance Directives
 - Protocol Checklist for Advance Directives and ACP Discussions

Chart Review of Advance Directives— Protocol Checklist

Check if completed	Protocol Checklist Items:
<input type="checkbox"/>	1. Identified from chart records who the legally authorized representative or next of kin is for medical decisions and (only one name should be listed below): Yes <input type="checkbox"/> No <input type="checkbox"/> Resident name and Room _____ Legally authorized representative or next of kin's name and phone number _____
<input type="checkbox"/>	2. Records in chart indicate who health care surrogate is. Yes <input type="checkbox"/> No <input type="checkbox"/> a. If yes, List name of health care proxy _____
<input type="checkbox"/>	3. Records in chart indicate who durable power of attorney is. Yes <input type="checkbox"/> No <input type="checkbox"/> a. If yes, List name of durable power of attorney _____

Checklist Items:													
1.	Introduce self, inform resident's legally authorized representative about purpose of call, and obtain permission to audio record conversation. Purpose: Confirm they are the durable power of attorney and to learn about any changes in choices for medical care, hospice/palliative care, advance directives they may want to make for the resident.												
2.	Reassure residents' legally authorized representative that nothing is wrong. We try to have this conversation with residents' families on a regular basis.												
3.	Determine whether the intervention nurse explained the current status of the resident's living will and other advance care directives. <table border="0"> <tr> <td>a. Living Will</td> <td>Yes <input type="checkbox"/> No <input type="checkbox"/> – if no, recommend the POLST in item 4.</td> </tr> <tr> <td>b. Health Care Surrogate</td> <td>Yes <input type="checkbox"/> No <input type="checkbox"/></td> </tr> <tr> <td>c. Durable Power of Attorney</td> <td>Yes <input type="checkbox"/> No <input type="checkbox"/></td> </tr> <tr> <td>d. Do Not Resuscitate</td> <td>Yes <input type="checkbox"/> No <input type="checkbox"/></td> </tr> <tr> <td>e. Do Not Hospitalize order</td> <td>Yes <input type="checkbox"/> No <input type="checkbox"/></td> </tr> <tr> <td>f. Other (e.g., POLST)</td> <td>Yes <input type="checkbox"/> No <input type="checkbox"/></td> </tr> </table>	a. Living Will	Yes <input type="checkbox"/> No <input type="checkbox"/> – if no, recommend the POLST in item 4.	b. Health Care Surrogate	Yes <input type="checkbox"/> No <input type="checkbox"/>	c. Durable Power of Attorney	Yes <input type="checkbox"/> No <input type="checkbox"/>	d. Do Not Resuscitate	Yes <input type="checkbox"/> No <input type="checkbox"/>	e. Do Not Hospitalize order	Yes <input type="checkbox"/> No <input type="checkbox"/>	f. Other (e.g., POLST)	Yes <input type="checkbox"/> No <input type="checkbox"/>
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d. Do Not Resuscitate	Yes <input type="checkbox"/> No <input type="checkbox"/>												
e. Do Not Hospitalize order	Yes <input type="checkbox"/> No <input type="checkbox"/>												
f. Other (e.g., POLST)	Yes <input type="checkbox"/> No <input type="checkbox"/>												
4.	Clarified if the legally authorized representative thinks the resident still has the capacity to be involved in the decision-making process. <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>a. If yes, an in-person meeting within was scheduled with the resident and LAR in the next 1-2 weeks to discuss completion of the living will.</p> <p>b. If no, ask if they would like to have more information about the POLST form.</p> <p>If yes to 4b, or would like to know more, set up a time to come in to meet. If not local, the conversation occurred on the phone and facilitation of copies of the advance directive documents were sent to review and follow-up meeting scheduled within one week.</p>												
5.	Determine if any of the above advance directives were signed and completed in a state other than Florida. Yes <input type="checkbox"/> No <input type="checkbox"/> <p>If yes, offer to assist the legally authorized representative to see if they would be accepted in Florida.</p>												

