

LIVING AT THE BOUNDARY:
HEALING AND INCURABLE ILLNESS

by

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I would like to introduce myself in a personal way because much of what I have to say about healing is a reflection of who I am and of my journey as a person living with incurable illness. At the age of twenty nine I was diagnosed with multiple sclerosis. Since then I have lived with increasing disability and have reflected deeply about what it means to live with illness and disability in the context of modern scientific medicine and the values of North American culture, as well as considering how we can best meet the personal and professional challenges of incurable illness. My reflections have been further deepened by the recent experience of sharing the last six months of my husband's life after he was diagnosed with cancer.

Today I want to draw on these experiences, as well as my experience of living in a Christian community, to explore what it means to heal and be healed. Healing relates to whole person care, to the preservation or restoration of a sense of personal well being, dignity and integrity that is not dependent upon the physical integrity of the body. Even in the absence of cure, it is possible to promote – and receive – healing.

I am convinced that such reflections have implications not only for medical practice and the care of patients but for the ways in which we ourselves respond to the existential challenges posed by illness, disability and death.

Healing as Opposed to Curing Disease

The need for healing relates to the fact that serious illness is experienced not just as a physical problem (the heart doesn't work right, the leg is paralyzed) but rather it represents a global experience of disorder – a loss of personal wholeness that includes loss of control, loss of certainty, loss of independence and self-respect, and the loss of the familiar world of work, home, and social activities.

A person can be **cured and not healed** (for example, a cancer patient whose disease is cured but for whom the radical alteration of her body through mastectomy causes a deep sense of loss of integrity and continued suffering); and a person can be **healed and not cured**, as in the case of someone with debilitating disease who retains a sense of personal integrity that enables them to live well in the face of illness. Indeed,

studies assessing the quality of life in patients with serious illness have demonstrated that the perception of wholeness or “health” does not correlate with physical well-being alone.¹ As an example, in a study of 50 cancer patients with active disease, one-third considered themselves to be “fairly healthy,” and two-thirds reported being “very healthy,” including twelve who died during the study.²

What I want to stress today is that healing is not a solitary endeavor. It involves health professionals, family members, friends, and other caregivers, and it relates in a significant way to the context in which we live our lives.

Loss of Wholeness in the Context of Modern Scientific Medicine

In thinking about loss of wholeness, it is important to recognize the profound impact of a diagnosis of incurable illness in the context of modern medicine. Given the undeniable success of scientific medicine, we harbor unrealistic expectations about the power of medicine to intervene and to “fix” medical problems. To find one’s condition cannot be cured is to experience an extraordinary sense of *loss of control*. I remember my sense of utter helplessness on hearing I had M.S. Incurable diseases happened to OTHER people, nameless people. People like me went to a doctor, got a prescription, took medicine and got better. I was completely unprepared for the possibility that there were limits to what medicine could achieve. In our culture we have an almost “magical” faith in doctors.

In particular, I recognized that M.S. was not just a problem with my body. It represented a total disruption of my life. We don’t just “have” a body (as we have a car, a house, or a dog) rather we live our lives through our bodies. Because of this, diagnoses always have personal significance. You could have 2000 patients with breast cancer who have the same pathology, and they will have 2000 different experiences of the illness.

Diagnoses mean much more to patients than simply the identification of a disease state. The dread diseases – cancer, AIDS, multiple sclerosis – carry with them particularly powerful symbolic meanings. In receiving such a diagnosis, one is forced to deal not only with the physical symptoms of the illness, as well as the profound uncertainty that accompanies it, but to confront the personal and cultural meanings associated with the disorder. The stigma that accompany diseases such as cancer, as well

as the negative stereotypes associated with physical disability, set one immediately apart from others and contribute to a profound sense of aloneness. One is faced not only with the question, “What does this illness mean for ME now and in the future?” but, as importantly, “What does this illness mean for me in my relationship with others?”

