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About spiritual care

A terminal illness leads us to grapple with a range of emotions, questions, and insights. Many of these feelings – including fear, anger, powerlessness, and despair – are signs of spiritual distress. Yet, even when facing death, we can find solace in feeling appreciated, sharing our life stories, and expressing gratitude and hope. Spiritual care encourages reflection on successes and failures, hopes and sorrows, and values, goals, and wishes.

Mission Hospice’s spiritual counselors offer care to those from a broad range of cultural and religious traditions, as well as those with no religious or spiritual beliefs. Knowing we are more alike than different, our spiritual counselors and their calming presence create an environment in which spiritual healing can occur.

Spiritual care at the end of life

Few of us are comfortable facing death, so by its very nature, admission into hospice care can create a spiritual crisis for patients and families. Spiritual counselors are there to identify spiritual strengths and concerns, and guide the clinical team by adding relevant problems, issues, opportunities, goals, and interventions into the patient’s Plan of Care.

A comprehensive spiritual assessment is not a one-time event but an ongoing process. Therefore, when newly admitted patients decline Spiritual Counselor support at admission, the clinical team and volunteers involved should informally assess the need for spiritual care throughout the patient’s hospice care. When the needs become apparent, as a volunteer you should notify the Volunteer Services Director.

Research evidence shows that spiritual care is essential to patients’ and families’ sense of well-being. People with life-limiting illnesses consider that their quality of life improves when their spiritual needs are addressed. In addition, they value spiritual beliefs and practices, often using them as a way to cope with their fears or to strengthen their hope.

As a Direct Care Volunteer, you might notice spiritual pain and suffering arising during this tender, vulnerable time for both patients and their families. This overview of spiritual care will help you:

- Understand compassionate service
- Learn the difference between religion and spirituality
- Define spiritual pain and suffering
- Recognize signs of spiritual pain and suffering
- Identify interventions hospice spiritual counselors use to address spiritual needs
- Know when to report spiritual issues to the Director of Volunteer Services

1 • Compassionate service

Just as birth and death are spiritual acts, giving one's time and talent through compassionate service to others is a spiritual act, as well. At the center of these acts are mystery and awe.

At their core lies a deep connection to that which is greater than we are – the Ground of Being, the Great Mystery, God, or any of the many names given for The Divine. When we give of ourselves from this place in consciousness, all that we give is sacred; all that we receive is holy.

Understanding the differences between “fixing,” “helping,” and “serving” allows us to approach patients and families with compassion and genuine warmth, rather than with pity and professional warmth. As clinicians and volunteers, we are not their personal friends; we are their “anam cara” – their soul friends – accompanying each one on this final part of his or her earthly journey. Blending our education and training with compassionate hearts, we aim to create spaces where their pain and suffering are minimized and their sense of peace increased.

Differences between fixing, helping, and serving

Fixing

Fixing is a mechanistic model for objects. We fix or discard broken things. Dying is a natural process that all of us will experience one day. Because nothing is broken when one is dying, nothing requires fixing. Death is not the enemy. Although slowly improving, the medical system has, for decades, been incongruent with human needs, especially with those of the dying. Hospice and palliative care movements have led the way in correcting this by joining warmth and compassion with clinical skills and practices.

Helping

Helping is the “follow me” model. “I am the professional. I know the way.” Helping is characterized by separation and difference, by one being superior and the other subordinate.

Difference hurts when one is vulnerable, and the dying and their families are always vulnerable. Eliminating a sense of separation between ‘them’ and ‘us’ fosters a healthy, caring relationship.

Serving

Serving brings our whole and authentic selves to the encounter – our strengths and limitations. This authenticity moves us closer to the sufferer with empathy. In a sense, we become gardeners rather than mechanics. Mechanics fix things. Gardeners enable the garden to bloom under good conditions. In this kind of compassionate service, we encourage deeper, more meaningful connections with and between patients and families, fostering wholeness and growth.

Compassion vs. pity

“Compassion is the spontaneous response of love; pity, the involuntary reflux of fear” (from “How Can I Help?” by Ram Dass). Patients and their families respond well to compassion but are put off – if not repulsed – by pity. Often we equate the word “pity” with “sympathy.” The American Heritage Dictionary shows them as synonyms. Still, they differ. Pity often leads to a sense of superiority, where the “pitier” stands above the pitied. Sympathy, however, is a social affinity in which one person stands with another person, closely understanding his or her feelings. It is an accompaniment, a companionship.