6. During any needed follow-up meeting in 1-2 weeks, review advance directives and indicate which advance directives document/decisions were updated if any:			
a.	Living Will	Yes <input type="checkbox"/> No <input type="checkbox"/>	
b.	Health Care Surrogate	Yes <input type="checkbox"/> No <input type="checkbox"/>	
c.	Durable Power of Attorney	Yes <input type="checkbox"/> No <input type="checkbox"/>	
d.	Do Not Resuscitate	Yes <input type="checkbox"/> No <input type="checkbox"/>	
e.	Do Not Hospitalize order	Yes <input type="checkbox"/> No <input type="checkbox"/>	
		<u>Under</u>	<u>Discussed/</u>
		<u>Done</u>	<u>Discussion</u>
a.	Living Will	<input type="checkbox"/>	<input type="checkbox"/>
b.	Health Care Surrogate	<input type="checkbox"/>	<input type="checkbox"/>
c.	Durable Power of Attorney	<input type="checkbox"/>	<input type="checkbox"/>
d.	Do Not Resuscitate	<input type="checkbox"/>	<input type="checkbox"/>
e.	Do Not Hospitalize order	<input type="checkbox"/>	<input type="checkbox"/>
7.	If under discussion, set up another follow-up meeting within two weeks		
8.	Clarify any updates and address concerns.		
9.	Document in resident's chart phone conversation and outcomes and make copies of any changes for the legally authorized representative.		
10.	During any follow-up meetings, document conversation and outcomes and make copies of any documents that were updated for the legally authorized representative.		

Mock Chart Review and Protocol Checklist Activity

Resources for ADRD Residents

- Dementia Road Map: Guide for Family and Care Partners
 - Search “ALISA Dementia Road Map” on the Internet and click on the link that is a pdf
- The Conversation Project’s “Starter Kit”
 - <https://theconversationproject.org/wpcontent/uploads/2017/02/ConversationProject-StarterKit-AlzheimersEnglish.pdf>
- End of Life Washington’s “Dementia Directive”
 - <https://endoflifewa.org/alzheimersdiseasedementia-advance-directive/>
- Dr. Gaster’s “Health Directive for Dementia”
 - <https://dementia-directive.org>
- End of Life Washington’s “Instructions for Oral Feeding and Drinking”
 - <https://endoflifewa.org/documents/>

(Webster & Fedna, 2018)

Additional ACP Resources

- <http://www.honoringchoicesfl.com/>
- <https://agingwithdignity.org/five-wishes>
- <http://theconversationproject.org/starter-kit/intro/>
- www.Polst.org

Session 4 PPT

Pain Management

And the Role of Palliative and
Hospice Care

Session Goals

- Goals To educate participants about the services provided by hospice and the structure of hospice.
- To educate participants about approaches to pain assessment and identification of assessment tools.

Specific Session Objectives

- To recognize when residents with dementia are experiencing pain and how to assess pain and respond appropriately until a resident is comfortable.
- To educate about the differences in hospice care and eligibility criteria for patient with or without dementia
- To recognize hospice as a vital resource for residents who are in need of pain and symptom management beyond what the assisted living staff can provide.
- To train nursing staff on the pain assessment protocol
- To complete case studies to help nurses determine best approach for pain assessment with dementia patients.
- To understand post PCEAL intervention requirements and activities.

What are barriers to treating pain?

- Misconception that pain is inevitable, is part of the aging process, and cannot managed
- Residents' unwillingness to "complain" about pain
- Fears about addiction
- **Most common barrier: Failure to ask about and assess pain**

Steps for successful pain management

- Ask every resident routinely!
- Use a pain scale if possible
- Observe the resident, looking for non-verbal clues
 - Changes in behavior, vital signs
 - Expressions of distress or withdrawal
- Review diagnoses—are any of them painful conditions?
- Review treatment history and current medications
- Use both medications and nondrug (complementary) treatments

Steps for successful pain management (continued)

- As a general rule, use scheduled meds instead of PRN meds
- Reassess pain after giving treatment
- Adjust treatment plan as needed
- Work as a team: CNAs, nurses, doctors, and other staff members each play an important role in successful pain management

How can you assess pain in residents with dementia?

