

The Resource Center



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Detecting Discomfort in Dementia: Focus on Behaviors

Tools for inservice education

Overview.....	2
Notes for introducing the video	3
Discussion Guide.....	5
Role-Play	8
Knowledge Test	13
Knowledge Test Answer Key.....	14

Detecting Discomfort in Dementia: Focus on Behaviors

Overview

Detecting Discomfort in Dementia: Focus on Behaviors is an educational video that provides a framework for and examples of behaviors that suggest the presence of discomfort in persons with dementia. It also suggests ways in which nursing assistants can help identify and contribute to the care of persons in pain.

The companion written materials provide the person responsible for staff education with tools to lead an educational session for a group of nursing assistants. The educator can use all of the materials or select a subset.

- *Notes for Introducing the Video*: an outline of discussion points to help frame the reasons why pain is an issue that requires attention in long-term care.
- *Discussion Guide*: questions to review the key concepts in the video
- *Role-Play*: scenarios that assist participants to work through communication and system issues. There are also follow-up questions to stimulate further discussion.
- *Knowledge Test*: A 6-item test to give before and after participants view the video to allow them to evaluate their knowledge.

Audience

The primary audience for the video is nursing assistants. It was created to educate, and also to acknowledge and affirm the key roles nursing assistants play in helping to identify and assure better care of residents in pain.

Adaptation for other audiences

RN/LPN Education

This video focuses on the role of the nursing assistant, and would not be appropriate as a standalone tool for RNs and LPNs. However, an educator could show excerpts of the examples of resident discomfort in this video, and follow-up with discussion and supplemental materials about pain screening, assessment and management. The American Geriatric Society Panel on Persistent Pain in Older Persons published a helpful reference in 2002: The management of persistent pain in older persons (*Journal of the American Geriatrics Society*, 50(6 Suppl), S205-S224.) In addition, the *Effective Pain Management Practices* video series available from The Resource Center (www.trc.wisc.edu, 608-262-0978) is a resource specifically designed for RN education on pain management.

Education for Culture Change Efforts

The nature of culture change efforts varies among facilities. Each educator will need to evaluate and adapt these tools for their specific efforts. Review and update your facility's policies, procedures, and current clinical practices for pain management to be sure they support the role of the certified nursing assistant in identifying and reporting pain. We have added questions for culture change education to the *Discussion Guide* and *Role-play*.

Non-nursing staff

Long-term care facilities engaged in culture change efforts often provide education that engages the entire staff, rather than having separate sessions for nursing assistants. The video and accompanying tools may be used for education of non-nursing staff that have contact with residents. See the suggestions for adapting the role-play and discussions included throughout the material.

Notes for introducing the video

If you are showing this video to a group, it is useful to give a brief introduction that frames the issue of pain and the particular challenge of detecting pain in the cognitively impaired. The outline below suggests a framework for this introduction.

1. Pain in long-term care
 - a. is common. Between a third and a half of residents have moderate to severe pain.
 - b. is often unreported and undertreated.
2. Many barriers stand in the way of good pain care in long-term care
 - a. Staff may:
 - not view pain as a patient care priority
 - be desensitized to pain and pain behaviors because pain is so common
 - attribute behaviors suggestive of pain or discomfort to other problems
 - have received little education about pain assessment and management
 - have mistaken beliefs about pain and pain medicines, especially about addiction
 - b. Residents may not seek help for pain because they believe that...
 - they should not complain
 - their pain can't be relieved
 - their reports of pain will not be believed if they do not have a physical deformity
 - their pain medicines will stop working
 - analgesic use is likely to lead to addiction, even though the actual risk is very low.
 - c. System issues:
 - pain is not a priority of care
 - lack of time to deal with pain problems
 - staff turnover
 - failure to recognize the adverse effects of pain on residents and staff
3. Pain Assessment
 - a. Licensed staff are responsible for pain assessment, but nursing assistants can help by screening for pain and pain behaviors. Nursing assistants can help by learning to recognize and report pain, and by continuing and expanding the many ways they provide comfort to residents.
 - b. Ask residents who are cognitively intact if they have pain and then believe them. Self-report is the most reliable indicator of the presence and intensity of pain. Even residents with mild dementia may be able to respond to questions about pain.
 - c. Identifying pain in persons with advanced dementia is a special challenge.
 - d. This video is designed to help nursing assistants recognize and report the behaviors that signal that a resident with advanced dementia has pain. Nursing assistants spend more time with residents than other staff, so they are key to helping make sure that residents get good care for their pain.

