



# A Meditation On Suffering

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By Sr. M. PETER LILLIAN DiMARIA, O.CARM., LNHA and ALFRED W. NORWOOD, MBA

*The extreme greatness of Christianity lies in the fact that it does not seek a supernatural remedy for suffering but a supernatural use of it.*

— Simone Weil, *Gravity and Grace*

**T**he diagnosis of dementia is devastating to the person with the disease and to the family, friends and caregivers. Dementia is a progressive, irreversible loss of memory and cognitive abilities. As a person progresses through dementia, there are different types of pain that may cause behaviors. The pain-experiencing behavior often is attributed to physical pain, but caregivers also should consider whether these behaviors are a result of the person experiencing emotional, mental, spiritual or familial pain.

Every human being experiences pain at least once in his or her lifetime, and along with that pain comes a suffering unique to each person. Pain occurs in the body — we describe it by its intensity — and we experience it through physical, mental, emotional, familial and spiritual symptoms.

Suffering, on the other hand, takes place in the soul, a place so intimate that no words can help us express how it actually feels. Suffering is truly a mystery. This mystery is not a problem to be solved, rather, it is a journey we share with God, ourselves and, if we are able, with others. Our understanding of how we have suffered gives us the ability to soften the impact it may have.

Pain brings suffering that is different for each of us. Physical pain, which is the easiest kind of pain to address, affects each person differently in terms of how he or she may suffer. Simply put, a broken ankle brings a professional ballet dancer a kind of suffering that is unlike what I might experience if I broke my ankle.

A myriad of research has linked physical pain

to changes in mood and behavior. For example, osteoarthritis pain — not unusual in an aging population — was documented to create depressed mood because of the increased fatigue and disability osteoarthritis brings to a senior.<sup>1</sup> This combination of depression and pain all too often creates a downward spiral in which patients adhere less to pain interventions,<sup>2</sup> or they experience reduced effectiveness from formerly successful pain reduction therapies. These spirals lead to worsening of pain and disability over time.<sup>3</sup>

Recent research has found that different areas of the brain process pain that stems from different sources. For example, neural regions of the brain supporting empathy for psychological pain are not the same as those linked with empathy for physical pain.<sup>4</sup> We therefore have to look at pain from a number of perspectives and accept that not all pain is alike.

Most people spontaneously feel distress when they see someone in physical pain — observing the physical pain automatically triggers the response. In contrast, nonphysical pain can be complex and



relatively ambiguous, so simply watching someone who is experiencing emotional or spiritual pain may not automatically elicit distress.<sup>5</sup> That's probably because witnessing nonphysical pain requires additional thought processes in which the observer tries to understand the situation and imagine how it is affecting the other person. Only the most empathetic caregivers will show pain-

related neural activity.

According to research, "Nonphysical pain is a lasting feeling in that it endures, it does not pass quickly and it takes time to resolve. ... One does not experience psychological pain for just a few seconds or minutes. Usually, it is hours, days, weeks, or even longer, although the intensity of the pain may vary during that period."<sup>6</sup>

## FORMS OF PAIN

**H**elping a person understand what may be happening as he or she journeys through one or more form of pain may not remove the pain altogether, but it helps change his or her attitude toward it and, so, reduces the suffering. Many palliative care professionals refer to five types of pain:<sup>1</sup>

### PHYSICAL PAIN

People hold many misconceptions about physical pain when working with elders. For example, most people believe aches and pains are to be expected as one ages, and elders frequently feel they should not report them. However, physical pain left untreated can lead to a loss of stamina and independence. The person experiencing the pain begins to feel misunderstood and frightened as he or she becomes more dependent on others. Behavior challenges often are seen in people who experience different forms of dementia when physical pain is not addressed.

As caregivers, it is important that we allow each elder to express his or her physical pain and its impact on their lives. Our clinical skills are crucial to helping a person remain as independent as possible.

### FAMILIAL PAIN

Often a loved one's disease affects each family member in ways that are difficult to express to one another. The person with the illness begins to wonder, "What will my family think of me?" "Will I become a burden?" and "Will I still be

important in their lives?"

Families experience a roller coaster of emotions through any illness a loved one is experiencing. You hear things such as "Dad was the rock of our family, where will we turn now?" and "My wife, my love, did not recognize me today..."

### EMOTIONAL PAIN

The type of emotional pain each of us experiences is never easy to express. It takes time to name. Even in the naming, a person may find it is so personal that it never gets shared.

