



BAI Beacon

*The Newsletter from Family and Community Services
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Common Symptoms of Pain Behavior

Facial Expressions:

- Frowning, sad, frightened face
- Grimacing, wrinkled forehead
- Rapid blinking, closed/tightened eyes

Negative Vocalization:

- Sighing, moaning, groaning
- Grunting, chanting, calling out
- Noisy breathing
- Verbally abusive, swearing

Change in Body Movement:

- Rigid, tense body posture, guarding
- Fidgeting, picking
- Increased pacing, wandering, rocking
- Changes in gait (walking)

Change in Interaction with Others:

- Aggressive, combative, resisting care
- Decreased social interactions, withdrawn
- Socially inappropriate, disruptive

Change in activities/routines:

- Change in appetite, refusing food
- Increased sleep
- Sudden ending of common routines
- Increased wandering/pacing

Change in mental state:

- Worsening of normal mental state
- Increased confusion
- Increased irritability, anxiety or distress
- Crying, tearful

Understanding Pain in Dementia

The World Health Association notes that “pain is whatever a person says it is.” In fact, pain is very personal, and depending on the person and the type of pain, may produce a wide vocabulary to describe it. Words describing pain include: burning, aching, throbbing, stabbing, tingling, tightness, soreness, sharp, shooting, excruciating, dull, and/or tender. The reality is that pain is a very complex phenomenon that requires memory, language, insight and judgment – all the things the person with dementia begins to struggle with. It’s no surprise when family caregivers have difficulty trying to understand their loved one’s pain and pain-related behaviors.

Common examples include:

- Observing their loved one groan and grimace and then asking if the person has pain and being told, “No, I don’t have pain.”
- Listening to the person talk about pain and then visiting the doctor with the person only to hear him/her deny pain!
- Observing the person eat less and less – even sweets!
- Having the person resist care – particularly when moving a sore joint.
- Watching the person become more restless as the day continues and despite the caregiver’s best efforts, they can’t seem to get the person comfortable.
- Witnessing the person become more verbally aggressive, hostile, or swear without any environmental triggers.

It is important to keep in mind that many people with dementia are generally older and therefore more likely to have a chronic condition that may cause pain such as arthritis, shingles, back pain, diabetic nerve pain, etc. Those with poor oral hygiene or dental care are at greater risk for mouth pain due to fractured teeth or infections due to abscess. Walking/moving less will lead to pain when joints are forced to move. Constipation is common and causes discomfort when people drink less fluid or eat less fiber. “Psychic” pain due to grief, loss and depression can also look like physical pain in people with dementia.

We must also recognize other barriers that get in the way of effectively identifying and treating pain. Sadly, there are still long held beliefs that pain and aging go hand in hand, and nothing can be done about it. Many people (including health care providers) often believe that people with dementia are unable to experience pain. Cultural and gender differences may limit reports of pain and be seen as a sign of weakness. People with dementia who are living alone may under report their pain for fear their family or health care provider may think they are in need of more care. Additionally, families are concerned that their person may be prescribed a medication that is perceived as “addictive” or make the person more confused – therefore they

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Understanding Pain in Dementia (Continued)

don't report pain symptoms during medical visits. Some caregivers will say, "he has never even so much as taken an aspirin for pain and he won't do it now" - even when it is evident that pain is present!

So what must family caregivers learn in order to report and advocate to optimize their loved one's comfort?

First, write down any current or past health issues or injuries that have resulted in pain or discomfort. Remember that a recent fall or injury, such as burning a mouth on hot coffee, will result in discomfort and can result in changes.

Second, ask the person about discomfort - but remember the word "pain" is very broad and abstract. If the person has a burning, tingling or aching sensation, they are not likely to interpret it as pain. If you suspect a location where there is discomfort, try to gently place your hand over that location and ask, "Does it hurt here?" This is a simpler statement and more likely to be understood, even by very confused individuals.

Third, watch for pain behaviors that include: facial expressions, negative vocalizations, changes in body movements, a change in interaction with others, a change in activities/routines, or increased confusion. (See sidebar for a full list of common symptoms)

Fourth, keep a record of the person's verbal reports of pain/discomfort along with pain behaviors that you observe.

Fifth, work closely with your person's health care providers on a plan to relieve discomfort. Recent studies have demonstrated that routine use of acetaminophen is very effective in treating many types of pain. Sometimes, stronger medications will be needed and should be utilized to manage pain and minimize most pain-related behaviors. When pain is chronic and/or persistent, pain medications need to be given routinely rather than as needed. Remember, the person with dementia will not know how to express growing pain; nor will they remember to ask for medication.

What else works?