How can we avoid pitying the dying? We must ask ourselves these questions: “Does my understanding scare me or aid me in being with suffering?” “Can I sit with my own fears?” If we as clinicians and volunteers cannot sit with our own suffering, we will be unable to sit with the dying in theirs. When families are suffering, they often find it difficult to ask for or accept support. If they do accept, they may do so grudgingly. And if we ourselves cannot accept support, we cannot really give it. The more conscious we are of dealing with our own suffering, the more sensitive we will be to the needs of others in their own difficult places.

Roshi Joan Halifax, Founder of Upaya Zen Center in Santa Fe, NM, and world-renowned author and speaker, says the following about compassion:

“Compassion may be defined as the capacity to be attentive to the experience of others, to wish the best for others, and to sense what will truly serve others. Ironically, in a time when we hear the phrase ‘compassion fatigue’ with increasing frequency, compassion as we are defining it does not lead to fatigue. In fact, it can actually become a wellspring of resilience as we allow our natural impulse to care for another to become a source of nourishment rather than depletion.

Developing our capacity for compassion makes it possible for us to help others in a more skillful and effective way. And compassion helps us as well. Findings from recent studies suggest that compassion plays a significant role in reducing physiological stress and promoting physical and emotional well-being.”

2 • Religion and spirituality

Variety of faiths & belief systems in patients

Our Spiritual Counselors have cared for patients and families of many faith beliefs, including:

Roman Catholicism	Shinto
Byzantine Catholicism	Church of the Latter-Day Saints of Jesus Christ (Mormon)
Greek Orthodox	Jehovah's Witnesses
Russian Orthodox	Seventh-Day Adventists
Protestantism	Unity
Judaism	Gnostics
Islam	Agnostics
Hinduism	Atheists
Buddhism	"Spiritual but not religious"

Definitions from the Health Care Chaplaincy Network

Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices.

Religion is defined as a subset of spirituality encompassing a system of belief and practices observed by a community, supported by ritual that acknowledge worship, communicate with or approach the Sacred, the Divine, God (Western cultures) or Ultimate Truth, Reality, or Nirvana (Eastern cultures.)

“To live is to suffer; to survive is to find some meaning in the suffering.”

– Friedrich Nietzsche

Pain and suffering in spiritual matters

Problem-centered	Existential/transcendental
Fear of dying/death	Philosophy of life
Fear of abandonment	Expressions of spirituality
Hopelessness	Important past or current events
Spiritual emptiness	Feelings about a higher power and self
Guilt, shame	Disbelief or doubt about an afterlife
Unresolved grief	Existential meaningfulness
Loss of meaning in life	Loss of faith
Loss of identity	Desire to forgive or to be forgiven
Unfinished business	Desire for comfort and peace
Unresolved conflicts	Desire to be loved
Confusion or doubts about spiritual beliefs	
Reconciliation	

Pain and suffering in religious matters

Rituals	Problems and barriers
Anointing	Alienation from faith community or God/Higher Power
Baptism	Religious concerns about hospice or palliative care
Confession and penance	Unanswered prayers
Expressed feelings toward God/Higher Power	Confusion or doubts about religious beliefs
Meditation and guided imagery for the emotionally healthy	Difficulties carrying out religious practices
Prayers and blessings	Desire for stronger faith or beliefs
Sacraments	Desire to resolve feelings of guilt & shame
Religious/scriptural readings	Desire to forgive or to be forgiven
Worship service	Religious differences that create family conflict
Weddings/vow renewal	

3 • Spiritual pain

Spiritual pain is “any unpleasant sensation occurring in varying degrees of severity as a consequence of injury, disease, or emotional disorder.” (From *The American Book of Living and Dying: Lessons in Healing Spiritual Pain.*)

It is not optional but it is purposeful, in that it allows us to identify the source of the pain and to find ways (interventions) to address it. Left untreated, spiritual pain can exacerbate physical pain and lead to spiritual/existential suffering.

Spiritual suffering is an optional response to the pain of disease, old age, and dying because it is often a choice that one makes for the good of others – for family, friends, beliefs, or patriotism. Suffering can worsen physical pain and prevent effective pain and symptom management. Often, pain causes us to feel helpless and motivates us to end the suffering. Supporting the patient and family in using their spiritual strengths as coping tools can alleviate suffering.

