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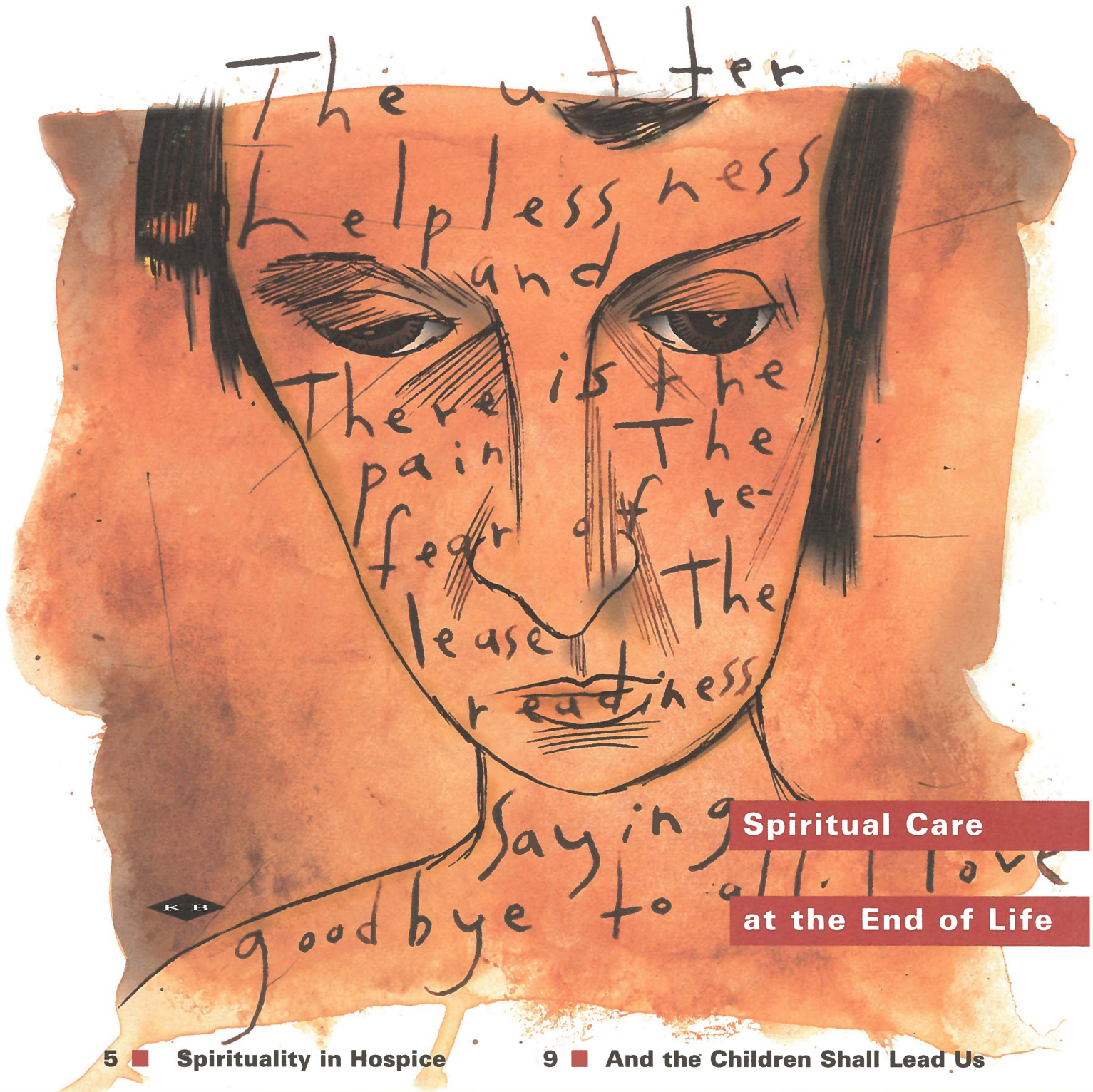
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# Bulletin

MAY/JUNE 2001



**Spiritual Care**

**at the End of Life**



# Bulletin

The Park Ridge Center for the Study of Health, Faith, and Ethics  
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The Park Ridge Center explores and enhances the interaction of health, faith, and ethics through research, education, and consultation to improve the lives of individuals and communities.

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# A Sweeter Sorrow

david b McCURDY

As the authors in this *Bulletin* point out, the sorrow of parting is often anything but sweet for the dying.

It is not only that death means the loss of relationships as we have known them, or that death threatens the meaning of life itself for many dying people. But such distress is magnified when care of those facing death takes place in medical settings where the sorrow and meaning of parting receive secondary attention, where the demands of technology and even bureaucracy are priorities. Care for the human spirit is still too often an afterthought in the medical environment.

Even some concerted efforts to promote better dying in the hospital have, by their designers' own admission, produced disappointing results. In the 1995 SUP-PORT study, published in the *Journal of the American Medical Association*, patients' preferences about medical treatments still went unheard and unfollowed, despite interventions carefully crafted to improve physician-patient communication. Moreover, the study's own focus

incorporated a shortcoming still widespread in hospitals. A singular focus on treatment preferences tends not only to medicalize dying—by attending mainly to the use or non-use of medical treatments—but also to “proceduralize” and “decisionalize” the dying process. Care of the dying is virtually reduced to communication of treatment choices—essentially, “Does the patient have an advance directive?”—and to physicians' implementation of those choices, such as writing no-CPR or “treatment limitation” orders.

Clearly, the process of dying—and of living until we die—involves far more than making and implementing medical decisions, vital as these are. As hospice caregivers have long known, a whole person lurks somewhere behind those treatment preferences, a person whose dying evokes yearnings of the spirit as well as needs of the body and hunger for relationship.

Our authors show that much more can be done to provide spiritual care and support to those who are dying. Yet increasingly, as these writers also point out, attention to the spirit during the dying process is more than an afterthought. Nurturing the spirit will not dispel the sorrow of death's parting, but it may sweeten that sorrow and help us find meaning in the parting. ■

The Nathan R. Cummings Foundation and the Fetzer Institute provided funding for the Park Ridge Center's research project, “Spiritual Care at the End of Life,” which has, in part, inspired the theme of this issue of the *Bulletin*.



