



OCTOBER 2017

You are **not** alone...

Education on Caring for  
the Patient with Dementia



Veterans Health  
Administration





## Join Dr. Buenaver for the second part of the series Family Involvement in Dementia Care: “Don’t Be Shy”

The goal of “Don’t be Shy” is to encourage and illustrate ways to:

1. Ask difficult questions
2. Offer different information
3. Speak up for yourself and your needs
4. Stay focused on issues most important to you



The goal is to review ideas of how to:

- ◆ Not be intimidated by healthcare providers/staff.
- ◆ Be polite, but clear about:
  - ⇒ what you want
  - ⇒ what you know
  - ⇒ what you think best for your loved one
  - ⇒ what you are willing to do to help



### Polite but Clear: Being Assertive

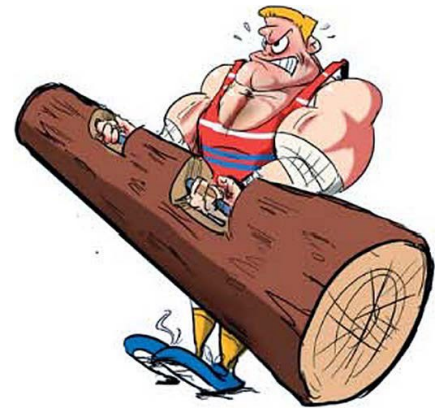
Expressing your feelings, thoughts, beliefs and opinions in an open manner that doesn’t violate the rights of others!



## Polite but Clear: Stereotypes about Assertiveness

But I was taught...

Men who show or talk about their emotions are weak...



Women who state their needs or opinions are aggressive...

People who disagree with experts are disrespectful. ...



## Polite but Clear: The Importance of Speaking Up:

Not saying what we really think or believe has consequences like: feeling powerless, resentful, unhealthy/uncomfortable relationships, and frustrations.

Saying what we think only when angry also has consequences such as loss of respect, avoidance by family and friends, and others stop listening.



### Tips from Family Caregivers

- ◆ If you have difficulty being assertive with providers, bring an assertive friend with you!
- ◆ Remember the impact all the care expectations have on you as a caregiver. Be prepared to say “I can’t do it”.
- ◆ You are an important part of the team. Your needs should be recognized/discussed.

## Starting Points: When Emotions Run High

When you begin to feel frustrated, angry, hurt or resentful, these are understandable responses to stress. They are common reactions if a provider doesn't seem to understand or care and can shut down clear thinking for both sides.

The greatest risk of violating the rights of others is when emotions run high. Words, gestures, and the tone of one's voice all contribute.

## Starting Points: Recognizing Emotional Triggers

Recognize triggers to negative emotions:

- ◆ Situations, settings
- ◆ People, providers
- ◆ Topics

You may want to try keeping a diary of who or what is upsetting you. What triggers uncomfortable emotions? What thoughts do you have? How might you approach it differently?



## Starting Points: Using “I” Statements

- ◆ Speak up for yourself by using “I” statements
  - ⇒ Avoids blaming the other person: **“you make me...”**
  - ⇒ Shifts responsibility to you: **“I feel...”**
  - ⇒ Makes it difficult to disagree/argue
- ◆ Many ways to do this
  - ⇒ Self-disclosure: **“I feel nervous.”**
  - ⇒ Understanding: **“I know you are busy at the moment, but I would like to make a request.”**
  - ⇒ Consequences: **“If this occurs again, I’m left with little choice but to talk with your supervisor.”**

## Starting Points: Expressing Negative Feelings in 4 Steps

1. Describe the situation objectively. Avoid interpreting or judging. **“When I see my husband sitting in soiled clothing after lunch...”**
2. Clearly and specifically describe the impact of the situation on you. **“...it makes it**

**difficult to get to our next activity on time...”**

3. Describe your feelings. **“...and I feel both sad and angry...”**
4. State how you would prefer the situation to be addressed in the future. **“...so in the future, I ask that he be taken to the restroom prior to lunch.”**