In my own case I found that my diagnosis affected the way others thought about me. Once others knew that the symptoms indicated I had M.S. they treated me differently. Many urged me to immediately change my life plans in light of the future possibility of debilitating disease. Indeed, a survey carried out at a large MS clinic in Ontario showed that simply receiving a diagnosis of MS was equivalent to moderate disability, regardless of the actual severity of the symptoms.³

Diagnosis of Cancer

A diagnosis of cancer carries with it the possibility of particularly severe forms of threat. In his book, “At the Will of the Body,” Arthur Frank shares how differently people reacted to his experiences of heart disease and cancer. While heart disease simply evoked sympathy, cancer carries with it a stigma that made people withdraw in the face of the diagnosis.⁴

When my husband, Dee, was diagnosed with advanced oral cancer the world, as we knew it, was totally and effectively shattered. In an instant we were faced with the terrifying reality that he was going to die, not just at some unimaginable and unidentifiable point in the future but in a finite span of time. Although all of us acknowledge in an abstract way that we are going to die, most of us act in the present as if we do not really believe it. Life-threatening illness brings us face-to-face with the fact that our most cherished assumptions about personal indestructibility and the absolute control we have over our lives are illusions. It raises ultimate questions of meaning and value. What things are truly important to me? How best can I live out the life I have left? What choices should I make? What is the source of ultimate meaning in my life? In this sense, life-threatening illness is experienced as an existential and spiritual crisis, not just a physical one. Many patients report that paradoxically this existential crisis represents a healing opportunity – the occasion to clarify personal values and to think deeply about what is meaningful in their lives. Many also report that it is an occasion for deepening their experience of God.⁵

In confronting these questions of meaning and value in my husband's situation, the most urgent question we faced was the medical choice: whether to undergo radiation and chemotherapy treatments and the *possibility* of prolonging his life, or to let the disease run its course. This decision was, of course, influenced not only by the medical facts but by the totality of meanings and values that permeated the entire narrative of our lives individually and together. After much thought and discussion, Dee concluded that the burdens of treatment outweighed the possible benefits. His major concern was for the quality of the remainder of his life. He never wavered or doubted his decision and was perfectly at peace with it. As he put it, "I have lived 80 good years and we have had 31 wonderful years of marriage. So we're not complaining, are we?" Dee's decision was not a passive resignation – a hope-less 'giving-up' in the face of his diagnosis. Rather, it was an active determination to live as fully as he could in the face of death.

We were buoyed in our decision by the unwavering support of family, friends, and a physician, who all told us from the very beginning, "We will be with you every step of the way." These were not just empty expressions of support. On hearing the diagnosis, friends in the 900-member Christian community at Brazos de Dios, of which I am a part, immediately volunteered to help provide total care for Dee (just as they have for several other aging and terminally ill patients). We then met to formulate specific plans. Dee fully participated in all the decisions, indicating what kind of medical interventions and other forms of help he desired. For instance, he did not want the insertion of a feeding tube; he preferred not to have morphine, if possible; he wanted to die at home. Knowing these plans were in place and having the assurance that we would never be alone, no matter what the future held, gave us courage and allowed us to remain whole.

We also held fast to the hope that is ours by virtue of our Christian faith. As Christians, we believe that physical death is not the end of the story in God's eternal purposes. Beyond the suffering of Calvary lies the promise of the Empty Tomb. As Dee told the cancer doctor, "We know this is not the end – it's a new beginning." Living in the context of Christian community, we know this promise is not an illusion. We have witnessed the deaths of several dear friends and have seen firsthand the grace and peace that carried them through the pain and the suffering. Each one shared powerfully about

the faithfulness of God. For instance, our friend, Perry – who died of Lou Gehrig’s disease at the age of 35 – had been unable to talk for more than a year. Just moments before he died, he regained the ability to speak. In a clearly audible voice, he asked those gathered with him to tell everybody that God is “faithful all the way to the end.”

We were also sustained by the many prayers offered on our behalf – by the cancer physician, by friends in churches in Waco and around the U.S., by the congregation of a little country church in England, and in the 24-hour prayer chain and daily prayers of all in our community. The prayers were healing not only in the sense that they gave us the grace to face the daily trials with courage but they provided healing in very specific ways. Whenever my husband experienced severe pain, we would alert the healing prayer chain and our ministers would come immediately to the bedside to pray for Dee. Each time they laid hands on Dee and prayed for the relief of his pain, he would fall into a deep healing sleep.