# Preparing for Death

*Linking medicine, spirituality, and end-of-life care*

edwin r DuBOSE

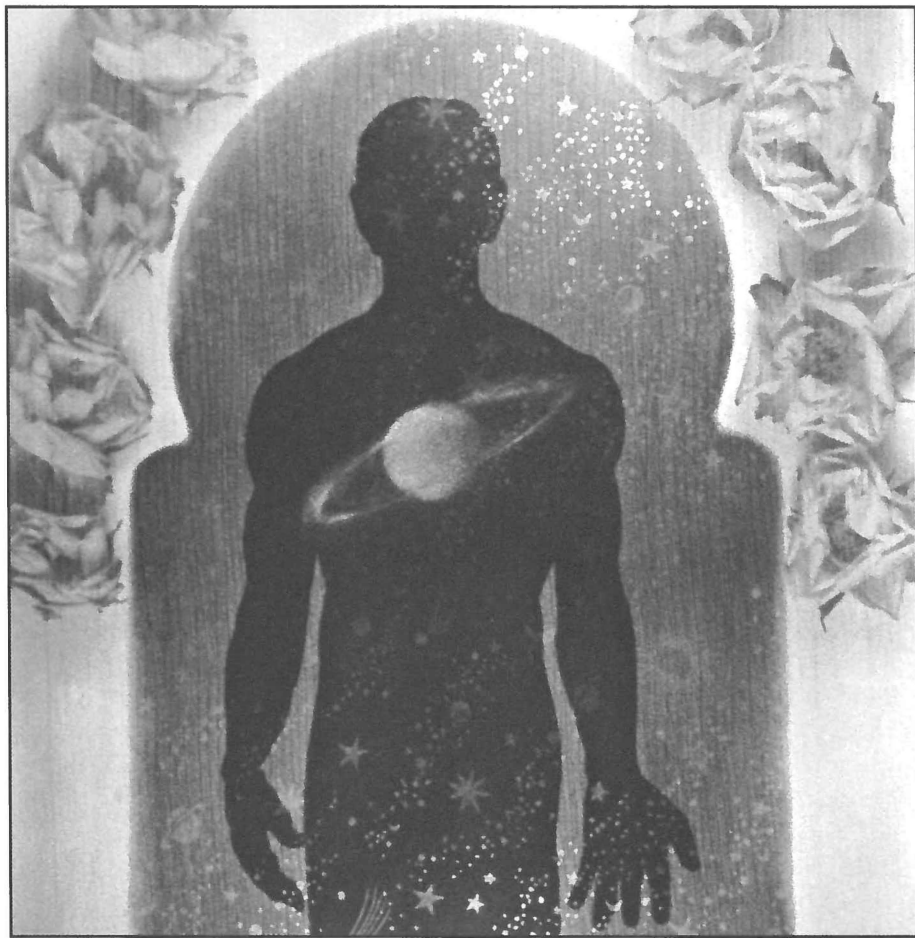
Those who face death reach for medical and spiritual resources, among others, to make sense of what is happening to them.

Healthcare organizations and providers, therefore, attend to both medical and spiritual needs. This is nothing new. Spiritual and physical health have always been closely connected. In the past, responsibility for both spiritual and physical health rested in the same individual; clergy were often doctors, for example. Faith communities founded and sponsored medical endeavors, and nursing was perceived as a religious calling.

As health care developed, however, labor sharply divided, and by the beginning of the last century, medicine and religion had clear boundaries and different professional approaches. Physicians and nurses diagnosed and treated physical and mental disease. Clergy and pastoral caregivers attended to the soul. Yet, the often-overlooked religious aspect of medicine's history forms the background for contemporary concerns linking medicine, spirituality, and end-of-life care.

Chaplains insure that clinically oriented pastoral care is present in the medical center. Such pastoral care inte-

Edwin R. DuBose is a Research Associate at the Center and project director of "Spiritual Care at the End of Life," funded by the Nathan R. Cummings Foundation and the Fetzer Institute.



© Kathy Vargas

*Papa Day: Shrine for Papa Day, 1995 (detail)*

grates particular theory and techniques regarding the place of religion in health care with a commitment to the spiritual well-being of patients, their families, and staff. The philosophy of holistic care allows clergy a place on the modern medical care team.

The rise of professional healthcare chaplains, however, reduced broader clergy involvement with the dying. Congregational clergy now concentrate

on nurturing the healthy religious and spiritual lives of their communities. As a result, these clergy are not much better prepared than any other Americans to support the chronically or acutely ill through death and dying, according to a recent assessment by the American Medical Association's Institute for Ethics.

The gradual separation of medicine and religion reflects a shift in the way death is approached in our culture.



Philippe Ariès, in his *The Hour of Our Death*, proposed that the effort to bring “wild” death into the controlled environment of the hospital is the effort to domesticate it. To some extent, medicine has succeeded: 80 percent die in a hospital or long-term care facility. Ariès argued, however, that our anxieties about death and dying will seep through any levees we build to contain them. For example, many people now fear losing control of their lives—and their deaths—to the medical machine and, thus, losing the chance to find meaning in death.

For the past twenty-five years, those striving to reform the way medicine cares for the dying have stressed legal and ethical issues, including questions of terminating treatment, euthanasia, and assisted suicide. Patient autonomy is the overriding concern as we try to manage death medically. Every state has now enacted legislation on advance directives, and a growing body of judicial opinion focuses on associated issues. Reformers have also focused on improving communication between patient and physician to combat seeming professional bias and insensitivity.

Unfortunately, there’s no evidence that these efforts have succeeded. For example, patients, families, and physicians still seem terribly reluctant to raise the subject of death. Perhaps we have focused too much on healthcare institutions, patient-caregiver relationships, and legislative reform. We need to look anew at the spiritual resources the dying draw upon when facing the physical, emotional, and social pain and suffering that accompanies a life-threatening illness.

The 1997 Gallup survey *Spiritual*

*Beliefs and the Dying Process* reinforced claims that American medicine often fails to provide what dying patients seem to want most—death at home among close family and friends, recognition of and support for the deeper spiritual dimensions of dying and death, and assurance that their families will not be overburdened with their care or neglected in their loss. Not many respondents—only 36 percent—saw the clergy providing broad spiritual support in their own dying days. Even less, 30 percent, would look to physicians for spiritual comfort; 21 percent to nurses. The findings suggest that people do not trust professional caregivers with spiritual care and support in their dying days.