Still, sometimes patients and families choose not to address their suffering, which often creates challenges for their hospice team. At these times, we must remember that this is their process, their journey, which requires that we meet them where they are and be with them in their suffering as compassionate, empathic companions, secure in our understanding that accompaniment can be comforting, if only for brief moments.

Assessment of spiritual pain

from the Sacred Art of Living Center, www.sacredartofliving.org

Meaning Pain

In the dying, Meaning Pain leads to the questions, “Who am I now?” “Who am I becoming?” “What has my life meant?” “How do I make sense out of my illness and death?” A crisis in meaning creates even more questions, such as those pertaining to The Mystery, ambiguity, purpose, and transcendence.

Forgiveness Pain

Forgiveness Pain results from our inability to forgive. It is not condoning the hurt and suffering that resulted from the sense of betrayal. It is not denying that the insult ever occurred. It is not inviting reconciliation with the offender or forgetting that emotional scars remain. Instead, it is “releasing our hold on the other person’s jugular,” letting go of negative emotions that no longer serve us. It is freeing us from remaining the victim. Often the most challenging person to forgive before death is not another, but ourselves.

Relatedness Pain

Relatedness Pain results from resisting the reality that the seasons of life are natural cycles, as we learn in *Ecclesiastes* 3:1-2, “To everything there is a season, and a time to every purpose under the heaven: A time to be born, and a time to die....” It is the inability to accept life as it comes. It is the unwillingness or fear of making the best of difficult situations, by turning away from them rather than *leaning into* them.

Hopelessness Pain

As described in *The American Book of Living and Dying: Lessons in Spiritual Healing*, Hopelessness Pain is the terminal illness of the human spirit. It results from a fear of letting go of the familiar, and it is an inability to imagine what could be life-giving. Even as one is dying, Hopelessness Pain is a loss of the will to live as well as one can for as long as one can, and the resistance to adapting and adjusting to the ongoing physical, emotional, and spiritual changes occurring as the illness progresses. Most distressing can be our discomfort in living with the ambiguity that dying brings.

Signs of spiritual pain and suffering

In addition to the religious and spiritual issues shown in the two previous tables, the following signs may also warrant intervention from a Spiritual Counselor:

- Family's moral conflict when patient stops eating and drinking
- Fear of patient dying in the home (concern that the spirit will linger, or the home will not sell, or the seller will not receive a fair price)
- "Am I being punished?"
Or, "What did I do to deserve this?"
- Guilt or shame (sexuality, addictions, abortions, criminal convictions, etc.)
- Fear of dying or suffering while dying
- Reflection on losses, failures
- A great expectancy of secular and/or religious miracles, healing
- A desire for euthanasia
- Sense of purposelessness
- Family's guilt about wishing the patient would not linger and suffer
- Loss of identity
- Ready to meet God
- Inability of family to discuss death/dying
- Patient/family conflicts
- Visions of religious figures, or of deceased relatives, friends, or pets
- "Is there an afterlife?"
- "Have I lived a good life?"
- Unexplained agitation, restlessness, or anxiety, despite use of appropriate medications (existential pain)
- Frequent statements that the patient long ago stopped attending religious services
- Sorrow over and a desire to heal broken relationships or estrangements
- "Does hospice care mean 'giving up'?"
Or, "Is hospice care the right thing to do?"
- Unfulfilled hopes
- Suicide ideation
- Sense of meaninglessness
- Not ready to die
- Religious conflict with clergy or others representing their faith tradition
- Family's instruction not to use the "H" word with patient
- Sadness or grief over past, current, and future losses (anticipatory grief)

Knowing when a spiritual counselor is needed

If a patient declined spiritual counselor support at admission, but you as the volunteer are seeing spiritual issues shown in this guide, OR if you notice any one the situations below, please notify the Director of Volunteer Services.