Notes about the video

- Certain practices are shown in the video that may not be allowed in some states or in some nursing homes. Some facilities always use gait belts; some allow nursing assistants to apply medicinal creams, others may not. Don't focus on these details. What's important is that nursing assistants learn to recognize potential pain behaviors

Detecting Discomfort in Dementia: Focus on Behaviors

and start to think about how they can help residents get the care they need to be comfortable.

- Culture Change: Review your facility's culture change efforts, and relate the importance of resident comfort to those efforts. If your culture change plan includes all staff as contributors to resident care, note that although the video focuses on the role of the nursing assistant, all staff can learn how to recognize the behaviors that signal that a resident may be in pain or discomfort and report those behaviors to direct care staff.

Discussion Guide

Discussion leader: The purposes of the discussion are to: 1) review and help participants integrate the major concepts in the video, and 2) discuss the impact of undertreated pain on the resident and the staff.

The stem of each of the items below provides the frame for the discussion points that follow. There are some sample questions for each discussion point. Don't read the text that follows each question out loud, but rather use it as a reference to guide the discussion.

If your facility has adopted a form for the assessment of discomfort in the cognitively impaired, make copies of the form to pass out to the nursing assistants. Relate the discussion to the language on the form.

1. Think of the residents you have cared for in the past several days. What behaviors have you seen that might signal that the resident is in pain?

What behaviors were shown in the video?

or.....What behaviors are listed on our form?

- Guide the group members to organize their understanding of the behaviors they have observed by relating them to your facility's assessment form, or to the behaviors as they were organized in the video:
 - Sad, or frightened facial expressions, grimacing
 - Agitated or rigid body language
 - Changes in behavior or routines
 - Irritable or withdrawn mood, confusion
 - Moaning, calling out, crying

Can you list some behaviors that are not as obvious, but still might mean discomfort?

- Some behaviors are more obviously related to pain (moaning, saying "ouch," rubbing), but there are also less obvious cues. Further assessment may show that these behaviors are due to another problem, but often these occur because of pain:
 - Physical or verbal aggression
 - Socially inappropriate or disruptive behavior
 - Resisting cares
 - Crying, sadness
 - Changes in appetite, sleep, or gait
 - Decreased function or participation in daily routines
 - Exiting behavior (trying to get off the unit), wandering, elopement

2. Residents' pain also affects the staff

If a resident you are caring for has pain, what effect does it have on your ability to provide the care he or she needs?

- Residents may be harder to care for: they might resist movement, require more lifting, and be more withdrawn and reluctant to participate in day-to-day activities and treatments.

Detecting Discomfort in Dementia: Focus on Behaviors

If a resident has pain, how does that make you feel (particularly if something you have to do seems to make the pain worse)?

- Acknowledge that the feelings of staff matter. Bearing witness to suffering can itself be a burden, particularly if the caregiver feels frustrated or unheard in his or her desire to advocate on behalf of the resident.

3. Think about the following example:

One of the residents in the day room is frowning and rocking back and forth. When the nursing assistant puts her hand on his shoulder and asks how he's doing, he pushes her arm away and says "No! No! No!" What should the nursing assistant do?

What basic needs of the resident might need attention?

- Is the resident cold? Offer a blanket or sweater, or turn up the heat.
- Is the resident hot? Turn down the heat, turn on a fan or air conditioner, change to cooler clothing.
- Is the resident hungry or thirsty? Offer fluids or a snack
- Is the resident clean and dry? Check to see if he/she needs to go the bathroom, or if soiled clothing needs to be changed.

What are some comfort measures nursing assistants can offer residents?

- Massage. Backrubs are a time-honored standard. Try a hand massage with lotion, or a foot rub.
- Reposition the resident (think if you had to sit in one spot without moving for a couple of hours!), use pillows or supports to take the strain off muscles. Take a walk, if possible.
- Turn down the noise. Take the resident to a quiet space away from the TV and loud noises, or substitute music that the resident likes.
- Make sure the room looks and smells clean.
- Provide some face-to-face time or a hug. Many residents find comfort in having some interaction with the nursing assistant or another kind and caring person.

What should the nursing assistant do if the resident's basic needs are met and comfort measures are ineffective?

- The nursing assistant should report to the nurse without delay. The report should include the behaviors observed and the comfort measures offered.

What if the nursing assistant notices that a resident seems to show the same behaviors each time he/she is having pain or discomfort?

- A nursing assistant who notices a pattern in the way a resident expresses pain should tell the nurse so those behaviors can be documented in the care plan.