Ironically, these findings come during a boom time for research on the potential effects of religion and spirituality in treatment interventions and outcomes, including the effects of spirituality on end-of-life care. Also fueling interest in spiritual care at the end of life have been the palliative care movement—with a stress on physical, emotional, social, and spiritual support during dying—and the Joint Commission on Accreditation of Healthcare Organizations’ standard on a patient’s right to spiritual care.

Still, recent attention to spiritual care for dying patients in acute care and hospice settings reveals a particular concept of secularized spirituality, according to A. Bradshaw, writing in *Social Science and Medicine*. The effort in health care to disassociate the spiritual dimension from religion produces a lowest common denominator that replaces the traditional notion of spirituality—the human being in relation to the transcendent—with a spiri-

tuality that is a personal and psychological search for meaning.

If spirituality is understood in this way—as a health benefit—there is the danger that spirituality will become a silver bullet; the more spirituality, the better the outcome, even when one is dying. The recent interest in spiritual care at the end of life may ironically represent the effort to domesticate spirit. Even if spiritual care is important for dying people, does not the spiritual life need to be pursued in terms of its own goals—a deeper relationship with the transcendent—and not in terms of any beneficial effects?

Finally, attention to spiritual care at the end of life raises ethical issues. Are there standards of practice or competence for spiritual care? How do we appropriately respect spiritual diversity? Is there an expectation of pastoral confidentiality? What are the ethics of a spiritual assessment? Do patients have a right to spiritual care on their terms? Is there an obligation to intervene in an unhealthy or harmful spirituality?

While there are many components to providing quality care to dying people, including physical, social, and emotional care, attention to spiritual concerns seems a poorly understood feature. To improve the spiritual component of care at the end of patients’ lives, clinicians and clergy caregivers must understand persons’ spiritual needs and the processes that support or the obstacles that impede high-quality spiritual care in the hospital, hospice, or congregation.

What spiritual care do people facing the end of their lives really want from their healthcare providers and from spiritual or religious leaders? How can caregivers better relate to people’s spiritual needs over an extended time leading up to their deaths? How can we better coordinate spiritual care among medical personnel and the clergy? Spiritual care and support does not have to occur only in the last few days of a person’s life; how can such care be offered over time to better prepare people for death? ■

### Art in this issue:

This *Bulletin* features art by Kathy Vargas. Her art celebrates “the lives of a few people who died and . . . the essence of their memories,” according to the artist. Vargas “worked with the complementary concepts of life, death, and memory, and the idea of remembrance as eternity . . . [and] created shrines from these memories.” Her art was included in *Hospice: A Photographic Inquiry*, an exhibition organized by the Corcoran Gallery of Art and the National Hospice Foundation.

# Spirituality in Hospice

## *The challenge of success*

paul r BRENNER

**T**he difficult questions raised by individuals as they near life's end resonate with deep spiritual significance.

What and why is death? Is there any meaning or value in the experience of dying? What is the role of hope in the care of the dying? Do dying and death offer anything to those who are not at life's end?

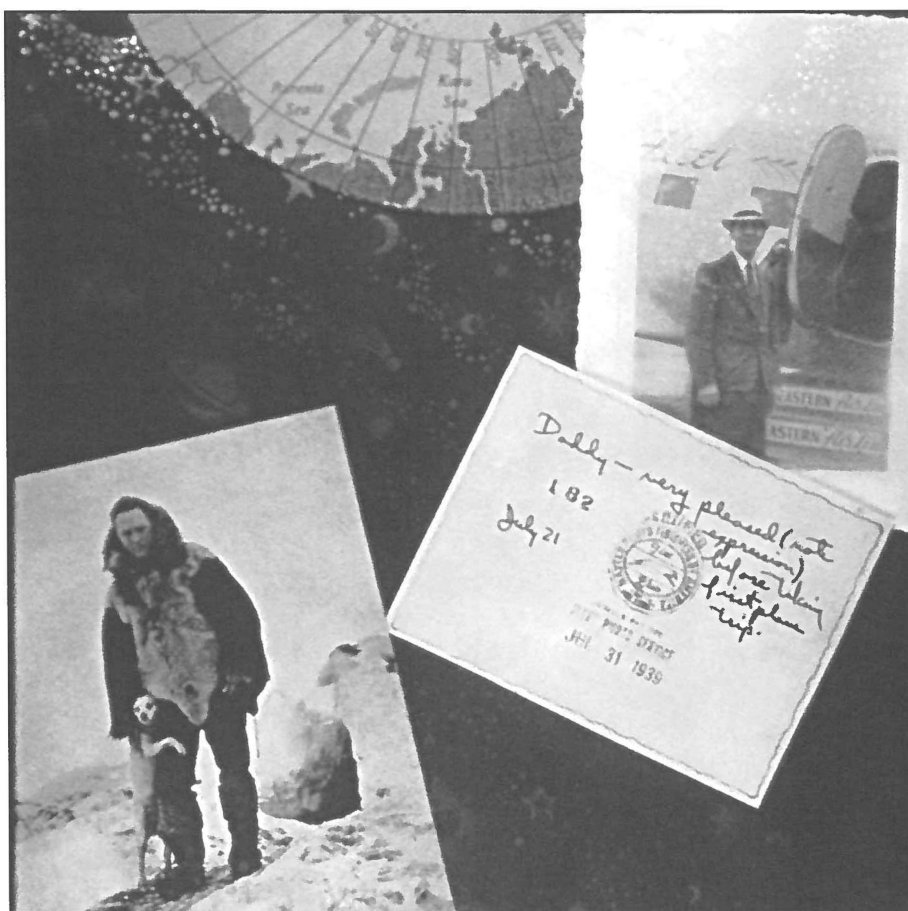
The existing medical model, built upon Cartesian-Newtonian reductionistic and deterministic assumptions, is ill-equipped to meet not only these spiritual questions, but also the need for physical comfort at life's ending.

Since the only permissible goal of patient care in the medical model is to cure or stop the progression of disease, patients whose disease continues to progress can be seen only as failures.

Therefore, as patients approach death, medical practitioners tend to do even more of the same kinds of things that have not prevented the disease from progressing, regardless of the physical, emotional, or spiritual stress these efforts cause patients and their families. Meanwhile, the absence of adequate palliation—pain control, for example—has been widely documented.