- Ask them—4 out of 5 residents with dementia can report pain if asked
- Ask about pain “right now”
- Look for changes in
 - breathing
 - vocalizations
 - facial expressions
 - behaviors

Nurses and Pain Management

Different types of pain require different treatments

- Somatic—localized tissue discussion
 - e.g., arthritis, bone pain, pain after surgery, trauma
- Visceral—stretching internal organs
 - e.g., bowel obstruction, angina, urinary retention, constipation
- Neuropathic—injury to nerves
 - e.g., diabetic foot pain, shingles, pinched nerves

Pain Assessment with Dementia

- | | |
|--|--|
| <ul style="list-style-type: none"> • Self Report <ul style="list-style-type: none"> • Use in earlier stages of dementia only • Simple verbal or numerical categorical scales are recommended • In advanced dementia, consider a proxy rater (usually a primary caregiver) | <ul style="list-style-type: none"> • Behavioral Observation <ul style="list-style-type: none"> • Valuable approach • Assess facial expressions, body movements and vocalizations • Use pain assessment instruments <ul style="list-style-type: none"> • PAINAD • Distinguish pain behaviors from other behavioral symptoms |
|--|--|

Achterberg et al., 2013

Elements of complete pain assessment

- Know why a resident may have pain
 - Diagnoses, progression of a disease, acute problem
- Know the specifics of a resident's pain
 - Character, location, intensity, timing, aggravating/relieving factors, effect on function, physical assessment of pain site, know pain history and coping mechanisms
- Know the specifics of a resident's treatment
 - Current pain medications (dosage and schedule)

Important issues in medication use

- Scheduled dosing, not PRN
- Begin with short-acting dose. Once this works, switch to long-acting dose
- Use short-acting medications for breakthrough pain
- After giving medication, assess response
- Increase dose and/or frequency until desired effect is achieved or until the resident experiences side effects
- Give dose before pain becomes severe
- Bowel regimen starts when opioids start

Talking with Providers

- When you find that a resident is in pain, call her/his physician.
Be prepared to give:
 - vital signs
 - severity (use pain scale if possible)
 - problem list and description of pain
 - medications already tried
 - your suggestions for treatment
 - If pain and symptoms have become too difficult to manage, talk with physician about a referral for hospice or palliative care consult.

Working with CNAs

- Remember the vital role that CNAs play in pain management
 - They are at the bedside and often the first to notice signs of pain
- Encourage CNAs to report signs of pain
- Provide feedback to CNAs regarding changes in the treatment plan
- Encourage CNAs to provide feedback about effects of treatment
- CNAs' personal relationship with residents can be very helpful in pain management
- CNAs should take an active role in pain management

Examples of comfort measures CNAs can offer

- Supportive talk
- Gentle touch
- Music
- Soft lighting
- Decreased noise
- Warm or cold packs, if OKed by nurse
- Massage
- Repositioning
- Soothing activities
- Prayer and spiritual support
- Listening and conversation
- Favorite foods and drinks
- Help with personal cleanliness
- Reminiscing
- A walk

Helping residents with pain management

- Ask about both pain and discomfort
- Ask, "Where does it hurt?" "What makes it better?"
- Report what you observe to the nurse
- When you find something that works, let the CNA on the next shift know
- Work as a team with other staff members
- When pain becomes difficult to manage consider consulting with the nurse on your care team about the possibility of a referral to hospice.

Treatment Fidelity Protocol for Pain Screening

Check if completed	Item
Step 1. Chart Review for Identification of Pain Observation	
<input type="checkbox"/>	1. Verified in the chart that the last recorded pain screening entered was more than 30 days?
<input type="checkbox"/>	2. Confirm with administrator if resident has a consent form to be video-taped and review list of eligible residents for pain chart review to make sure that it was not already completed for the resident.
<input type="checkbox"/>	3. If yes to video-taped consent, schedule a time with research team to do a video-taped pain observation within 48 hours.
<input type="checkbox"/>	4. If no, schedule a time with a Facilitator to come and observe you conduct the pain observation within 48 hours.

Pain Screening (continued)

Check if completed	Items
Step 2. Pain Observation	
<input type="checkbox"/>	1. Ask about discomfort and observe pain behaviors to determine whether pain is present.
<input type="checkbox"/>	2. For verbal residents, administer the visual pain scale informing the resident that zero is no pain and 10 meaning the worst possible pain.
<input type="checkbox"/>	3. For nonverbal residents, observe the resident for 5min and score the behaviors using the PAINAD.
<input type="checkbox"/>	4. Document the pain screening in the chart.
<input type="checkbox"/>	5. Determine whether the resident is currently taking medication to treat pain.
<input type="checkbox"/>	6. Communicate the resident's pain to the physician or other staff members (esp. if new onset).
<input type="checkbox"/>	7. Document what pain intervention was provided.
<input type="checkbox"/>	8. Recommend alternative/nonpharmacological treatment and did they document this.
<input type="checkbox"/>	9. Update the resident's chart, if necessary.
<input type="checkbox"/>	10. Communicate any changes to pain management or care plan to the family.
	11. Evaluate the resident's pain after treatment was provided to determine whether the resident reached their goal of pain relief.