Isolation

A major source of suffering in incurable illness is social isolation. In an era when we have incredible technology engaged in keeping people alive under the direst circumstances, many have come to view death as a failure of medical science, rather than accepting it as a natural part of life. Given this perspective on death, people tend to withdraw from the incurably ill. A hospice patient shared: “You know my wife used to kiss me on the lips, then she kissed me on the forehead, then she patted my shoulder, and this morning when she left, she wiggled my toes.”⁶ Although his wife was probably unaware of her behavior, she was slowly but steadily withdrawing from her husband. When others withdraw in the face of illness, the sick person experiences a social death prior to physical death.

Loss of Voice

One of the isolating factors in illness is what I shall call “loss of voice.” The sick person feels alone because he is unable to communicate his experience of personal distress to others. This often occurs in the clinical context where two distinct “voices” characterize the dialogue between medical professional and patient: the “voice of

medicine” articulating the biomedical perspective, and the “voice of experience” articulating the existential perspective.⁷ The “voice of medicine” is reflected in the medical history and expressed in the terminology of objective clinical data: blood counts, EKG’s, pathology reports, and so forth. The “voice of experience” is reflected in the clinical narrative – the patient’s account of the many ways in which the illness disrupts daily life.

As many patients know from firsthand experience, and as empirical studies have shown, more often than not the voice of medicine predominates in the typical medical interview.⁸ One study found that, on average, physicians interrupted patients 18 seconds after the patient began to speak and patients were able to complete their statements in only 23 percent of visits.⁹ When patients are unable to share their particular stories of illness, they feel themselves marginalized and cut off from an important source of healing.

Attentive listening is vital to the healing endeavor. As Sir William Osler told a medical student, “Don’t just *do* something, *stand* there!” While health professionals do not (and cannot) have all the answers, they are in a unique position to be present as incurably ill patients come to grips with the reality of their physical condition.

In terminal illness the “loss of voice” also occurs when others refuse to acknowledge that the patient is dying. While the dying person does not want to focus exclusively on his death, when others act as if nothing has changed and refer to the future as if the person is going to fully recover, this pretense closes off all possibility of sharing feelings, hopes and fears. A recent study of terminally ill cancer patients revealed that many doctors are uncomfortable talking about death with their patients. Only one third of the patients surveyed said their doctors had discussed end-of-life care, even though patients who had such discussions were no more likely to become depressed than those who did not; they were less likely to spend their final days in hospitals, tethered to machines; they avoided costly, futile care, and their loved ones were more at peace when they died.¹⁰

For my husband, one of the most important healing relationships was with his doctor, a member of our community who acted not only as Dee’s medical adviser but as his trusted friend and counselor. He came to our home almost every day, as much to visit

and pray with Dee as to check on his physical state. Throughout Dee's illness, he provided healing communication and relationship.

Healing Communication

Healing communication is possible even when the "loss of voice" is a physical manifestation of disease. Even though Lou Gehrig's disease robbed him of speech, our friend, Perry, continued to be very much a part of our lives, attending community events, gathering with friends, ministering to his family as a loving father and husband. Nobody ignored Perry because he could not speak normally, nor were they discomforted by his affliction. Indeed, the healing communication worked both ways: In the midst of his struggle with adversity, Perry encouraged others to persevere in their own trials.

As the tumor in Dee's mouth grew, he too found it hard to speak. But our experience taught me anew about the varied ways in which we communicate with one another: through speech to be sure – and I spent many hours bent over Dee, watching his lips, and trying with all my might to decipher the words he so laboriously tried to pronounce – but we also communicate loudly with one another through touch, through gesture, through facial and bodily expressions, through demeanor and attitude. Dee was surrounded by caregivers who provided healing communication not only through their words, but through their gentle and loving touch, their patience, diligence and good humor in carrying out every task, their care-full (rather than care-less) attitude, and through their unwavering regard for his dignity and personal well-being.

