



► Prolonged pain, either physical or emotional, can cause a person to feel hopeless.

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ALZHEIMER'S *In-Service*

M O N T H L Y

BEST PRACTICES IN RESIDENT-CENTERED CARE

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Dementia, Depression and Pain Are Intertwined

KEY POINTS

- Both physical and emotional pain are common as people age.
- Depression can result from prolonged physical or emotional pain or from the reality of facing a difficult condition such as dementia.
- Dementia has many symptoms in common with depression. The inactivity that often results from dementia can also increase physical pains.
- Pain, depression, and dementia can and should be treated.



Dementia, depression, and pain are like three strands of a braided rope. When they are woven together, it's hard to distinguish one from another.

As people age, or at various times within older adulthood, many people experience physical or emotional pain. They may have arthritis, a bad back, or receive bruises from a fall. They may experience the death of a spouse, a beloved sibling, or a close friend, or they may have vision loss or mobility challenges that keep them from doing work or activities they once loved. Prolonged pain, either physical or emotional, can cause a person to feel hopeless, as if life no longer has meaning and value. This is also known as depression.

Many people use the term "depression" flippantly, exaggerating normal feelings: "We lost the football game. I'm so depressed!" Others make light of dire signs: "Well, of course, she's depressed! Her husband of 50 years just died three months ago!" Clinical depression is a serious mental illness that requires active treatment. Professional help is probably needed if you or someone you love has several of the following symptoms that are pervasive throughout each day and last longer than two weeks:

- Change in appetite and accompanying weight loss or gain
- Change in sleeping patterns; sleeping either too much or too little; having fitful, restless sleep; feeling constantly tired
- Loss of interest in previously enjoyed activities
- Loss of energy
- Feelings of hopelessness, worthlessness, and/or guilt
- Inability to concentrate accompanied by indecisiveness
- Physical symptoms without other obvious causes, such as stomach aches or headaches

CAREGIVER TIPS

FOR RELIEVING YOUR OWN PAIN AND OTHERS'

With new and more effective drugs constantly being tested, we are fortunate to live in a time when there are medicines to treat pain, depression, and the symptoms of Alzheimer's disease. We are also fortunate to have many non-medicinal means of providing comfort. For example:

- Changing the environment - Leaving noise and confusion of crowds behind.
- Changing position - Stretching; fluffing pillows, elevating feet.
- Changing the temperature - Adding a sweater or a fan.
- Providing tasty food and pleasant company at mealtime.
- Providing distraction - Including soft music, colorful kites, singing birds, children or puppies at play, or an engaging game.
- Providing purpose - People always appreciate opportunities to help others.
- Increasing a person's sense of being valued - Offering a hug, loving touch, or kind words.
- Helping a person to relax - Deep breathing, singing, laughter, and a walk



Dementia, Depression and Pain Are Intertwined

FROM PAGE ONE

Note: If someone expresses suicidal thoughts, always take him seriously, and seek immediate professional attention.

All of us have days when we feel "blue" or "down," but most of us recover fairly quickly. People who are clinically depressed can't just "snap out of it," but they may be jump-started on the road back to good mental health with the aid of anti-depressants. On the other hand, sometimes a persistent low mood is a side effect of a medication being taken for another condition, such as high blood pressure or heart disease. In these cases, changing a medication is all that is needed. Often, people benefit from improved eating habits, regular exercise, exposure to the outdoors, or a project that helps them feel valued. Many also see psychologists or psychiatrists and find relief in talking about their feelings.

The challenge for caregivers is that many symptoms of depression - such as apathy and disinterest in what were formerly enjoyable activities, poor sleep patterns, lack of energy and initiative, difficulty concentrating, indecisiveness and lowered self-esteem - are also signs of

dementia. Is the fact that Mother is losing weight due to depression now that Father has died, or had he been cooking for both of them to help her cover her dementia?

Furthermore, people who become inactive lose stamina and flexibility. If a woman who had played tennis regularly gives up the game because her dementia has affected her ability to keep score, she may soon find her lack of activity brings her more aches and pains, and the lack of interaction with friends could lead to depression. Depression can also result from the awareness a person with AD has of a loss of abilities and an inability to stop the progression of those losses.

While it may be difficult to untangle the tightly woven strands of pain, depression, and dementia, each can and should be treated.



KEEP IN MIND: MORE REASONS TO PROVIDE RELIEF

Whenever it is in our power to do so, most of us would choose to relieve the physical or emotional pain of others out of simple human kindness. However, there are also a number of other legitimate reasons for helping people with AD live as pain-free as possible.