Mock Chart Review and Protocol Checklist Activity

Case Study: Ms. Miller

- An elderly woman, Ms. Miller has been diagnosed with lung cancer. After some time, her disease spreads to her neck, which causes difficulty swallowing. She has mild dementia but can make her own care decisions. She also suffers from chronic pain, which has now become more severe. Facility staff have known her for years. She loves classical music and is deeply religious. She had an abusive marriage and tends to not talk about her own needs and avoid disturbing others. Staff describes her personality as very passive. Ms. Miller never says she is in pain and avoids answering a direct question such as 'Are you feeling any pain now?'
- Nurses who know Ms. Miller observe she is less physically active than in the past months. She is less willing to move from her bed to a chair and appears tired and withdrawn when they try to talk with her. Aides have reported she grimaces during bathing but responds with gentle touch. These observations lead staff to agree that she is experiencing daily physical pain.
- She has a DNR order, and the hospice team is providing additional palliative care and spiritual and emotional support. She has taken Percocet for back pain in the past, but has recently received long-acting oxycodone 30mg PO BID plus oxycodone 10mg every 4 hours for breakthrough pain. This still does not seem to be enough.

Hospice Care

- Hospice is not necessarily a place, but a program of caring oriented toward the needs of patients who are terminal or in need of palliation and their families.
- The focus is on comfort rather than cure.
- On the contrary to “there is nothing more I can do”

History of Hospice and Palliative Care in the U.S.

❖ **1967:** Dame Cicely Saunders started St. Christopher's hospice in London, England
(<http://www.stchristophers.org.uk/about/history>)

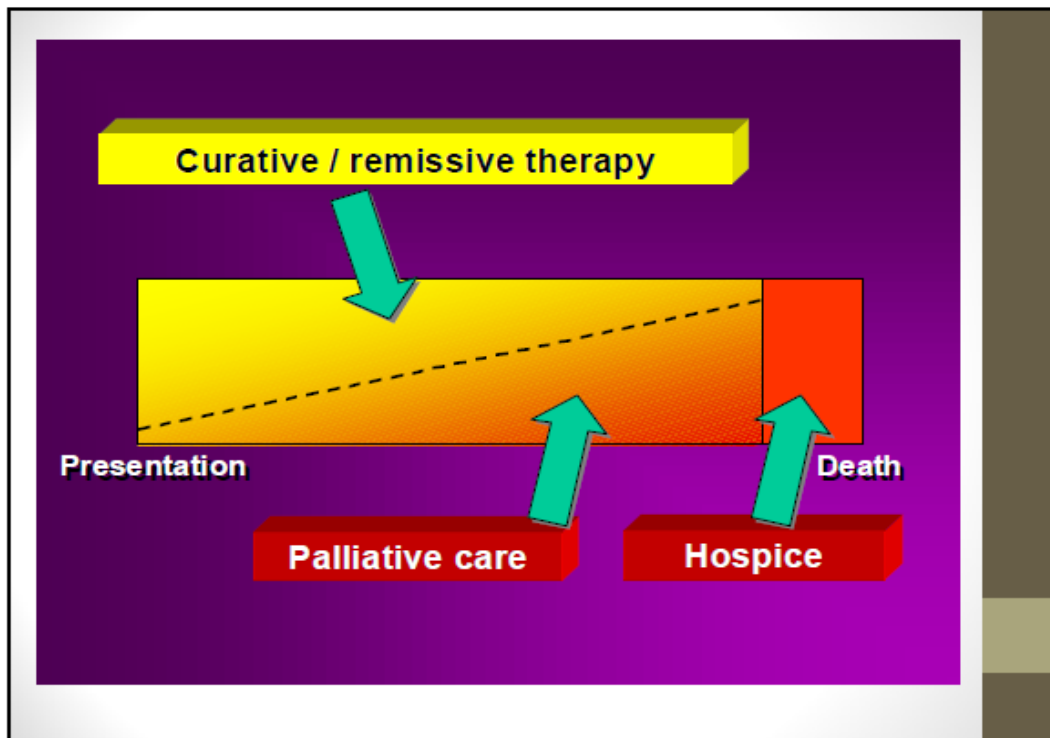
❖ **1974:** Florence Wald, along with two pediatricians and a chaplain, founded Connecticut Hospice in Branford, Connecticut.