Dee also never felt isolated. Until the last couple of weeks of his life, he would sit in his recliner from mid afternoon till nine or ten at night, visiting with friends and family. A young couple came by each week to sing for us, teenagers brought their gifts of music, and small children drew pictures for him. Others telephoned regularly and sent cards and words of encouragement. When Dee became bedridden, people came each day to sit by his bedside. Dee died in my arms and in the presence of two of his closest friends.

Relationship vs. Independence

In reflecting on these healing experiences, I am reminded again that healing is not a solitary endeavor. We need each other to provide healing and to be healed. Studies with terminally ill patients have demonstrated that those patients who experience a sense of connectedness and relationship are more likely to retain a sense of personal integrity and wholeness.¹¹

The paradox is that we live in a culture that de-emphasizes relationship, placing inordinate value on autonomy and self-reliance. This perspective greatly adds to the suffering of the incurably ill. There is a strong cultural message that we should be able to look after ourselves, make our own decisions, “stand on our own two feet.” Dependence on others is perceived as weakness. Furthermore, connected to this ideal of autonomy is the sense that each person should be able to “do their own thing” without a sense of limits. Given this emphasis, the act of serving another is often negatively equated with self-denial. Full-time caregiving is deemed less valuable than pursuing activities that will bring individual fulfillment. When caregiving is conceived in these terms, this inevitably arouses feelings of resentment on the part of the caregiver and incalculable feelings of guilt and self-recrimination on the part of the person receiving care.

Given this cultural perspective it is not surprising that the fear of “being a burden to others” can be overwhelming for patients with incurable illness. Indeed, published statistics on physician-assisted suicide show that this fear is a prominent reason that patients give for requesting physician-assisted suicide.¹²

Doing vs. Being

The loss of autonomy is also profoundly disturbing because of the cultural emphasis on “doing” as opposed to “being.” A person’s worth is judged according to the capacity to produce (to be useful) or the ability to achieve a certain professional status. When we say to our children, “You can *be* anything you want to be,” what we mean is that you can achieve worth through *doing*.

A person who is unable “to do” feels diminished by the inability to engage in projects that are judged meaningful according to societal standards. Also, illness disrupts

social roles – husband, mother, friend – causing the sick person to feel that he is failing to fully contribute in areas of family and social life. This is particularly the case in terminal illness where not only is one unable “to do” things *now* but there is a recognition that life (and the future possibility of “doing”) is coming to an end. Dee shared with me many times that the most agonizing aspect of his illness was the recognition that he would not be able to take care of me. He had looked after me faithfully “in sickness and in health” for 31 years and he couldn’t bear the thought that he could no longer fulfill this role. “I am supposed to be the caregiver in the family,” he would tell me. When I assured him that we were surrounded by friends who would step in to help me, Dee responded, “But I wanted to do it.”

Recognizing that the assessment of personal worth has as much to do with “being” (or character), as it does with “doing,” is a vital step in achieving wholeness (in health or in illness). As a woman with Parkinson’s disease told me, “I always imagined that when I became a grandmother, I would *do* a lot with my grandchildren. Then I got Parkinson’s. However,” she added, “now I realize that I can *be* for my grandchildren.” This was a very empowering realization for her.

Acknowledging the importance of “being” also reminds us that it is vital to look *beyond* the disease to the *person*. We live in a culture that is obsessed with physical fitness, sexuality and youth. Health is equated with complete physical integrity. Consequently, the able-bodied find it difficult to imagine that persons with disabilities can live meaningful lives, or that they have anything to offer to others. Towards the end of his life, our friend Perry was in a store with his wife and children. Emaciated from advanced ALS and in a wheelchair, he did not meet the worldly ideal of physical beauty and strength. A saleswoman, eyeing his physical condition, said to his wife, “I can’t believe you’ve stuck with him!” In judging Perry’s worth solely on the basis of outward appearance, this woman completely missed the strength and beauty of his spirit.

I have experienced similar negative attitudes. Often strangers have said to me, “Aren’t you *lucky* to have your husband?” This remark was not so much a comment on my husband’s character, as it was a perception that my relationship with him was solely one of burdensome dependence.