Untreated pain:

- Increases stress
- Inhibits the immune system and delays healing
- Interferes with sleep
- Tends to reduce appetites and lower chances for adequate nutritional intake
- Compromises mobility and puts people at increased risk for falls

- Can raise heart rates and blood pressure and exacerbate other medical conditions
- Is a primary contributor to depression

Relieving pain or discomfort automatically improves a person's quality of life.

Key Points:

There are many physical and emotional reasons to treat pain.

Relieving pain is an act of human kindness that also improves a person's quality of life.

Assessing Pain and Discomfort

Both doctors and patients often see pain as a natural side effect of aging. In fact, reports of pain from older adults are so pervasive, they are the most common complaint made to primary care physicians. The view that pain is a normal part of the aging process leads many physicians to ignore complaints of pain among older adults, as well as patients themselves to expect they'll have to endure a certain amount of pain as they age (although they tend to prefer words like soreness, discomfort, or ache). Some older adults intentionally minimize or make light of their pain, perhaps hoping to postpone its consequences. For example, if Mrs. Jones reveals her knee pain, she may fear that her doctor will press her to have the surgery she has delayed or encourage her to use



a cane that she perceives will make her look "old and decrepit."

People with dementia present an additional challenge.

Particularly as

their condition progresses, they have difficulty expressing their discomfort or its cause. They cannot communicate that they have not had a bowel movement for a week or that they have a burning sensation when they urinate. Even something as simple as, "My shoulder hurts," or "I have a headache," may be beyond their verbal abilities. Instead, they frequently express discomfort through anxious or restless behavior and are given medications for the behavior rather than its cause. In the later stages of Alzheimer's disease, it is not uncommon for people to express their discomfort in terms of frightening hallucinations or delusions. Studies have shown that people with AD are severely under-treated for pain, but successful caregivers assume every behavior has meaning and do their best to decipher that meaning.

Here are the classic non-verbal signs of discomfort:

- Noisy breathing - labored, loud, gasping, or rapid, for example
- Distressed vocalizations - moaning, groaning, muttering, repeating words in a mournful tone.

Note, too, that the commonly uttered "help me" is often an expression of physical pain, emotional pain, or both.

- Facial expressions - clenched jaws, distorted and distressed expressions, tightly closed eyes or dilated, glazed eyes, frowning, pleading looks
- Body position/language - clenched fists, wringing hands, rocking, fetal position, hunched shoulders, self-protective gestures such as an arm in front of one's stomach
- Fidgeting, pacing - restlessness, impatience, altered gait or posture, forceful rubbing of a body part such as a sore arm. Pacing is sometimes an effort to escape the pain - to literally walk away from it.
- Uncharacteristic anxiety, irritability, or aggression - crabbiness, hostility, striking out
- Change in daily activities, habits - difficulty sleeping, loss of appetite, decreased ability to concentrate, withdrawal from activities. Notice that many of these are also signs of depression.

A person with dementia who has a pre-existing condition such as arthritis or osteoporosis does not suddenly stop feeling discomfort from the condition when she is unable to express that discomfort. Some studies have shown that people with AD who are given a daily analgesic (aspirin or ibuprofen) under a physician's supervision exhibit fewer signs of discomfort through their behavior. More study is needed, but it seems to be an avenue worth pursuing further.

KEY POINTS

- | People with dementia often find it difficult to express their discomfort in words, but they may act it out through anxious or agitated behavior.
- | Know and watch for nonverbal signs of discomfort; then treat the cause.
- | People with a painful condition such as osteoporosis before their dementia arose, continue to need treatment for that condition.

RESOURCES

Type "Dementia and pain," or "Dementia and depression" on the search line of your Internet browser, and you will get thousands of entries. You can also go to well-known sites on Alzheimer's disease and search these topics within the sites. Here is a sampling of sites where reputable information can be found:

- <http://www.alz.org>
- <http://www.alzheimers.org.uk>
- <http://www.alzfdn.org>
- <http://www.lumetra.com> (Assessing pain)
- www.masspro.org (look for their "Fast Facts")
- <http://healthlink.mcw.edu/article/967581724.html>
- www.healthinaging.org
- <http://www.healthyplace.com>

In addition, *Alzheimer's Basic Caregiving - an ABC Guide* by Kathy Laurenhue (www.wisernow.com) also has a useful chapter on this topic.

TRAINER'S CORNER

IN-SERVICE GUIDE

The "Trainer's Corner" helps you relate the topic to caregivers' personal experiences in order to make it relevant and memorable. With each issue, we will provide

discussion questions and an engaging exercise. A quiz is available on Page 5 to test participants' knowledge. (The answers appear on the bottom of this page.)