- Exercise and gentle movement are very effective forms of pain relief. An order for physical therapy is often beneficial with guidance given to the caregiver to continue exercise, stretching, and range of motion movements at home.
- Complementary therapies such as acupressure, acupuncture, therapeutic touch, and chiropractic care can be helpful.
- Comfort measures such as frequent repositioning, gentle touch, light massage and verbal reassurance are helpful. Alternating a warm blanket/towel (with care to avoid burns) with a cold pack over a sore joint is helpful. Use of topical ointments such as Ben Gay can ease pain. Holding a favorite, comforting object, such as a pillow, prayer shawl, rosary beads, etc., can provide a welcome distraction. If religious, saying a prayer also can bring a sense of safety and relief.
- Using pleasant events as distracters are very effective. Think about engaging the person with favorite music, discussing a favorite topic/events, relaxation exercises, use of pets, watching humorous TV shows, looking at photos or picture books.

In summary, pain is a complex phenomenon that is more complicated in the face of dementia. However family caregivers bring tremendous knowledge about the person, their daily patterns and their pleasures that can be successfully factored into providing comfort. Combining the expertise of the caregiver, a responsive health care team, the right medications and a variety of comfort measures, it is possible to not only understand a person's pain but to bring comfort!



Our Mission

To end Alzheimer's disease without losing a generation, to set a new standard of care for patients and their families, and to forge a model of collaboration in biomedical research.

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Banner Alzheimer's Institute, visit:

www.banneralz.org/waystogive

or call

602-747-4483.



Ask The Expert

Helle Brand, PA
Physician Assistant

Dear Helle:

How do I know when my husband is really in pain? So many times he complains about something hurting, but when I take him to the doctor he acts as though there never was a problem!

Signed,
Sandra

Dear Sandra:

I can hear and feel your frustration, which is very common for people taking care of someone with dementia. Just as we talk about identifying triggers in the environment or in our communication that provoke unwanted behavioral changes, so, too, do we look to identify times and activities that appear to cause discomfort and/or pain. Remember that we are dealing with people who may or may not remember what they just experienced or heard, so give special notice when they do complain of pain so that you can review with the doctor.

Your role is one of advocacy, voicing for your husband what he may not remember or recognize. Part of your role, as well, is to follow through with recommendations for treating pain, keeping the focus on quality of life for him. Your husband may not have taken medication in the past, but most of us don't have chronic pain in our younger years!

An equally important role you play is to be knowledgeable and ask questions about the medications. Doctors will often prescribe more potent medications than warranted, or not provide guidelines for tapering off such medications, such as following a surgical procedure. The cardinal rule is always to use the lowest possible dose, and the medication with least side effects. We typically recommend Acetaminophen (Tylenol) to begin with as it is both safe and effective. However, if pain is severe and/or increasing, the medications have to change accordingly; sometimes requiring narcotics also known as opioids. You need not fear addiction or misuse at that point because you are managing the medications, giving them in a timely and appropriate manner. There may be a bit more confusion or sleepiness when using these medications but the goal is focused on your husband's comfort level at that point.

Remember to keep in mind that when we treat pain, we see improvement in mood, sleep, activity; and overall sense of well-being, which allows for better day to day experiences. Lastly, always trust your gut. Pay attention to those non-verbal signs that may indicate pain, even when nothing is voiced, and review with your doctor. Use your power of touch to assess an area that appears to be causing pain, and encourage your doctor to do the same. It is good that you care and pay attention to what your husband is and isn't saying to you, and that you want to do what is best for him.

Helle Brand

Have a Question?

To submit your question for future consideration
email us at:
baiinfo@bannerhealth.com



Banner Alzheimer's Institute

Banner Health
901 East Willetta Street
Phoenix, AZ 85006

Beacon Bits

GPS Lecture:

Important Discussions and Decisions Faced During Dementia

Friday, August 9, 10:30 a.m. – noon
Ahwatukee Recreation Center
5001 E. Cheyenne Drive, Phoenix
Free but registration is required.
To register, call (602) 230-CARE

Planning Ahead Class for Caregivers

Monday, August 12, 4– 6 p.m.
Banner Alzheimer's Institute,
Third Floor Conference Room
901 E. Willetta Street, Phoenix
Free but registration required.
Call (602) 839-6850 to register.

COMPASS Class for Caregivers

Thursday, August 15, 10 – 11:30 a.m., OR
Monday, August 26, 4 – 5:30 p.m.
Banner Alzheimer's Institute,
Third Floor Conference Room
901 E. Willetta Street, Phoenix
Free but registration required.
Call (602) 839-6850 to register.

GPS Lecture:

Staying Afloat with the Changing Roles and Relationships in Dementia

Friday, Sept. 13, 10:30 a.m. - noon
Musical Instrument Museum
4725 E. Mayo Blvd.
Free but registration is required.
Call (602) 230-CARE to register.

Tips on Brain Health:

Memorizing things seemed so much easier when we were young – because we exercised that skill! Relearn that skill by choosing a short poem, wise saying or key sentence and begin to memorize it. Repetition is key. Work on it for several minutes; leave it and come back to it several times throughout the day. With time, this skill will become easier and your brain will be better because of it.