In observing my physical incapacities, strangers also assume that my intellect is

likewise affected. People address questions to my companion and refer to me in the third person, “Where would *she* like to sit?” This invariably occurs when we travel through airports. We roll up to the security barrier and the person at the barrier turns to my companion and says, “Can *she* walk at all?” My husband developed a standard response. He would say, “No, but *she* can talk!”

In a national survey, women with severe disabilities reported that doctors also routinely addressed questions to their companions. “Is *she* experiencing any pain?”¹³ Such negative responses from others reinforce the sick person’s sense that disability reduces personal and social worth.¹⁴

Living in a Christian community, I am reminded that Christian values turn the cultural perspective on the importance of “doing” versus “being” upside down, thus providing a context of healing. The emphasis for the Christian is not so much, “How do I define myself by my role?” but “How do I live out whatever role God has provided for me?” “What kind of a *person* am I?” Christian virtues such as compassion, kindness, humility, gentleness and patience, have to do with *character*.¹⁵ While these virtues *are* exercised through acts, they relate to a way of being in the world that is not dependent upon physical attributes or abilities and that does not look to the world’s criteria of success. Furthermore, a central tenet of Christianity is that all human beings have intrinsic worth, regardless of any contingent circumstances.

The Value of “Being” and the Reciprocal Nature of Caregiving

When I think of the value of “being,” I think of the many terminally ill patients I have known, who – at the end of their lives – were able to “do” nothing but who were (and remain) a powerful influence in the lives of others. For instance, I remember Robert, a 49-year old father of five who died of a brain tumor and who, throughout his illness and dying continued to minister, not only to those who came under his pastoral care, but to his caregivers and to all who came in contact with him. Indeed, dozens of young people in our community have testified that Robert’s experience of grace and fortitude has been a major influence for good in their lives.

I think also of Dee. As his cancer progressed, he became less able to “do” anything – he couldn’t walk, he was unable to eat solid food, he found it difficult to

speak, he couldn't hold a glass to his lips. Yet, he remained steadfast in courage and never once complained. He retained his sense of humor to the very end of his life. He accepted all the burdens and indignities of illness with grace. Rather than focusing on his own needs, Dee was more concerned about how his illness was affecting me and others who cared for him. When we would ask him how he would like us to do something, he would always respond, "Whatever is easiest for you." Almost every word that came out of Dee's mouth was a word of gratitude for the care he was receiving, for the life he had lived and for the love that he and I experienced together. On the day he died, speaking of the ladies who had served him, he said: "I love every one of them. I hope they know how much I love them ... and I am trying not to be a pain." In the last few days, he thanked every person who came to see him for everything they had ever done for him and for us.

That it was possible for Dee to be fully himself (to remain whole) in these circumstances was in large part due to the fact that he was surrounded by people who cared for him in a loving and respectful way. In this sense the healing relationship is a reciprocal relationship. In providing loving and supportive care, Dee's caregivers affirmed to him that his illness did not denigrate his worth as a person. This enabled him more easily to accept the increasing physical reductions and indignities that were an inevitable result of his disease. Thus, he responded in ways that were encouraging to us, as caregivers.

Too often we assume that caregiving is a one-way street – that the sick person, the recipient of care, has nothing to offer. This is a radically impoverished view of human relationship that inevitably frustrates the healing process. If we can recognize that caregiving is a form of communion with one another that (because of the difficult circumstances) offers unique opportunities to serve, to learn, and to develop deep and abiding relationships, then we can experience the giving and receiving of care as a blessing and not a burden.

In the context of Christian community the blessing of caregiving is a given. Rather than pursuing the goal of radical autonomy and self reliance, we are called to live out our lives in relationship – relationship with God and with each other. This covenantal relationship in our lives as Christians is built upon the foundation stone of self-sacrificial love, a love that is exemplified in the life and death of Jesus. "Greater love has no one

than this, that one lay down his life for his friends.”¹⁶ Since love, rather than self-determination, is the cardinal value, caregiving (care of and for another) is not considered a negative form of self-sacrifice but, rather, the focus is on honoring and serving one another as an expression of the love of God. The values and practices that spring from this ethic of love necessarily promote healing.