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Paul R. Brenner is Executive Director of Jacob Perlow Hospice, Beth Israel Medical Center, New York, N.Y.



© Kathy Vargas

*Papa Day: Admiral Byrd with His Dog; Willard Day Boyer (Papa Day), 1995*

It was this inability of the medical model to deal with the reality of patients who die that motivated Dame Cicely Saunders and the interdisciplinary team she gathered in London in the 1960s at St. Christopher's Hospice. Accepting that death is a normal part of human life, Dame Saunders and her team established a system of comprehensive care that embraces the physical, emotional, spiritual, existential, and relational dimensions of dying.

The focus of physical care in hospice is aggressive management of symptoms that cause distress. Without successful symptom management patients have little energy or ability to address the other stressful issues involved with dying, including those that are spiritual and existential.

### **Hospice Comes to the U.S.**

The integration of the spiritual mission of hospice continued through the work

of Florence Wald and her team in New Haven, Conn., as they planted the British model from St. Christopher's Hospice in American soil in 1974.

Hospice in the U.S. in the 1970s was essentially a grassroots movement that was radically mission-driven, volunteer-intensive, and dedicated to providing an alternative for individuals at life's end. Clergy and religious institutions often provided leadership, resources, and volunteers.

During this time the work of Elisabeth Kübler-Ross, Gerald Jampalsky, and Steven Levine, among others, focused very directly on the spiritual nature of the dying process. Within religious communities themselves there was an emphasis on engaging the community as an instrument of social change. Internally, congregations experimented with how to provide more meaningful corporate worship experiences and deepen the personal spiritual practices of individual members.

Hospices benefited from all this activity as they sought to provide clear options so that persons could self-direct the quality of their dying by experiencing a broad range of visualizations, guided imagery, art and music, and spiritual practices. In this manner, the dying are "empowered" to review life. Using spiritual resources, the dying bring closure to life through attention to reconciliation, identity, meaning, purpose, and transcendence.

### Regulating Hospice

Congress affirmed the earlier successes of the hospice movement when in 1982 it voted to include hospice as a benefit covered by Medicare. In order to preserve the uniqueness of hospice while institutionalizing it, several requirements were built into the regulations that exist for no other healthcare provider: at least 80 percent of all care must be provided in the community at home; at least 5 percent of all care must be provided by

trained volunteers; spiritual counseling is a required core service, not an option; and bereavement services must be provided for family members.

### Impact of Reimbursement

The establishment of reimbursement resulted in a rapid expansion of the number of hospice providers with a corresponding dramatic increase in the numbers of patients and families who could access hospice care.

Consequently, hospices were established less to provide an alternative self-directed choice to traditional health care and more as another program of existing healthcare providers, such as hospitals, home health agencies, nursing homes, and for-profit and not-for-profit healthcare systems. These providers brought a business orientation that had not been necessary when hospice was almost exclusively a voluntary enterprise. Business expertise was essential because hospices had expensive drugs and treatments to pay for, salaries to support, and programs to maintain. Some flexibility and freedom were lost as the regulations and reimbursement scheme standardized admission criteria, mandatory services, policies, and staffing patterns.

### What of Spiritual Care?

Spiritual care is provided in the nation's 3,000-plus hospice programs in a variety of ways, whether by chaplains trained in Clinical Pastoral Education or by community clergy. The "role blurring" common in hospice means that spiritual care may also be provided by physicians, nurses, social workers, aides, and trained volunteers.

This care may address spiritual conflicts that sometimes arise in the disjuncture between personal experience and religious beliefs. The care may also address the presence of guilt, the need for forgiveness, the experience of reconciliation, completion of unfinished or unresolved

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## Poetry

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### Last Days (I)

by donald HALL

"It was reasonable  
to expect." So he wrote. The next day,  
in a consultation room,  
Jane's hematologist Letha Mills sat down,  
stiff, her assistant  
standing with her back to the door.  
"I have terrible news,"  
Letha told them. "The leukemia is back.  
There's nothing to do."  
The four of them wept. He asked how long,  
why did it happen now?  
Jane asked only: "Can I die at home?"

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From the poem "Last Days" from the book entitled *WITHOUT* by Donald Hall. Copyright ©1998 by Donald Hall. Reprinted by permission of Houghton Mifflin Company. All rights reserved.

*continued on page 8*



# Pastoral Care as a Community Endeavor

## *A sustaining presence through care team ministry*

earl e SHELP

Christian communities face significant challenges in providing pastoral support to individuals nearing the end of life and to their families.

Too often the church has accepted a role secondary to that of medical personnel, who tend to dominate while pursuing restorative and palliative goals. Equally, the church has too often misunderstood that the clergy are the primary providers of spiritual ministry in these circumstances because of the authority and representative features of the pastoral office. Both these responses to the opportunities for ministry occasioned by terminal illness reflect an understanding of caregiving as a professional service. Clearly there is a unique role for clergy as one nears life's end, but the ministry of the church ought not be reduced to the presence and ministry of clergy.

The term pastoral care denotes care that the whole church community provides to its members. It is a ministry of the congregation both through its ordained and its lay members. A call to ministry is inherent in baptism, which is,

in effect, a general ordination of all Christians from which specific ministries evolve. Accordingly, laypeople have no option but to discover their particular gifts for ministry and to express those gifts along with clergy. Some laypeople will discover gifts for pastoral caregiving that will direct them to care for people at the end of life.

Laypeople across the nation are effectively meeting this call through Care Team ministry. Dr. Ron Sunderland and I created the Care Team concept in 1985 as we sought to engage the faith communities in Houston, Texas, in a compassionate, hands-on ministry with people with AIDS whose needs for daily care and support were too great for a single caregiver to meet.

A Care Team consists of twelve or more members of a congregation who are trained to provide social, emotional, physical, and spiritual care to individuals and families caring at home for a disabled or terminally ill patient. By sharing and coordinating the care provided, a Care Team can have a meaningful and more comprehensive ministry with people whose multifaceted and intense needs cannot be met by a single caregiver.

The success of AIDS Care Teams in Houston led us to adapt the model to respond to the comparable needs of others, such as dementia patients (Alzheimer's Care Teams), frail or terminally ill adults (Second Family Care Teams), and impaired children (Kids' Pals Care Teams). Presently 1,500 members of eighty congregations participate in our Care Team program. Faith-based groups

have replicated our Care Team model throughout the U.S.

