**Dementia and Pain Management: A Personal Story**

*Donna Schempp, LCSW and daughter*

My father was screaming in the nursing home. The staff had tried changing any number of his medications, but nothing stopped his agitation until the physician ordered Vicodin, a strong painkiller. I called the physician and asked him to assess what might be causing my father’s pain. The physician suggested it might be arthritis. In a calm voice, I suggested that perhaps the pain was from something more serious—would he please do an evaluation? He told me that this would be hard to do since my father has dementia and can’t tell him what hurts. I pointed out to the physician that, although limited in his speech, my father does respond to "yes"and "no" questions and that the doctor might be able to tell what hurt by looking at my father’s facial expression.

Having recently attended a meeting of the American Chronic Pain Association, I was very aware of the undertreatment of pain, especially in certain population groups— the old myth is that people with dementia had less sensitivity or awareness of pain.

I started to look at what was available for assessing and managing pain for people with dementia. Unfortunately, I found that there currently is not a lot of literature on how to assess and treat pain in people with cognitive impairments. As we become aware of the importance of pain management for all people, however, more helpful information will become available.

Generally, we think of pain as an acute situation—you break a bone, have surgery, sprain an ankle, etc. These kinds of pain go away as we heal. Then there is the pain we associate with major illness, e.g. cancer pain. Finally, there is chronic pain, which can come from any number of sources, from neuropathy pain in diabetes to lower back pain to jaw pain from grinding your teeth. People with dementia can have all or none of these ailments. The problem is that they are often not able to tell us that they are hurting. Yet, with proper pain management, our job as caregivers will be easier. My father had recently bumped his head and had a black eye. I touched the bruised skin under his eye and asked if it hurt. He said, "a little." This was the one coherent thing he said during that visit, but he was able to respond.

How do we tell if a person with dementia is in pain? Sometimes we can push gently on an area and ask if it hurts. Another way is to check for changes in facial expression, such as grimacing. Behavioral changes such as restlessness, agitation, vocalizations and even a faster heart rate may be signs of discomfort.

Doing a proper pain assessment takes time, and harried physicians often don’t take the time to do such an assessment. Physicians often do lab tests to rule out the major causes of discomfort, such as a pneumonia, prostate problems, constipation or a urinary tract infection. Further, everyone has a different pain threshold, so a physician who is unfamiliar with a patient might not know how to "read" the person with dementia who cannot respond verbally. Family members can be the best advocates for their loved ones in this case.

Elderly patients, raised in an era when it was not appropriate to complain, may also not acknowledge discomfort. Social and family norms about pain also play a role. In some families, half an aspirin is considered major medication!

Untreated pain has now been shown to be a co-factor effecting outcomes in other ailments, so treating it is important for the patient at many levels. There are many methods to treat pain when it is diagnosed. Pain management is usually started with anti-inflamatory or mild analgesics, such as aspirin or Tylenol, but stronger medication may be called for. Often people do not get good pain management for fear of addiction to opioid medications, such as the Fentanyl patch or oxycontin. But there is little incidence of addiction when the medication is taken properly for pain. Anti-depressants are also often used, particularly for chronic pain such as neuropathy, fibromyalgia, etc. Sometimes physical therapy, nerve blocks, cortisone or muscle stimulation systems are helpful in dealing with muscular pain.

If you are concerned that your loved one is in pain, start by assessing for yourself what the source of the pain might be. Touching areas and asking if it hurts is a good beginning. When you have identified some possibilities, the next step is to inform your loved one’s physician that you think he/she is in pain, explaining as much as you know about the pain—when it started, where it is, how much discomfort the person might be exhibiting. What you want is for the doctor to explore further the possible cause of the pain.

Lab tests can be helpful to determine if the pain is from a urinary tract infection or a systemic infection. A physical exam can help the physician determine if something is swollen or an internal organ is enlarged. If the doctor can determine the cause of the pain, he/she can then consider treatments. If the physician cannot determine the cause of the pain, it might be necessary to work proactively with the physician to treat the pain even without a cause.

Be persistent in encouraging the physician to try different medications until there is relief for your loved one. Staying informed by checking the websites at the end of this article, for example, keeps you aware of your options and alternatives. If your loved one is a candidate for hospice, the nurses and physicians are experts on pain control and will work together with you to make your loved one comfortable. Facilities are required to have pain protocols, and if the nursing home or hospital is not assessing your loved one, you can ask to see  
their protocol.

Just because someone cannot talk does not mean everything is okay. It is important for family members to work together with physicians and facilities to make sure that they are evaluating, monitoring and treating pain in people with dementia. We can’t cure the dementia, but we can alleviate some of the suffering.

*For more information on pain management:*

**American Chronic Pain Association**, [www.theacpa.org](http://www.theacpa.org/)

**American Pain Foundation,** [www.painfoundation.org](http://www.painfoundation.org/)

**The National Pain Foundation**, [www.painconnection.org](http://www.painconnection.org/)

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