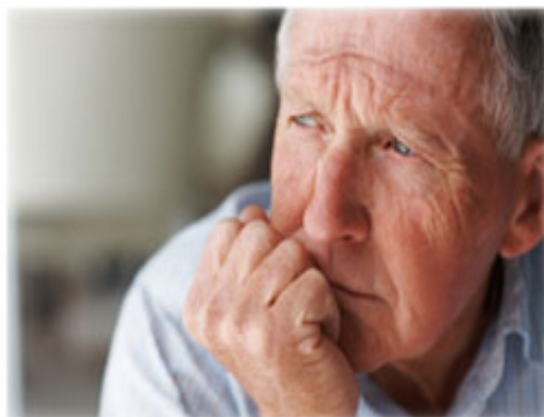
### Starting Points: Adjusting Your Perspective

Work to recognize unhelpful thoughts.

- ◆ “They should know better than to do that”
- ◆ “That nursing assistant is really bad”
- ◆ “Why can’t they seem to get it right?”
- ◆ “How long is this going to take?”

Try re-framing your thoughts.

- ◆ “Okay, she made a mistake. That doesn’t make her a bad person, or even a bad caregiver...”
- ◆ “This is frustrating, but I can do it. It is worth the effort.”



### Having the Conversation: “I” Statements

- ◆ “I understand that you have a lot of residents and are very busy, but I feel really frustrated when...”
- ◆ “I would like to find a way we can work together to improve this situation?”
- ◆ “I can’t afford this option. Can we explore other choices?”
- ◆ “I am concerned that the medication is sedating my loved one. I don’t support this approach.” .”

### Having the Conversation: Options & Choices

Explore the options

- ◆ “What are the pros and cons
- ◆ “What are the other choices?”



# Any Questions?

Does the option make sense...

- ◆ At this stage of the disease?
- ◆ Given your loved one's other health conditions?
- ◆ Based on your loved one's wishes or characteristics?
- ◆ In light of costs?
- ◆ Given your other demands? (work, leisure, family needs)

## Having the Conversation: Taking a Break

Be ready to pause and think, in case you get frustrated or unsure of what you want.

- ◆ "I'm not sure what is best right now. I can't answer that question."
- ◆ "I need to think about this some more."
- ◆ "Let me get back to you."
- ◆ "Let's talk about this again later."
- ◆ "I'd like to talk this over with my children and see what they think."

## Summary

Things to consider when talking with providers

- ◆ Being prepared is key
- ◆ Be open and honest
  - ⇒ Recognize common emotional reactions
  - ⇒ Work to recognize unhelpful thoughts
  - ⇒ Use "I" statements
- ◆ It is your right to:
  - ⇒ check for understanding
  - ⇒ ask questions
  - ⇒ explore choices
- ◆ If needed, excuse yourself and regroup.



# PALLIATIVE CARE FAIR

*EMPOWERING OUR PATIENTS*

## OPEN HOUSE

**Everyone is invited!**

An Educational Fair that Promotes  
Understanding About  
Palliative Care for Veterans, Families and Staff

**Wednesday November 8, 2017**

**9am - 1pm**

**Hawley Auditorium, Topeka VA**



Please come and learn more about Palliative Care.





The Caregiver's meeting is held the 3rd Thursday of each month at 2:30pm, Building 24 in the Recreation Hall of the hospital. We meet informally at 2:00 pm for support and snacks.

Do you have a story you would like to share? Are there questions you would like answers to from other caregivers? Would you like to know how other caregivers handle difficult situations? If so, approach Dr. Buenaver at the meeting. We will be gathering at 2:00 pm, 30 minutes before the meeting starts.

**Join Dr. Buenaver on October 19th at 2:30pm for the second part of the series Family Involvement in Dementia Care.**

*This material is funded in part by HRSA 1 U1QHP28731-01-00 Interprofessional Strategic Healthcare Alliance for Rural Education, and is the result of work supported with resources and the use of facilities at VA Eastern Kansas Health Care System.*

Presently we have a program for education on caring for the Veteran with dementia. It includes a monthly newsletter which can be mailed to your home, or if preferred emailed to you. You are welcome to bring the veteran to these meetings. Due to technical issues, we can't accept incoming emails at this time.

# You are not alone.