Palliative Care

Palliative Care is an approach which improves quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain, and other, physical, psychosocial, and spiritual problems.

• World Health Organization, 2008



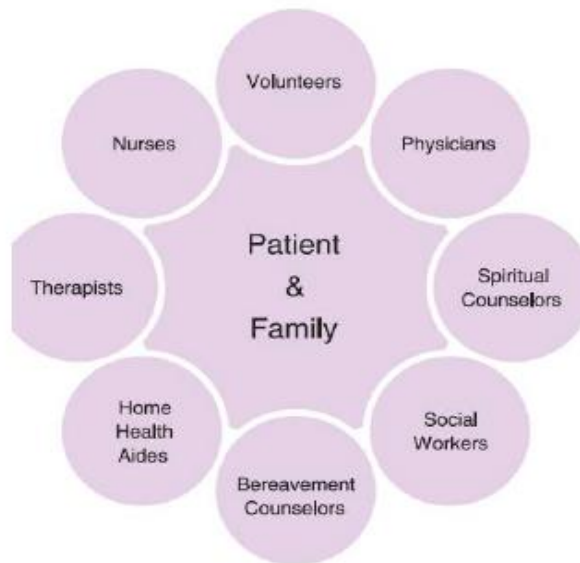


Figure 1. Interdisciplinary team

The Many Settings of Hospice and Palliative Care

- Home
- Hospital
- Assisted Living Facilities
- Extended Care Facilities
- Care Centers

Levels of Hospice Care

- Routine Hospice Care (RHC) is the most common level of hospice care. With this type of care, an individual has elected to receive hospice care at their residence.
- General Inpatient Care (GIP) is provided for pain control or other acute symptom management that cannot feasibly be provided in any other setting. GIP begins when other efforts to manage symptoms are not sufficient. GIP can be provided in a Medicare certified hospital, hospice inpatient facility, or nursing facility that has a registered nurse available 24 hours a day to provide direct patient care.
- Continuous Home Care (CHC) is care provided for between 8 and 24 hours a day to manage pain and other acute medical symptoms. CHC services must be predominately nursing care, supplemented with caregiver and hospice aide services and are intended to maintain the terminally ill patient at home during a pain or symptom crisis.
- Inpatient Respite Care (IRC) is available to provide temporary relief to the patient's primary caregiver. Respite care can be provided in a hospital, hospice facility, or a long term care facility that has sufficient 24 hour nursing personnel present.

National Hospice and Palliative Care Organization, 2018

TABLE 8. LOCATION OF DEATHS

Location of Death	Percentage
Home	44.6 %
Nursing Facility*	32.8 %
Hospice Inpatient Facility	14.6 %
Acute Care Hospital	7.4 %
Other	0.7 %

* Includes skilled nursing facilities, nursing facilities, assisted living facilities, and RHC days in a hospice inpatient facility.

National Hospice and Palliative Care Organization, 2018

When to Refer to Hospice

- When aggressive curative treatment is no longer effective, and when palliation of symptoms becomes the focus of care
- Would you be surprised?
- Patient's can often remain in ALF/ECF
- Who can refer to Hospice?

Hospice Functional Assessment Staging Tool (FAST), Criteria for end stage dementia

Hospice appropriate when **FAST** score is 7 or greater

Stage 6

6a Difficulty in putting clothes on properly without assistance

6b Unable to bath properly; may develop fear of bathing. Will usually require assistance.