Understanding pastoral care as a ministry of the congregation is one strength of the Care Team concept. The New Testament presents life in Christ as a compassionate life lived together as community (Phil. 2:1-4). It is this compassion that draws members to offer care and support to others who are vulnerable and broken. By their presence and care on behalf of the community, they are expressions of God's presence.

Pastoral caregiving is fundamentally a ministry of sustaining presence. Both "sustaining" and "presence" denote key elements of the relationship. Caring relationships, from a theological perspective, are grounded in God's sustaining love and seek the growth and well being of the care partners. Thus, the focus should be God, who is present and who brings people together in the midst of need.

As God seeks to embrace people and empower them to realize the divine purpose in and through relationship, pastoral caregivers in end-of-life situations should seek the same end.

Although through their compassion caregivers provide practical comfort and assistance, this is not the ultimate intent of their compassionate acts. Rather, acts of compassion should seek to realize the underlying divine purpose. The relationship of and care by the community of faith has a sustaining quality that invites and nurtures openness to God's grace and redemptive purpose. It is by and through presence, an expression of

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Earl E. Shelp is President of Interfaith CarePartners, Houston, Texas. This article is adapted from *Sustaining Presence: A Model of Caring by People of Faith*, (Abingdon Press 2000).

Pastoral caregiving among Care Teams is a form of servanthood characterized by mutuality among the participants and an openness to God's grace and redemptive purpose. It is thoroughly spiritual. It is an expression of God's promise that "I am with you." For one at the end of life, there may be nothing more to be said or sought. ■

Although hospices in the 1970s primarily served an elderly white, middle class,

To answer these challenges we look to the historic creativity of the hospice movement, the way it engages cultural forces to change Americans' attitudes and perceptions about dying and death, and how its boards, paid staffs, and volunteers reflect and identify with the diversity of populations in the community served by the hospice. Central in this creative work will be the reframing of the core of hospice's inherited spiritual mission: What does it mean to be dying? ■

## The Buddhist Tradition

Religious Beliefs and  
Healthcare Decisions

by Paul David Harnack

Religion originated as a personification of spiritual forces, a personification of the gods, a personification of the universe. It is the belief in the existence of a higher power, a power that is not subject to the laws of nature, and which is the source of all life, death, and destiny. It is the belief in a personal God, a God who is the creator, the sustainer, and the preserver of the universe, and who is the source of all life, death, and destiny. It is the belief in a personal God, a God who is the creator, the sustainer, and the preserver of the universe, and who is the source of all life, death, and destiny.

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# And the Children Shall Lead Us

## *End-of-life issues for children and adolescents*

pat FOSARELLI

**I**ll children and adolescents vary according to age in their understanding of what is happening to their bodies.

When they are facing death, these young patients confront unique physical, psychological, and spiritual concerns.

### Developmental Issues

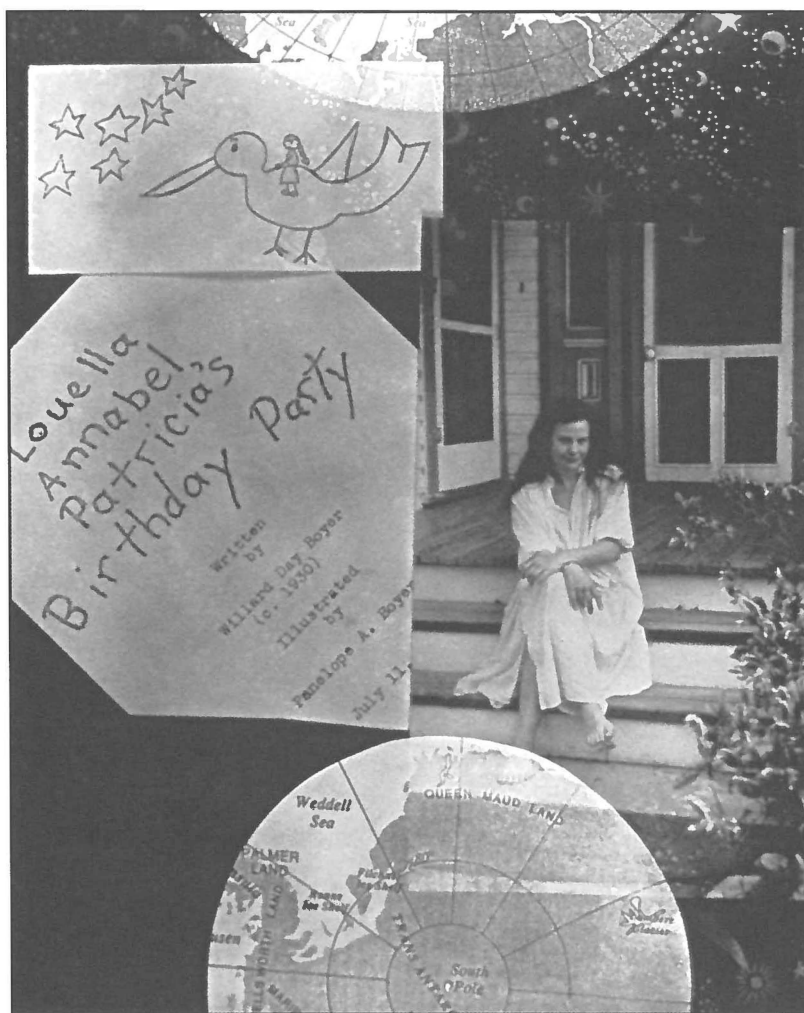
**Infants and toddlers.** Infants and very young toddlers do not understand much of what adults say. Hence, parents or other caregivers cannot adequately explain to these youngest of patients why they must be subjected to yet another examination or diagnostic procedure. Healthy children at this age are usually afraid of strangers, and of being separated from their parents or other caregivers. When very ill infants or toddlers are separated from parents by strangers, they become almost frantic. If this separation involves physical pain in addition to the emotional pain of separation, they are inconsolable, and their parents are likely to feel completely helpless.

**Preschool children.** "If I die, it will be OK 'cause when I wake up I'll still be here," said four-year-old Andrew.

Pat Fosarelli is a pediatrician at the Johns Hopkins Intensive Primary Care Clinic, a clinic for children and adolescents infected with or affected by HIV/AIDS. She teaches at the Ecumenical Institute of Theology at St. Mary's Seminary and University.