When a resident with dementia shows problem behaviors or behavioral changes, does most of our staff think about pain as a possible cause?

- Nursing assistants and all long-term care staff need to recognize that pain is a more likely cause of problem behaviors than is dementia.

Detecting Discomfort in Dementia: Focus on Behaviors

- Most health care professionals, indeed most people, have not been taught to consider the possibility of pain when a person with dementia shows problem behaviors or behavioral changes. Ask the group to discuss how your facility can help all staff understand that behavioral change or problem behaviors might signal discomfort.

Additional questions for Culture Change education:

Take a moment to frame and review the central features of your facility's culture change initiative and how it relates to residents' pain and its management. Ask the group to discuss how to ensure that residents' pain/discomfort is identified and cared for within the context of your larger culture change effort.

If the focus includes resident choice:

*How do we honor the choices of residents with pain who cannot speak for themselves?
How should we approach a resident/family that is leery of pain treatment or thinks that pain is simply something one has to put up with?*

- Nursing assistants and all staff can encourage residents and families to understand that pain relief is an important part of health and well-being. Residents who have pain are not likely to sleep well or be as able to participate in rehabilitation and day-to-day activities

If your facility is creating "neighborhoods" or care teams:

What do your teams need to do in order to work effectively together to make sure that residents get good care for pain?

- The whole team needs to be aware that pain is a potential problem for many residents and to know how to respectfully communicate and follow-up about pain problems.

If your facility is working to engage all staff to help create the culture change environment, ask each group that is present about their previous experiences or observations of residents and discuss their roles:

What should housekeepers (maintenance persons, activities aides, etc...) do if they notice discomfort behaviors?

- Guide the discussion to clarify to whom they should report. Also emphasize that the direct care staff needs to honor and value the contributions of the other staff in the facility.

4. How can nursing assistants help with pain management?

What should a nursing assistant do if a nurse has given a resident with dementia a treatment or medicine for pain?

- Nursing assistants can help by continuing to watch the resident's behavior, and telling the nurse what they see – whether the discomfort behaviors go away, don't change at all or even get worse. Finding the right treatment for pain and discomfort in dementia can require trying many different approaches and take a long time. The observations and reports of the nursing assistants can speed the process.

The video showed the nursing assistant applying pain treatment cream. Can a nursing assistant do that in our facility?

- In some states, nursing assistants are permitted to help apply creams or ointments. ***If your state does not allow nursing assistants to administer such treatments, the discussion leader should clarify this with the group.***

Detecting Discomfort in Dementia: Focus on Behaviors

Role-Play

Teaching Guide

Discussion leader: The purpose of this role-play exercise is to help nursing assistants learn to work with other staff members to make certain that everyone knows how to recognize and respond to behaviors that suggest the presence of pain in residents with dementia.

- *Before the role-play exercise, make packets that contain one copy of each of the Role Descriptions on the second page following (page 9). Each role description should be on a separate piece of paper. To determine the number of packets you should make, divide the number of persons you anticipate will be present at the exercise by four. Make a couple of extra packets just to be sure you'll have enough.*
- *Divide your group into teams of four. Tell them that two will "play" the role of Nursing Assistants, one will be a Resident, and one an Observer. If there are only three team members, one person should play the roles of both the Resident and the Observer.*
- *Before you pass out the role-play packets, instruct the participants that **each person should silently read only his or her own role, and not the roles of the others.** Give each group a packet with the roles, and tell them to distribute the roles to the members of the group.*
- *The Role-Play exercise itself should take about 3-5 minutes. After 4 minutes, remind the teams that they should be finished in one minute. After 5 minutes, instruct the Observers to begin their critiques of the role-play.*
- *After the critiques are finished, bring the participants together for a large group discussion.*

If you have a large group...

If you think it would be cumbersome to have multiple groups doing separate role-plays, consider asking for volunteers to do the role-play in front of the group. No one may want to play the "bad" nursing assistant (#1). One solution is to play that role yourself, thus providing the other participants with a non-threatening opportunity to convince you to change your ways. After the brief role play in front of the whole group, continue with a large group discussion about their observations and recommendations.

Culture Change Alternative role descriptions

Use the alternate descriptions on page 10 if you are teaching a group that includes all staff. In this alternative, the facilities staff notices the discomfort behaviors. There is not a specific RN/LPN role written, but you could easily add one, and carry through the role-play to the point where the nursing assistant reports to the nurse.