Patient requests

- A spiritual counselor, minister, priest, rabbi, imam, or other clergy
- Prayer, meditation, or readings from religious or spiritual texts
- Sacraments and/or rituals
- Honoring of religious observances (such as Ash Wednesday or Rosh Hashanah)

Change in patient's condition

- Patient or family are anxious, distressed, overwhelmed, or angry
- Patient states they will commit suicide or asks us to hasten death
- Patient desires reconciliation with the Divine or others

Moral, ethical, religious, or spiritual issues

- Patient, family, or hospice team member is concerned about any of these issues
- Patient/family's existential suffering or religious beliefs prevent effective symptom management
- Patient/family wonder aloud about the mysterious and the transcendent
- The medical diagnosis has complex emotional and spiritual dimensions, such as HIV/AIDS, body image, history of substance abuse or incarceration, abortion, prisoner of war, or PTSD
- The hospice referral itself has created deep grief and suffering

Religious delusions, obsessions, aversions

- Patient may feel "chosen," "persecuted," or "possessed"
- Patient's expression of anti-religious sentiments may be a cry for help (i.e., "If there is a God, then why is the world such a mess?")

Patient is actively dying, or patient has died

- Families are overwhelmed
- Families seek spiritual support as patient is actively dying or after the patient has died

Spiritual counselor interventions

After a spiritual counselor completes comprehensive and ongoing spiritual assessments, they add the pertinent problems, issues, and opportunities to the patient's Plans of Care. These include spiritual strengths and issues assessed, goals set for resolving them, and interventions used to achieve those goals. Spiritual counselors update the Plan of Care after each visit and discuss the patient and family's progress in the weekly Interdisciplinary Group (IDG) meetings.

Spiritual counselors align their support with the patient and family's beliefs, not with their own beliefs. Spiritual counselors never proselytize, condemn, or judge. They do not manipulate or push, but sensitively accompany patients and families through this most sacred and mysterious part of their journey. Below are a few interventions spiritual counselors use with patients and families:

- Identify sources of spiritual nourishment and pain
- Support their culture and beliefs
- Explore the meaning and purpose of their lives
- Assist with healing relationships, facing fears, and overcoming regrets
- Guide them through the mystery and awe enfolding them; offer spiritual direction
- Offer or provide prayers, blessings, communion, sacred or scriptural texts, and music to soothe the soul
- Arrange for religious rites and sacraments
- Officiate funeral, memorial, and graveside services
- Lead guided meditation and imagery
- Offer or provide complementary therapies, such as Healing Touch, Reiki, and The Threshold Choir
- Provide a loving presence
- Provide pastoral presence, counseling, and support
- Lead patient or family in life review
- Enhance understanding of Divine compassion and forgiveness
- Provide empathy, deep listening, and positive reinforcement
- Collaborate with the other hospice team members about the patient and family's spiritual care issues

Helping, fixing, or serving?

By Rachel Naomi Remen, MD

"Fixing and helping create a distance between people, but we cannot serve at a distance. We can only serve that to which we are profoundly connected."

Helping, fixing, and serving represent three different ways of seeing life. When you help, you see life as weak. When you fix, you see life as broken. When you serve, you see life as whole. Fixing and helping may be the work of the ego, and service the work of the soul.

Service rests on the premise that the nature of life is sacred, that life is a holy mystery which has an unknown purpose. When we serve, we know that we belong to life and to that purpose. From the perspective of service, we are all connected: All suffering is like my suffering and all joy is like my joy. The impulse to serve emerges naturally and inevitably from this way of seeing.

Serving is different from helping. Helping is not a relationship between equals. A helper may see others as weaker than they are, needier than they are, and people often feel this inequality. The danger in helping is that we may inadvertently take away from people more than we could ever give them; we may diminish their self-esteem, their sense of worth, integrity or even wholeness.

When we help, we become aware of our own strength. But when we serve, we don't serve with our strength; we serve with ourselves, and we draw from all of our experiences. Our limitations serve; our wounds serve; even our darkness can serve. My pain is the source of my compassion; my woundedness is the key to my empathy.

Serving makes us aware of our wholeness and its power. The wholeness in us serves the wholeness in others and the wholeness in life. The wholeness in you is the same as the wholeness in me. Service is a relationship between equals: our service strengthens us as well as others. Fixing and helping are draining, and over time we may burn out, but service is renewing. When we serve, our work itself will renew us. In helping we may find a sense of satisfaction; in serving we find a sense of gratitude.

Harry, an emergency physician, tells a story about discovering this. One evening on his shift in a busy emergency room, a woman was brought in about to give birth. When he examined her, Harry realized immediately that her obstetrician would not be able to get there in time and he was going to deliver this baby himself. Harry likes the technical challenge of delivering babies, and he was pleased. The team swung into action, one nurse hastily opening the instrument packs and two others standing at the foot of the table on either side of Harry, supporting the woman's legs on their shoulders and murmuring reassurance. The baby was born almost immediately.