Preschoolers are constantly expanding their repertoire of words. They also fear separation from loved ones and the experience of pain when they are ill. Young children may wonder if their illness is a punishment for wrong behavior. This association is made because they have heard their parents say things like, "If you don't button your coat,

you'll get sick!" Preschoolers trust adults; if adults say such things, they must be correct. Thus, they experience sadness and guilt for their illness, frequently asking many questions about their condition. If their parents have spoken about God's punishment of wrongdoers, children may wonder what they did to make God so angry. They



*Papa Day: Penelope Alice Boyer, 1995*

© Kathy Vargas



may, in return, become angry at or fearful of God.

Preschoolers do not understand that death is irreversible. Because they have seen cartoon characters run over by a truck and jump back up, they do not understand that people or animals do not do the same when they die. Hence, dying preschoolers are not concerned that they will be away forever; they are concerned about their present separation from parents and their pain.

*Elementary school-age children.* Eight-year-old Cyndi was dying, and she knew it. Initially angry, she had become profoundly saddened. "It's so unfair that I'll never grow up to be a lady and a teacher. I would have been a good one, too."

School-aged children are concrete and learning to be logical, for example, if a child does A, B will result. This is reinforced by formal education which, at this age, emphasizes concrete abilities, such

as counting, spelling, adding, and subtracting. These children are learning what it means to be a friend to others. They value fairness in their friends—"If you play with me, I'll play with you,"—and in every aspect of life.

When school-aged children are seriously ill, they have many questions that are not easily answered: "Why me? Am I being punished? What did I do wrong?" Unlike younger children, they do understand that death is final. They frequently realize that they are dying before anyone has told them and may attempt to protect their parents from the news: "Don't tell my mom, but I don't think I'm ever going home." They are struck by the unfairness of the fact that they will never grow up like their siblings or friends.

Like younger children, school-aged children are saddened by separation from friends and school and by the physical and emotional pain they must endure.

They understand only too well what they used to be able to do and what they can no longer do. They may express anger at their parents, the doctors, and God. They may bargain with God: "If you let me get better, I'll never forget to say my prayers again." This fits well with their desire for fairness. After all, if they have been good, why should they be ill? Continued or worsening illness may shake their faith in a good and loving God.

*Preteens and early teens.* "I don't want any stupid visitors," twelve-year-old Frank screamed. "I don't want them to see how gross I look. What don't I just die, and get it over with?"

Preteens and young adolescents can be completely devastated by their serious illnesses. They understand completely how well they used to be, how ill they are now, and their present limitations compared to their peers. Healthy children of this age are planning for their future: what courses they will take in school, what they will be when they reach adulthood, what kind of person they would like to marry. Terminally ill preteens and young teens know that these dreams may never be reached, and they have a sense of being cheated. Although many are weepy, others are angry and act out their frustrations. These young people are especially hurt if friends or schoolmates do not call, send cards, or visit. Although they may say that they do not want visitors because of their appearance, they grieve the loss of an active social network, especially the rhythm and work of the normal school day.

Appearances are very important. Hair loss, weight loss, skin lesions or discolorations can be depressing. "Not only do I have to die young," said an angry thirteen-year-old, "but I also have to get ugly. No one even wants to look at me now. I'm a freak."

Anger at parents or God can be intense. "Why didn't you protect me so that I wouldn't get sick?" screamed a ten-year-old. "Kids aren't supposed to die before adults." "I don't think God loves me,

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## Poetry

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### Last Days (XI)

by donald HALL

In the last hours, she kept  
her forearms raised with pale fingers clenched  
at cheek level, like  
the goddess figurine over the bathroom sink.  
Sometimes her right fist flicked  
or spasmed toward her face. For twelve hours  
until she died, he kept  
scratching Jane Kenyon's big bony nose.  
A sharp, almost sweet  
smell began to rise from her open mouth.  
He watched her chest go still.  
With his thumb he closed her round brown eyes.

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From the poem "Last Days" from the book entitled *WITHOUT* by Donald Hall. Copyright ©1998 by Donald Hall. Reprinted by permission of Houghton Mifflin Company. All rights reserved.

because if He did, He would hear my prayers and let me live. So, who needs God?" This anger can be mixed with fear, because these children believe that they will be meeting this God in a very short time. "When I die, where will I go?" worried a twelve-year-old. "Suppose God is mad at me. Will I go to hell?" Death is clearly understood as irreversible.

*Mid and older adolescents.* Several days before her death, Janese said to her doctor, "I know I'm dying, but don't let people ignore me and park me in the corner. It's bad enough that I have to die when I don't want to, but I don't want to die alone. Promise me I won't die alone."

Older teens face the same issues that younger teens do—maybe even more so. At a time when most teens their age are thinking about proms, graduation, college, and their lives as adults, these teens are wondering how long they will live in their present condition. Will they lose their ability to speak? Walk? Toilet themselves? Think? What kind of a future and how much of one do they have? Like younger teens, they are upset by their appearance and their lack of social contacts. They may be weepy or angry at the

unfairness of it all. Their anger may be directed at God, who fails to cure them; at their parents, who failed to protect them from becoming ill; at their friends, who fail to visit or support them; or at health professionals, who fail to "get it right."

### **Approaches to Ill or Dying Children and Adolescents**

We can best serve seriously ill children and adolescents—and their families—by acts of gentleness and kindness. Words spoken softly often comfort a young child—even in the absence of parents or other familiar persons. The emotional trauma of separation can be minimized by permitting parents to be present as much as possible; pain can be reduced by limiting painful procedures and by providing adequate pain relief when such procedures must be done.

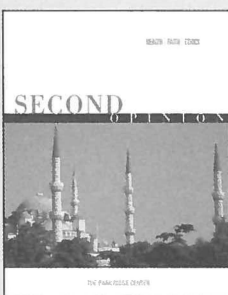
Adults should answer young patients' questions as honestly, but as sensitively, as possible. Most ill children and adolescents greatly appreciate an adult's empathy with their situation, even if the adult can't make it better. Sometimes, all that is

needed is the simple presence of a "safe" adult who gives them permission to voice their anger, fears, and disappointments without reproach or being talked out of such feelings. Such active listening and simple presence bring strength and comfort not only to children and adolescents, but also to parents, who may be questioning their parental abilities. When parents and their children differ on the future course of therapy, the presence of a caring third party may facilitate a resolution more promptly than a roomful of experts.