Detecting Discomfort in Dementia: Focus on Behaviors

Role Descriptions

Resident

Imagine you are an 80-year-old resident with dementia. Words don't come too easily anymore, and you often can't put a sentence together. You know you've seen most of the people taking care of you before, even if you can't recall their names. There are some especially kind and gentle nursing assistants that are your favorites. One day, as you are sitting in the day room, your lower back starts to hurt. It's pretty stiff, so you try to hold as still as you can and to rest against the back of the chair

One of your favorite nursing assistants comes in to get you up for lunch, with another one that seems nice but that you don't know too well. They start to sit you forward and your back hurts a lot more. You just want the pain to stop, but you can't find words to say so. You swat away their hands and pull back so you can let your back rest.

Think of other ways you might show your discomfort, and use those in the role-play.

Nursing Assistant 1

You have been a nursing assistant for several years, and have worked a lot with residents with dementia. You are pretty confident that you know how to take care of the residents. You have been taught that dementia causes a lot of behavioral problems. You were also told when you first started as a nursing assistant that "residents with severe dementia can't feel pain anymore." You and most of the staff you've worked with have always assumed that to be true. You are assigned to an 80-year-old resident with dementia. You've taken care of her before, and she has always seemed to trust and respond well to you. You want to get her up for lunch, and you ask one of the newer nursing assistants on the unit to help you.

Approach the "resident" and start to get her up for lunch.

Nursing Assistant 2

You have been a nursing assistant for about 6 months, and have recently watched a video about how to help residents with dementia who have discomfort or pain. You have noticed that some of the experienced nursing assistants on the unit don't seem to notice if residents have pain. Some have even said they don't think that residents with dementia can feel pain. One of those nursing assistants asks you to help get one of the residents up for lunch.

Go with the nursing assistant to help get the resident up for lunch.

Observer

Silently observe the role-play, and complete the checklist at its end.

Did the nursing assistants

- Communicate well with one another?
- Recognize that the resident's behavior might be a signal of pain or discomfort?
- Check the resident for obvious sources of discomfort? (cold, hungry, lonely, etc)
- Try to make the resident comfortable? (offer blanket, water, backrub, repositioning, or other comfort measure)
- Go to tell the nurse about the resident's behavior if the efforts to make the resident comfortable did not work?

Detecting Discomfort in Dementia: Focus on Behaviors

Culture Change – Alternate Role Descriptions to include Facilities Staff

Resident

Imagine you are an 80-year-old resident with dementia. Words don't come too easily anymore, and you often can't put a sentence together. One day, as you are sitting in the day room, your lower back starts to hurt. It's pretty stiff, so you start to shift around and rock in your chair, but you just can't find a comfortable spot. One of your favorite staff members walks over and says "hello". You're not feeling yourself because of the pain in your back and respond, "What do you want? Go away. Leave me alone".

The nursing assistant comes to get you up for lunch.

Think of other ways you might show your discomfort, and use those in the role-play too.

Facilities Staff Person

As you are going about your work, you greet a resident who you see nearly every day. The resident is often confused, but usually enjoys a short talk with you, even if the talk doesn't always make sense. Today, the resident responds by saying, "What do you want. Go away and leave me alone". You notice that the resident is sitting in her chair rocking back and forth and just doesn't seem like her usual self. You see one of the experienced nursing assistants come to get her up. The nursing assistant doesn't seem to notice that the resident is uncomfortable. As a second nursing assistant approaches to help get the resident up, you decide to speak up about what you have seen.

Nursing Assistant 1

You have been a nursing assistant for several years, and have worked a lot with residents with dementia. You are pretty confident that you know how to take care of the residents. You have been taught that dementia causes a lot of behavioral problems. You were also told when you first started as a nursing assistant that "residents with severe dementia can't feel pain anymore." You and most of the staff you've worked with have always assumed that to be true. You are assigned to an 80-year-old resident with dementia. You've taken care of her before, and she has always seemed to trust and respond well to you. You want to get her up for lunch. Approach the "resident" and start to get her up for lunch.

Nursing Assistant 2

You have been a nursing assistant for about 6 months, and have recently watched a video about how to help residents with dementia who have discomfort or pain. You have noticed that some of the experienced nursing assistants on the unit don't seem to notice whether the residents have pain. Some have even said they don't think that residents with dementia can feel pain. You notice one of those nursing assistants getting a resident up for lunch. One of the facilities staff is nearby and looks concerned about something.

You go over to the nursing assistant and offer to help get the resident up.

Observer

Silently observe the role-play, and complete the checklist at its end.