While the infant was still attached to her mother, Harry laid her along his left forearm. Holding the back of her head in his left hand, he took a suction bulb in his right and began to clear her mouth and nose of mucous. Suddenly, the baby opened her eyes and looked directly at him. In that instant, Harry stepped past all of his training and realized a very simple thing: that he was the first human being this baby girl had ever seen. He felt his heart go out to her in welcome from all people everywhere, and tears came to his eyes.

Harry has delivered hundreds of babies, and has always enjoyed the excitement of making rapid decisions and testing his own competency. But he says that he had never let himself experience

the meaning of what he was doing before, or recognize what he was serving with his expertise. In that flash of recognition he felt years of cynicism and fatigue fall away and remembered why he had chosen this work in the first place. All his hard work and personal sacrifice suddenly seemed to him to be worth it.

He feels now that, in a certain sense, this was the first baby he ever delivered. In the past he had been preoccupied with his expertise, assessing and responding to needs and dangers. He had been there many times as an expert, but never before as a human being. He wonders how many other such moments of connection to life he has missed. He suspects there have been many.

As Harry discovered, serving is different from fixing. In fixing, we see others as broken, and respond to this perception with our expertise. Fixers trust their own expertise but may not see the wholeness in another person or trust the integrity of the life in them. When we serve we see and trust that wholeness. We respond to it and collaborate with it. And when we see the wholeness in another, we strengthen it. They may then be able to see it for themselves for the first time.

One woman who served me profoundly is probably unaware of the difference she made in my life. In fact, I do not even know her last name and I am sure she has long forgotten mine. At 29, because of Crohn's Disease, much of my intestine was removed surgically and I was left with an ileostomy. A loop of bowel opens on my abdomen and an ingeniously designed plastic appliance which I remove and replace every few days covers it. Not an easy thing for a young woman to live with, and I was not at all sure that I would be able to do this. While this surgery had given me back much of my vitality, the appliance and the profound change in my body made me feel hopelessly different, permanently shut out of the world of femininity and elegance.

At the beginning, before I could change my appliance myself, it was changed for me by nurse specialists called enterostomal therapists. These white-coated experts were women my own age. They would enter my hospital room, put on an apron, a mask and gloves, and then remove and replace my appliance. The task completed, they would strip off all their protective clothing. Then they would carefully wash their hands. This elaborate ritual made it harder for me. I felt shamed.

One day a woman I had never met before came to do this task. It was late in the day and she was dressed not in a white coat but in a silk dress, heels and stockings. She looked as if she was about to meet someone for dinner. In a friendly way she told me her first name and asked if I wished to have my ileostomy changed. When I nodded, she pulled back my covers, produced a new appliance, and in the most simple and natural way imaginable removed my old one and replaced it, without putting on gloves. I remember watching her hands. She had washed them carefully before she touched me. They were soft and gentle and beautifully cared for. She was wearing a pale pink nail polish and her delicate rings were gold.

At first, I was stunned by this break in professional procedure. But as she laughed and spoke with me in the most ordinary and easy way, I suddenly felt a great wave of unsuspected strength come up from someplace deep in me, and I knew without the slightest doubt that I could do this. I could find a way. It was going to be all right.

I doubt that she ever knew what her willingness to touch me in such a natural way meant to me. In ten minutes she not only tended my body, but healed my wounds. What is most professional is not always what best serves and strengthens the wholeness in others. Fixing and helping create a distance between people, an experience of difference. We cannot serve at a distance. We can

only serve that to which we are profoundly connected, that which we are willing to touch. Fixing and helping are strategies to repair life. We serve life not because it is broken but because it is holy.

Serving requires us to know that our humanity is more powerful than our expertise. In 45 years of chronic illness I have been helped by a great number of people, and fixed by a great many others who did not recognize my wholeness. All that fixing and helping left me wounded in some important and fundamental ways. Only service heals.

Service is not an experience of strength or expertise; service is an experience of mystery, surrender and awe. Helpers and fixers feel causal. Servers may experience from time to time a sense of being used by larger unknown forces. Those who serve have traded a sense of mastery for an experience of mystery, and in doing so have transformed their work and their lives into practice.

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