Any questions of God that arise may be difficult and painful. For if God is love and if God can do anything, why doesn't God cure the seven-year-old with a brain tumor, or eradicate the virus causing AIDS, or alleviate the traumas experienced by little children? Intellectual answers will not suffice, for these are heart and spirit questions. Empathy and simple presence—letting those suffering meet God through the concern and care of human beings—is, in the end, the best way to respond. ■

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# The Voice of Faith

*Can congregations claim the wisdom of their work?*

**kirsten PEACHEY**

**I**n *The Rise of Christianity*, Rodney Stark claims that Christianity grew as a religious movement because the early church cared for the sick and dying.

The community's healing work incorporated touch, personal relationship, physical care, nourishment, and spiritual concern. Stark believes that these simple practices were curative and won converts from the less holistic Roman religious system.

Attending to the sick remains one of the most important things that faith communities do. When life is threatened, congregations support, pray, bless, and root people in a tradition of faith and meaning. They organize care teams, visit the afflicted, hold healing services, and bring food.

A grounding in ancient traditions of healing and a wealth of experience in caring for the dying and their families ought to put congregational leadership, both lay and ordained, in a strong position to speak to the culture about what it means to approach the end of life. But most often, the voices that guide us are from the medical professions, the academy, the social sciences, or even the media.

Rev. Kirsten Peachey is Director of Community Ministry for Advocate Health Care, Oak Brook, Illinois. She is ordained in the United Church of Christ.

For instance, *On Our Own Terms*, the recent public television series on dying produced by Bill and Judith Moyers, spoke powerfully to the experience of the terminally ill and their families. The series highlighted spiritual issues and ways that palliative care programs can ameliorate suffering and restore hope and dignity to the dying, but it did not mention the role that congregations play in this process.

This omission is not limited to this television series. While faith communities are known to be active in caring, they are rarely featured as critical voices in the movement to improve the way we deal with death in our society. Congregations share some of the responsibility for this gap. They need to be more assertive in identifying and claiming their unique contribution.

To claim their voice, congregations will need to do some work. First, congregations should clarify what they bring to the table. In the past century, religious bodies have given too much authority over to medicine, psychology, and sociology. The theological and pastoral ground in which congregations are rooted is rich and needs to be made explicit.

For instance, an informal survey of Jewish and Christian resolutions on end-of-life issues found remarkably similar guiding assumptions. These assumptions included a recognition that life is a gift from God, not to be squandered; an awareness of the complexity of life; and an embracing of the ambiguities that exist across the spectrum between life and death. Each resolution addressed the importance of community to human

relationships. Each promoted a holistic view of human life and warned against idolizing the body and bodily life. And each resolution spoke to hope and the power of faith in preserving meaning and purpose as people approach the end of life. Congregants can feel confident in contributing these perspectives to the end-of-life movement.

Second, congregations must build time for reflection into their service framework. Professional and lay caregivers need to have meaningful conversation about their work. They need language and tools to process their activity, ground it in the theology and tradition of their faith, and develop their leadership ability.

Finally, congregations need to engage with others doing similar work. Too often, faith leaders and congregation members work in isolation from other caregivers. Training in interfacing with health systems and social service agencies would increase their confidence and facilitate interdisciplinary dialogue.

As Rodney Stark suggests, simple acts of caring can be profoundly healing, and their effects can transform culture. Congregations need to trust that they have a powerful perspective to share. They need to bring their work and wisdom forward. ■

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# Home and Community Services for Elders

## *An ethics resource for providers*

**martha b HOLSTEIN**

**F**ive years ago the Illinois Department on Aging established parameters for consumer-centered home care and adult day services.

At the same time, the Community Care Program Advisory Council recommended creating an ethics mechanism to enrich the provision of such care. The Park Ridge Center was invited to join this effort.

With generous funding from the Retirement Research Foundation, Center staff interviewed case managers, supervisors, and frontline workers to identify the troubling issues they faced daily. We also interviewed clients to find what they wanted from caregivers. Although we learned much, so many of the problems seemed intractable. We were, after all, talking about caring for people with fragile physical and or mental conditions in a public system with limited caregiving resources. This system also relied heavily on family members, most often women, who face multiple demands on their time.

Recognizing all these factors, the project working group developed an ethics training program. It uses a train-the-trainer model to educate frontline workers who have the most hands-on contact with elderly clients. Support materials are sufficiently rich to deepen and broaden

the trainer's knowledge about ethics. We developed two packages, one for home care and one for adult day services. The home care program includes a video portraying the case narratives that are in the training program. A separate handbook provides further support materials.

During a test of the program's usefulness, frontline workers were extraordinarily receptive. They brought insights from their own experiences to the case discussions and became a living testimony to the power of knowledge grounded in experience. The program was then revised and is currently being finalized.

The training program acknowledges that home and community-based care matters a great deal to elders and their families and that for many of those families the frontline workers are the key to its success. Thirty to fifty million older Americans cannot remain in their own homes—where most want to be—without assistance in the basic tasks of living. Home care involves a complex set of intersecting, and often unequal, relationships in an emotionally charged environment where physical and mental loss and approaching death are ever-present realities. The home, a place that vitally supports the older person's efforts to protect self-identity and moral worth, is also the scene of a moral drama. In this drama, all involved work to create an environment where givers and receivers of care can flourish against heavy odds, and where the right amount of helpfulness can be given in just the right way.

The training program has an expansive view of the moral life and ethics. It builds

upon the central themes of attentiveness and responsiveness, and the particularities of caring for this person in ways that enhance dignity and preserve self-respect. Built around case narratives, the training program encourages critical reflection about values and choices.

In one narrative, for example, the client gives every indication that she wants to die, raising questions for caregivers: What do the client's behaviors mean? What values are in conflict? What can the worker do and how can she approach her very busy supervisor?

Another narrative presents what seems to be an abusive relationship between a client and her son. This case narrative asks workers to think about questions of safety when protection might mean interrupting a relationship that means a great deal to the client, especially in situations where society has few alternatives to offer the older person.

In one day-services case, two clients are flirting, troubling some clients and staff at the site: Where does one draw the line between acceptable and unacceptable behaviors, and on what grounds? How can the day-services center preserve an atmosphere of emotional security?