Bringing the lesson home

Write this series of letters on a flip chart or white board:

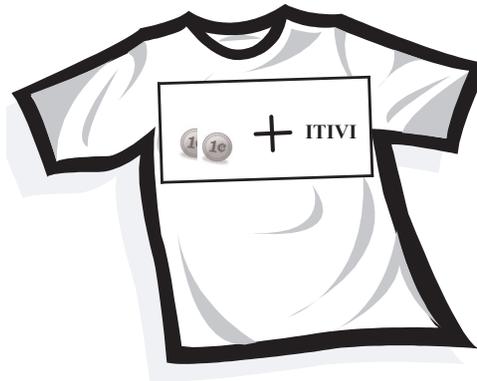
M F O U O T H

Ask participants what it says. The answer is "foot in mouth," - a condition we have all suffered from!

Then draw the shape of a T-shirt on the board or flip chart. On the shirt, draw a box. In the box draw a few pennies, a plus sign and the letters ITIVI.

Ask, "What does THAT say?" The answer is "Insensitivity." ("Cents" + ITIVI in a box on a Tee)

Tell this story: *One day a little boy came to his father who was sitting in a chair reading the newspaper. He said, "Daddy, daddy! Look at my knee. I fell on the playground at school." His father was pre-occupied with the sports page, glanced at the knee long enough to see a colorful band-aid, and before returning to reading, said, "Well, what can I do about it?" The little boy looked at his dad, and as he walked away, he said, "You could say 'Ouch!'."*



Let's talk

Most of us have had the experience of saying the wrong thing (foot in mouth) or an insensitive thing to someone who was in pain or depressed, even when we intended to be sympathetic. Most of us have also experienced someone saying the wrong or an insensitive thing to us when we were in pain or feeling blue. Give people a chance to share their stories of these experiences:

- What was the situation? What was said? What do you wish you had said or wish was said to you?

Point out the precise wording or gestures that made their example "right" or "wrong." Then ask:

- What are the obstacles to saying the right thing?

Sometimes we're just tongue-tied, but other times we may feel tired, unsympathetic towards a person who complains frequently, or we may simply have a tendency to use humor at inappropriate times in an effort to lighten difficult situations.

Finally, ask:

- What are the consequences to a relationship when you say the right thing? How about when you say the wrong thing?

While not always easy, the right thing generally quickly relieves a negative situation.

Answer Key for Quiz on Page 5

1) d 2) a 3) e 4) b 5) d

QUIZ: Pain and Depression in AD

PLEASE COPY AND DISTRIBUTE TO EACH PARTICIPANT

First Name

Last Name

Quiz Date

Supervisor's Signature

Date

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Please answer the following questions based on the information on the previous pages.

- 1) One premise of this issue is that pain, depression, and dementia are intertwined, meaning that their symptoms overlap. Which of the following are possible symptoms of all three conditions?**
 - a. An inability to concentrate
 - b. Change in appetite and sleep patterns, restlessness
 - c. Withdrawal from activities and lack of energy
 - d. All of the above
 - e. B and C only

- 2) The cause of depression can be a sad event, such as the loss of a spouse, but it might also be a side effect of certain medications.**
 - a. True
 - b. False

- 3) People with Alzheimer's disease who cannot express their pain in words usually give us many non-verbal clues that they are uncomfortable, such as:**
 - a. Labored breathing, groaning, distressed facial expressions
 - b. Wringing hands, irritability, fidgeting, pacing
 - c. A fake smile or a calm, blank expression
 - d. All of the above
 - e. A and B only

- 4) Treating pain is important, not only because it's the kind thing to do, but because it can prevent other physiological symptoms including all of the following EXCEPT:**
 - a. Delayed healing
 - b. Hyperactive immune system
 - c. Increased heart rate
 - d. Lowered appetite that can lead to nutritional deficiencies
 - e. Sleep deprivation

- 5) Medications for treating pain, depression, and dementia are available, but people with these conditions can also be eased by kindness and distraction. Which of the following is NOT an example of these methods?**
 - a. Providing a quiet, calm environment, such as rocking on an outdoor porch
 - b. Giving the person a hug or a gentle hand massage with scented lotion
 - c. Singing old, familiar songs together
 - d. Putting the person in the middle of a class of a dozen running, bouncing, vocal pre-schoolers
 - e. Laughing together at a humorous video, such as an old "I Love Lucy" show