Did the staff

- Communicate well with one another?
- Recognize that the resident's behavior might be a signal of pain or discomfort?
- Check the resident for obvious sources of discomfort? (cold, hungry, lonely, etc)
- Try to make the resident comfortable? (offer a blanket, water, backrub, repositioning, or other comfort measure)
- Go to tell the nurse about the resident's behavior if the efforts to make the resident comfortable did not work?

Detecting Discomfort in Dementia: Focus on Behaviors

Role-Play: Discussion Topics

1. What are some factors that make it easier to figure out what's going on when a resident's behavior changes? What makes it harder?
 - It's easier if...
 - the nursing assistant has been taught what behaviors suggest the presence of pain
 - the nursing assistant knows the resident
 - everyone on the unit understands which behaviors suggest the presence of pain
 - It's harder if...
 - staff believe that residents with dementia do not feel pain
 - staff do not understand that pain can be the reason behind problem behaviors or behavioral changes in residents with dementia
2. What are some ways that one nursing assistant can help others understand that certain behaviors may signal pain or discomfort in residents with dementia?
 - Tell others what you have learned about behaviors and pain.
 - Communicate respectfully with one another
 - Point out why it's important that nursing assistants know the behavioral signs of discomfort: residents will be more comfortable, suffer less, and be easier to take care of. Nursing assistants will feel better about their work.
3. How should the nursing assistant go about telling the nurse about a resident who is showing signs of discomfort?
 - Learn how to give a concise report on what you have seen and done
 - Identify the resident
 - Describe the behavior
 - Say why you think the behavior is related to pain/discomfort
 - Make a request to the nurse to help
Example: I tried to get Mr. Smith up to get dressed, but he kept pushing me away and moaning when I started to move his leg. He looks sad and worried. I've spent a little time sitting with him and made sure he's warm and dry. I'm concerned that he might be in pain. Could you please come look at him?
4. What do you think our facility needs to change to help us take the best possible care of our residents with dementia and pain/discomfort?

This question might evoke criticism or frustrations ("we get moved around too much and can't get to know the residents" or "the nurses don't listen to us"). Listen to these points non-judgmentally – they can include important cues about structural changes that need to happen in your facility.

 - What should the nursing assistant do if a co-worker ignores signs of a resident's discomfort or does not report those signs to the nurse? Is there a process in place to assist the nursing assistant and to guide discussions with a supervisor? Allow participants to discuss their feelings, and to identify ways they can try to help the

Detecting Discomfort in Dementia: Focus on Behaviors

situation (ex: talking directly with their co-worker or acting as a role-model by speaking up about their observations of the resident.)

- Does there need to be more education for nursing assistants? For nurses? For physical, occupational, and recreational therapists?
- How should our facility involve family members?
- Should there be a formal mechanism for nursing assistants to identify and report discomfort behaviors? How can such a mechanism be established?

5. Culture Change:

- *Frame your facility's efforts:* What is the purpose of our facility's culture change program?
- How does our culture change program influence what you do on a daily basis, particularly in regards to residents who have pain?
- What challenges do you face in trying to support residents in pain, and how do you respond to those challenges?
- What else could we do to routinely identify pain and improve residents' care?

Knowledge Test

Circle the ONE best answer to each question

1. Residents with advanced dementia don't feel pain
 - a. True
 - b. False
2. Residents with advanced dementia may show discomfort behaviors because they are
 - a. lonely
 - b. hungry
 - c. cold
 - d. in pain
 - e. all of the above
3. Which of the following behaviors suggest that a resident with advanced dementia may have discomfort?
 - a. wandering
 - b. resisting getting up
 - c. grimacing
 - d. rubbing
 - e. all of the above
4. A resident with advanced dementia might repeat words like "momma, momma" when she has pain
 - a. True
 - b. False
5. If a resident with advanced dementia shows discomfort behaviors, what is the FIRST thing a nursing assistant should do?
 - a. Call the family at home and ask them to contact the doctor.
 - b. Nothing – these behaviors are normal in a resident with dementia.
 - c. Make sure the resident's basic needs (warmth, food, liquids, toileting) are met.
 - d. Page the nurse to come see the resident right away.
6. If a resident with advanced dementia keeps calling out "help me, help me" even though you have made sure her basic needs are met, a nursing assistant should:
 - a. put the resident in a room by herself, so that the other residents will not be disturbed.
 - b. ask the nurse to assess the resident for pain.
 - c. do nothing because the resident is probably just confused.
 - d. ask the nurse to give the resident a sleeping pill.

Knowledge Test Answer Key

1. b (false)
2. e
3. e
4. a (true)
5. c
6. b