Emotional suffering is the most difficult to relieve. It has many faces. A person who has broken a hip not only has the physical pain to endure, but the incident may lead him or her to an entire lifestyle change. This change may bring feelings like this: "My grandchildren will never come to my home again because I am unable to return home." "My husband and I will never go on those vacation trips ever again."

### MENTAL PAIN

Mental pain, such as depression or delirium, includes emotional pain, but not all emotional suffering implies depression or delirium. Emotional suffering may manifest itself through different types of losses, such as making the transition to a nursing home. It can take on many forms of feelings — sadness, guilt, regret and anger. Those who do not express their feelings may demonstrate behavioral challenges.

### SPIRITUAL PAIN

Spiritual pain brings a feeling of a temporary loss of connection between the person and God. A person experiencing spiritual pain often feels that the meaning to his or her life is gone. The person may no longer find comfort in prayer or in his or her own faith traditions and begins to feel guilty. People who are experiencing spiritual suffering may feel spiritual concerns, spiritual despair or spiritual distress. Each of these must be recognized by the caregiver in order to help bring balance to a person's life again in the context of the new situation.

Clues to spiritual concerns are revealed in the questions a person begins to ask, especially the "why?" questions as the person tries to cope with a diagnosis. Spiritual despair results when a person's efforts to resolve distress are not successful. We begin to see a loss of hope, withdrawal, refusing assistance and a possible loss of a value system and/or God. Spiritual distress finds a person unable to apply beliefs to the new situation. The person may feel a sense of meaninglessness, guilt or anger towards God or the world.<sup>2</sup>

— Sr. M. Peter Lillian DiMaria, O.Carm.

### NOTES

1. I am grateful to Michael Brescia, MD, and Robert Brescia, MD, for teaching me about the five forms of pain.
2. Mary T. O'Neill, unpublished lecture, February 2013.



Psychological pain probably originated to protect ourselves or others from injury to experiencing emotions associated with lack of love or social support. The need to love and be loved is a core psychological need. We also know that untreated emotional, mental, familial and spiritual pain leads to a suffering that is very difficult to express in words.

### COMPASSIONATE LISTENING

As caregivers, we compassionately listen to the unspoken words of suffering. However, even in this compassionate listening, we must accept that we can never really know another's suffering. We must accept that people can begin to feel isolated and misunderstood when they sense that others do not know what they are experiencing.

Compassionate listening challenges us to be someone who brings peace to those who feel abandoned. It allows us to share in the silence of their inner being, thus opening their hearts and bringing new hope within.

What does compassionate listening look like? A priest friend of mine gave a splendid meditation on the Emmaus story in Luke 24 that I think helps us to understand the importance of listening. What is so striking about our Lord's example is that he taught us how compassionate listening can ease a person's suffering — not take it away, but helping to bring a “supernatural meaning to suffering,” as Simone Weil described it.

In the Emmaus story, we see that as Cleopas and his companion walk along the road from Jerusalem, they talk about all the things that had happened. During their conversation, we find them to be honest and emotional, and, all of a sudden, a stranger joins them. This stranger, the Lord, listens intently.

What our Lord does is accompany them. No matter what age we are, we need someone to walk with us. Accompaniment is always something very gently filled with empathy. As we accompany someone, communion is gradually built up, and mutual trust and desire for the truth increase over time. In all of our lives, at one time or another, we find it hard to look at the reality of the suffering we are experiencing. The one who accompanies has to wait patiently for just the right moment to help the sufferer accept reality.

The Emmaus story shows us what true min-

istry is all about. It means to walk with people patiently and compassionately, to be present for them, to listen — really listen — and to be non-judgmental. These are the essential good works of our day; they show the goodness of God, who makes all our experiences — sufferings, joys, successes, failures — come together in the most surprising of ways. All any one of us ever has to do is go to God in complete trust and to understand that all experiences seen through the eyes of faith bring us peace and hope.

### DEMENTIA AND PAIN

We begin to see the importance of understanding the various forms of pain: physical, mental, emotional, familial and spiritual. Skills alone do not make us better listeners; we must, as Jesus taught us, have a deep desire to connect with others. We connect by being present and allowing a person to share his or her pain.

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In order to be truly present, we must understand the loss of meaning, control, independence, position, status and ministry that is the impact of pain. The resulting suffering disturbs or disrupts the balance of emotional, physical, mental well-being and community and family life, thereby affecting the person's spiritual sense of wholeness.