6c Inability to handle mechanics of toileting (forgets to flush, doesn't wipe properly)

6d Urinary incontinence, occasional or more frequent

6e Fecal incontinence, occasional or more frequent

Hospice Functional Assessment Staging Tool (FAST), Criteria for end stage dementia

Stage 7

7a Ability to speak is limited to approximately 6 intelligible words or fewer, in the course of an average day or in the course of an intensive interview

7b Speech 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)

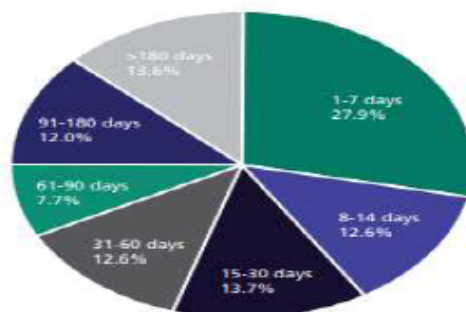
7c Ambulatory ability is lost (cannot walk without personal assistance)

7d Cannot sit up without assistance (patient would fall over without lateral support on the chair)

7e Loss of ability to smile

7f Loss of ability to hold up head independently

FIGURE 3. PROPORTION OF PATIENTS BY DAYS OF CARE IN 2016



In 2016 over half (54.2%) of patients were enrolled in hospice for 30 or fewer days.

National Hospice and Palliative Care Organization, 2018

TABLE 4. PERCENTAGE OF PATIENTS BY PRINCIPAL DIAGNOSIS

Principal Diagnosis	Percentage
Cancer	27.2 %
Cardiac and Circulatory	18.7 %
Dementia	18.0 %
Respiratory	11.0 %
Stroke	9.5 %
Other	15.6 %

National Hospice and Palliative Care Organization, 2018

TABLE 7. DAYS OF CARE BY PRINCIPAL DIAGNOSIS*

Principal Diagnosis	Mean # Days of Care	Median # Days of Care
Cancer	46 days	19 days
Cardiac and Circulatory	79 days	30 days
Dementia	104 days	54 days
Respiratory	71 days	21 days
Stroke	77 days	22 days
Other	62 days	16 days

*These values are computed using only days of care that occurred in 2016. Days of care have been combined for patients who had multiple episodes of care in 2016. Days of care occurring in other years are not included.

Benefits of Hospice among Dementia Patients

- Utilization of hospice increased in the past decade among AD/DRD patients (National Hospice and Palliative Care Organization, 2018)
- Benefits include:
 - Lower probability of hospitalization during the last 30 days of life
 - Higher probability of regular treatment for daily pain
 - Greater family satisfaction with care

(Kiely, Givens, Shaffer, Teno, & Mitchell, 2010; Shega, Hougham, Stocking, Cox-Hayley Sachs, 2008)

Who Pays?

- Medicare-86%
- Medicaid-5%
- Private Insurance-7%
- Charity-0.7%/9%
- Self Pay-0.8%
- Other-1%

[36]

Features & Benefits

- Symptom Management
- Medications and DME
- Holistic Care
- Patient Choice
- Bereavement follow-up for family and loved ones

Working with Patients

- Patient Autonomy
- Provide for symptom management
- Adequate pain control
- Unfinished Business
- Psychosocial issues
- Spiritual issues
- Quality of Life

Working with Caregivers

- Educate
- Signs and Symptoms
- Adequate Pain Management
- Bereavement Services



Pain and Symptom Management



- Pain – most problematic
- Physical
 - Dyspnea
 - Nausea and vomiting
 - Decreased level of consciousness
- Emotional
- Social
- Spiritual

Web Resources

- <http://hpna.org/Default2.aspx>[http://](http://www.nhpco.org/templates/1/homepage.cfm)
- www.nhpco.org/templates/1/homepage.cfm
- <http://www.aahpm.org/sites/index.html>
- <http://www.hospicefoundation.org/>
- <http://www.floridahospices.org/>

*Hospice educational materials courtesy of Suncoast Hospice, an entity of Empath Health, Clearwater, Florida.



Post Intervention Procedures

- Protocol Checklists
 - ACP Chart Review
 - ACP Phone call and Discussion
 - Complete weekly ACP calls tracking sheet/log
 - Phone conversation will be audio-recorded with LAR's permission
 - Pain assessment protocol
 - Will be video-taped by study team with LAR's permission
 - If there's no consent for video-tape, a Facilitator will be on site to observe pain screening.
- Booster Sessions at 2 and 4 months
 - Facilitated by Palliative Care Champion
 - Reinforce what was learned in the PCEAL program

Post Intervention Procedures

- **Location of Forms**
- All forms completed will need to be filed and stored in one systematic location
- Where will this facility stored the files?
 - Chart
 - Electronic Health Records
 - Study Binder
 - Other

Post-Test

- Please take 10-15 min to complete the demographic questionnaire and palliative care knowledge test