There are many forms of caregiving. For three months, I was able to take care of Dee’s personal needs myself, giving him showers, assisting him to dress, helping him to move from the bed to other areas of the house. As Dee became weaker, he would hold on to the back of my motorized wheelchair in order to walk (just like water-ski-ing, he joked). When Dee had to use a wheelchair, I simply got behind his wheelchair and pushed it with mine. One of my biggest struggles was to hand over this care to others when Dee became too weak for me to manage alone. However, around this time, one night Dee awakened in severe pain. I was holding him and praying for him and I felt an inner voice say, “*This* is the most important thing you do.” Accepting help with Dee’s physical care enabled me to focus more closely on other needs – emotional and spiritual – and gave us the opportunity to form deep relationships with those who cared for him.

Loss of Control

Studies with cancer patients have shown that loss of control is a major source of suffering. Learning to let go is an important step in healing.¹⁷ Often it is hard for patients to give up control in all aspects of their life. When a dear friend became debilitated from cancer, she found it particularly difficult to give up full responsibility for taking care of her own home. Yet she discovered that letting go in this area of her life gave her the opportunity to experience depths of affection and thanksgiving she had never felt before. Likewise, in deliberately asking others to take care of me in the future and accepting their love and service in return, Dee gained a peace that allowed him to step back and gratefully surrender my care into the hands of others.

Focusing on the present is also a valuable means of learning to live with the uncertainty of incurable illness. Living with MS and cancer taught us the importance of harnessing the imagination. Rather than dwelling on what might (or might not) come to pass, we learned to concentrate on real rather than imagined difficulties (for instance,

working out how best to transfer from bed to wheelchair rather than worrying about what we would do when Dee eventually became bedridden). Dealing with problems on a daily basis gives one a certain amount of control and prevents one from becoming paralyzed with fear. It is well to remember also that in sickness *or* health our knowledge is necessarily fragmentary. We can never know exactly what the future holds. In the case of illness, prognoses are necessarily uncertain and can never predict exactly what will happen in an individual case. In Dee's case, none of the really awful symptoms that the cancer doctor predicted ever came to pass.

Confronting Dee's mortality also showed us the healing power of surrendering our illusions about control, certainty, and physical strength and giving everything into the hands of God. We knew for certain that we could not rely on our own strength, that -- like the psalmist -- when our heart was overwhelmed we had to "reach for the Rock that is higher than I."¹⁸ But we also held fast to the promise, "My grace is sufficient for you, for my power is made perfect in weakness."¹⁹

Loss of Bodily Control

One kind of loss of control causes particular suffering. For many the loss of bowel and bladder control represents the most grievous experience of loss of dignity. Not only does one feel oneself reduced to the status of an infant (with the accompanying sense that, as an adult, one really "ought" to be able to exercise control) but there is the ever present threat of public humiliation. This threat can be overwhelming in light of cultural attitudes that treat such disorders with contempt. Indeed, losing control of bodily functions is one of the commonly mentioned reasons for requesting physician-assisted suicide.²⁰

In taking care of Dee at the end of his life, I was most grateful for the fact that I have lived with MS for over thirty years. I know what it is like to live with a body that does not work, with progressive weakness and limitation, with boundaries and givens in my life. Having experienced bowel and bladder disorders myself, I understand the powerful feelings of degradation that accompany them. Thus, I was able to help Dee recognize that his body's failings were a purely mechanical problem for which he was not personally responsible. This enabled him to retain his sense of dignity, and even humor,

in the most trying circumstances. It is vital that caregivers demonstrate by their actions and responses that they are not repulsed by the loss of bodily control. If you can demonstrate to me that my illness does not degrade my worth as a person, you affirm me in a powerful manner.

Bearing Witness --- Suffering

I do not want to give the impression that I am minimizing or “sugar-coating” the physical, emotional and spiritual challenges that are a part of incurable illness. Living with illness is hard – both for the sick person who must endure the physical symptoms, for the caregivers who must deal with the “mess” of sickness, and for loved ones who witness the battle. It was hard to see Dee in pain. It was heartbreaking to see his body eaten away with cancer. It was agonizing to think of losing him. But I would not give anything for the experience of caring for him the last six months of his life. Strange as it may seem, this time was very precious to us. Both of us agreed that it was a blessing and a gift. I have never really understood the purpose of suffering before but, in our experience of suffering, I saw how the incredible love that Dee and I shared for one another throughout our marriage was distilled and purified. As our boundaries constricted more and more, and the reductions of illness became greater and greater, our love became stronger and stronger until in the end there was nothing left but our love for one another, the love we felt from those around us, and the love we felt from God.