When we understand pain and recognize suffering, we can bring a new dimension in our ministry to those who experience different types of dementia. We are aware that behaviors seen in dementia often are rooted in untreated pain. Just as a cognitively intact person experiences the various forms of pain, so too does a person with dementia.

More progressive senior services are recognizing pain as a comorbidity within dementia. Nonfunctional behaviors (also called behavior problems) are common in nursing home resi-

dents and can be divided almost equally into two main camps: active, that is, agitated or aggressive, and passive or depressive. Depressed mood or passivity behaviors are expressed by virtually all new residents and can be observed in up to 80 percent of longer term residents. Active agitated or aggressive behaviors are exhibited by over 50 percent of residents with dementia.<sup>7</sup>

Agitation, aggression and virtually all non-functional behaviors are stress-driven. In addition to pain, the three primary causes of stress are novelty, lack of control and social isolation.<sup>8</sup> To a new resident, everything is new, control is lost to caregivers and most residents feel abandoned. They are chronically stressed, and their stress reaction can be either active “fight” behaviors, such as agitation or aggression, or passive “flight or freeze” behaviors such as withdrawal, refusals or wandering.

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Residents with dementia have the additional burden of a reduced stress threshold<sup>9</sup> in which cognitive and memory losses accentuate the primary causes of stress. For example a resident without dementia often can learn and adapt to a new schedule of activities (resolve novelty), ask for and obtain things (gain some control) and form new social relationships with other residents or staff (regain social support).

The resident with dementia does not have these abilities and often also lacks the ability to communicate any such needs. Even though they may have a greater reaction to pain, residents with dementia receive approximately half the pain medication for physical pain that non-demented residents receive, and they cannot communicate or compensate for nonphysical forms of pain.<sup>10</sup>

As we begin to understand the roots of behaviors, we also must recognize the pains in all the elders we serve, whether they are cognitively intact or memory-impaired. We need to understand the emotional pain of a person with dementia who is asking to leave because her mom is

waiting for her. Or the mental pain of the person who has beginning stages of Alzheimer’s disease and is depressed because everything around her is “not making sense.” Or the familial pain of the person who believes that his daughter is his sister.

A person experiencing an imbalance because of these kinds of pain feels a disruption in his or her spiritual wholeness — that is spiritual suffering.

#### **SPIRITUAL SUFFERING**

We have no better teacher than Jesus when it comes to easing another’s suffering. Throughout the Scriptures, we see why the Lord heals and the importance of presence. Jesus teaches us how to “be with” a person who is suffering. His journey through the Stations of the Cross is a reflection in spiritual suffering.

The condemnation of Jesus to death is unjust, and his followers go into hiding, for they are fearful and do not understand. Jesus felt abandoned by his companions. His journey begins where he feels very much alone and misunderstood. In reflecting on the stations, we know that Jesus’ journey does not end with the crucifixion. Rather, his “purpose” in life begins with the crucifixion and is revealed in the resurrection.

When people receive their diagnosis, they may feel condemned and alone. As they receive their cross, they begin to walk their stations and along the way, they may fall. Their caregivers are near to walk the journey with them — the Veronicas to wipe the face, the Simons to help carry the cross, the women who weep for them — help them and encourage them. Their loved ones are nearby, approaching them, allowing them to walk through their journey, not alone, but with those who are called to serve those who suffer.

We know that Jesus accepts his suffering for the sake of his brothers and sisters. He understands that the will of his Father is to be done in order for him to proclaim God’s glory. Jesus’ life does not end on the cross, but rather it continues through his resurrection. It is not until we hear the Emmaus story that his suffering begins to make sense.

We are the Simons, Veronicas, the women who weep and the people along the journey. We begin to understand the importance of being present to those who suffer, especially those who suffer



spiritually. We know we must, as one of my colleagues, Mary T. O'Neill, BCC and CPE supervisor at Catholic Health Services of Long Island, N.Y., says so beautifully, "Be there with those who ask the difficult questions about meaning and direction. Be there to hear the pain and distress deep in the inner core of the person. Be there to listen beyond the words to the pain the words describe. Be there to help people put words on the pain — and help them feel heard and accepted.

"Be there to help them name what is important — what they need most from family, friends, community. Be there, not as the one with the answers, but rather as the one who can listen to the questions as the person struggles through the journey."

As caregivers, our challenge is to accompany those we serve to a place of new understanding, to be introduced to a new normal and to allow them to express an honest relationship with self, with others and with God. When we do these things, we allow people to know that they are not alone in their Stations of the Cross, their Emmaus story, because we are there to accompany them on this sacred journey.

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#### NOTES

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