The training program's goals are to: familiarize workers with the moral importance of their work; prepare caregivers to engage in caring practices; increase the knowledge of caregivers about the ethical aspects of everyday caregiving; and develop skills to prevent problems or recognize and resolve them. We anticipate that the completed resources will be available this fall. ■

Martha B. Holstein is a Research Associate at the Center and director of this project.

## Live Long and Prosper

The gene controlling the life span of fruit flies and nematodes has at last been found, reports a study recently published in the journal *Science*. Researchers at the University of Connecticut Health Center discovered that manipulation of one gene—named “I’m Not Dead Yet,” a line borrowed from a Monty Python movie—extends the average life span of fruit flies from thirty-seven to seventy days.

Dr. Stephen Helfand, senior author of the study, assures us that the same gene exists in humans. He went on to say that not only do the genetically modified fruit flies enjoy longer life spans, but they also seem to maintain a high quality of life: “By the time that 80 to 90 percent of the normal flies are dead, these mutants are still doing just fine.”

There is hope that this technology will double or even triple the life spans of many different types of household pests,

including but not limited to: cockroaches, spiders, silverfish, and that unemployed family member who refuses to move out of the basement.

## Inappropriate Relic

A prominent New York doctor stands accused of loaning samples of the late Cardinal Terence Cooke’s blood to patients who considered it a holy relic. The charges surfaced in a wrongful-termination lawsuit filed against Dr. Thomas Fahey by his former assistant. Holly McMunn claims that Fahey told her to give a slide containing the deceased Cardinal’s blood to particular patients. “I was very uncomfortable with the fact that I had to be the one delegated to deal with it,” she told the *New York Daily News*. “I just don’t feel that handing out a body part is appropriate for someone of my level.” She is suing

the doctor and Memorial Sloan-Kettering Cancer Center because, she claims, Fahey fired her when she was diagnosed with breast cancer, which he said would keep her out of work too much.

Regarding the blood samples, McMunn gave the newspaper a copy of a 1994 letter to Fahey from the aunt of one of his patients: “I am eternally grateful to you for allowing my niece . . . to be given the Cardinal Cooke relic . . . We both feel the relic has given her an inner strength to accept what the future has in store for her.”

In the early 1980s Fahey led the team that oversaw Cooke’s treatment for leukemia at Sloan-Kettering. Hospital spokesperson Christine Hickey characterized McMunn as “a disgruntled former employee” and defended the doctor by saying: “The matters in question are personal to the relationship between Cardinal Cooke and Dr. Fahey and his religious beliefs.”

But New York Archdiocese spokesperson, Joseph Zwilling, said that as far as the Archdiocese knew, the Cardinal did not sign a release authorizing Fahey to loan samples of his blood. “As far as we can determine, Cardinal Cooke did not know this was going to happen.” Zwilling also noted that because the Cardinal has not yet been designated a saint it would be inappropriate to call the blood a relic.

Sloan-Kettering refused to comment on the appropriateness of a doctor passing around a patient’s blood, regardless of how holy it may or may not be.

—Kirston Fortune

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# Patient Presence

## *Attending to death and dying*

**martin e MARTY**

**B**eing hard to impress, critical, and impatient are traits that serve editors and columnists well.

Those who are easily awed, who drop their guard, who recommend everything they publish too enthusiastically can lead readers to become suspicious or weary, and hurt their publication's cause.

With that in mind, I am somewhat embarrassed to say: I really like the short articles that make up this issue and commend them to readers who have no room or inclination to file everything that crosses their desks. I have a hunch these pieces will be consulted, put to work, and reused as time passes. Here's why.

Their counsel to publics, especially those made up of people of faith, is to be a presence in the face of death and dying. Being a presence does not mean they will never have anything to say. But their narratives and their verbal counsel will more likely come in the context of urgings, as in wisdom attributed to Saint Francis: "Preach the Gospel. Use words if necessary." Being a presence may mean that silence rules. But Pierre Teilhard de Chardin was on to something when he reminded readers that "a presence is never mute."

I like this May/June issue also because it is practical. Earl E. Shelp, who shares a patent on Care Team ministry, one of a number of lay-directed presences, tells the story of organized efforts to enlarge the bedside presence of religious groups by

moving beyond clergy involvement. The Second Vatican Council said somewhere that the laity carries the Catholic church into places that are beyond the clergy's reach. The laity outnumber clergy, in any case, hundreds to one. And many of them, retirees especially, have more time to be with people who face death than do agenda-bound clerics. Trust them.

Pat Fosarelli offers good counsel in a zone where many of us are tongue-tied and tactilely challenged—the wards where children are coming to terms with terminal illness. Fosarelli shows great respect for the young. A friend once dedicated a book to his children with the words: "Like genius, simple; that is why they are the great teachers." So children have difficulty envisioning what is ahead? From the snippets and snatches we get in this article, it is clear that the young do not really know less than do their elders when they face what theologian Karl Rahner called "the abyss of mystery." They simply stumble and mumble in different ways than do their elders. They are worth listening to, and being addressed—again with patient presence.

Though it has considerable historical precedent, the modern hospice is in a

way a fresh invention by means of which people can minister to the dying. Paul R. Brenner takes up another invention often connected with hospice: spirituality. Where he differs from many talkers about the spirituality that is often so individualized is this: he sees the value of the communal efforts that back those who minister with presence in hospice circumstances.

I spoke to a Chicago-area version of Care Teams, lay ministries, and chaplaincies and at one point turned somewhat critical of such spirituality. "What's wrong with it?" came a question. Answer: not everything. There's much right with it. But ordinarily, and here let me read like a bumper sticker, "Spirituality Doesn't Make Hospice Calls." It does, or people devoted to it do, in Brenner's world.

Poet Donald Hall, author Kirsten Peachey, and the Center's own Ed DuBose reinforce these themes, in the latter case by providing historical perspective. This whole issue is not a noisy one; its authors unite quietly in their support of the value of presence. But, as Teilhard reminds us, in the world where people crave an empathic person at their side, a presence is never mute. ■

### On the cover:

"After experiencing the last days of loved ones, I couldn't look at end-of-life issues metaphorically or spiritually. These last days are physical, down and dirty, and terrifying. The cover art stems from recollections of fragments of voices and faces, transparent with emotion—faces that were no longer here, but not yet there."

—Karen Blessen



THE PARK RIDGE CENTER

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