Bearing witness to another’s pain is not an easy task but it is at the heart of the healing endeavor. What the sick need is someone to accompany them on the journey that is their illness. Genuine compassion (suffering with) is not possible from a distance.

On the day Dee was diagnosed with cancer, I wrote in my journal, “We are in the Garden of Gethsemane.” I thought of the disciples. While Jesus was in agony, *they* slept. One gospel account says they were “exhausted with sorrow.”²¹ And I shared with a friend that my greatest fear was that I would abandon Dee – that I would not have the fortitude to witness his pain and the courage to stand with him in his suffering. My friend responded: “We will stand with you.”

Knowing I did not face this trial alone enabled me to be fully present with Dee, to stare death in the face and remain intact. In thinking of the Garden of Gethsemane, I was comforted by the knowledge that Christianity does not turn its face away from the agony

of personal suffering. As Christians, we serve a God who shared in the experience of suffering –a “man of sorrows” and “acquainted with grief.”²² Our human suffering is not unnoticed, nor dismissed as meaningless, nor does God withdraw from us. The God of love is Immanuel which means God with Us.²³

I was also reminded that the gospels record that, in *His* agony, Jesus prayed “may this cup be taken from me,” but He finished His prayer with the words, “Not *my* will but *Thine* be done.”²⁴ As difficult as it was, when Dee and I prayed this prayer, we experienced a supernatural grace that carried us through every trial and that really did give us the peace that passes all understanding. The lesson from the Garden, says Balfour Mount, is that “God is with us in our pain.” His omnipotence is “not expressed through the banishing of our ills but in their ultimate defeat through His gift to us of his all-sufficient grace.”²⁵

One day, when Dee battled severe physical distress, I said to him, “I’m sorry you have to go through this.” He responded, “This is a healing experience for me.” The grounding for this “healing experience” was the supernatural love that encompassed us, as that love was expressed through the self-sacrificial service of others. We really could say, “Yea, though I walk through the Valley of the Shadow of Death, I shall fear no evil, for Thou art with me.”²⁶ From my personal experience of the deepest Valley, I can attest to the truth of the song: “Love lifted me, when nothing else would help, Love lifted me.” The lesson from the Garden is that suffering, no matter how intractable, can be redeemed.

I want to end with a quote from Michael Mayne, the former Dean of Westminster Abbey, who (following months of agonizing physical pain after radical surgery and radiation treatments) died from an oral cancer similar to Dee’s. Michael wrote:

“When he was dying of a rapid cancer my friend and colleague Giles Ecclestone spoke of his attempt to view his death as ‘a gift.’ That’s hard; some will even think a bit perverse. And yet he was entirely right. Our lives are sheer gift, as is the creation, and that our little lives are ‘rounded with a sleep’ as they transmute from one phase to the next ... is as natural as being born. We each choose to die in our own way, though for some it will be harder than for others, but if we can see it as ‘gift,’ then it will be so insofar as we face it in such a way as to draw good out of it; trying (however reluctantly, however painfully) to deliberately unseal our clenched fists and let go of what we have been given with open hands. To die with gratitude for all that has been, without resentment for what you are going through, and with openness towards the future, is the greatest gift we can leave those who love us and who are left behind.”²⁷

Dee left me this greatest of gifts. Our experience has changed forever the way I think about healing, about caregiving, about dying and what constitutes “a good death,” about grace and faith and hope and courage, and it has filled me with an immense gratitude for the life I have lived and all that I have been given. It has been a truly healing experience for me.

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- ¹⁸ Psalm 61:2
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- ²⁰ Eighth Annual Report on Oregon's Death with Dignity Act.
- ²¹ Luke 22:45.
- ²² Isaiah 53:3-5.
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