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# Caring for the Human Spirit<sup>®</sup> magazine

SPRING / SUMMER 2016

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HealthCare Chaplaincy Network™ is a global health care nonprofit organization that offers spiritual-related information and resources, and professional chaplaincy services in hospitals, other health care settings, and online. Our mission is to advance the integration of spiritual care in health care through clinical practice, research and education in order to improve the patient experience and satisfaction, and to help people faced with illness and grief find comfort and meaning—*whoever they are, whatever they believe, wherever they are*. We have been caring for the human spirit since 1961.

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*I am impressed greatly by your magazine since it brings CPE theory and practices up to date—meeting the current issues we face in chaplaincy.*  
—Chaplain W. Ray Bailey, Bonner Springs, Kan.

*The [fall 2015] issue with its emphasis on pediatric spirituality is a wonderful resource for spiritual care providers in all venues. I plan on sharing it!*  
—Bob Swope, M.Div., RN, Fairbanks, Alaska

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Vol.3, No.1 Caring for the Human Spirit® magazine is published semi-annually: spring/summer, fall/winter.  
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## A LETTER FROM REV. ERIC J. HALL



**Rev. Eric J. Hall**  
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As a member of the clergy, with a growing congregation in Eastchester, N.Y., I am continually coming face to face with grief—whether in interactions, prayer requests, or unspoken words; whether at hospital bedsides, home visits, funerals, church, or even in the street. People are grieving all the time. All of us have been there.

This past Easter Sunday was no different. During the service as we were celebrating Eucharist, an elderly congregant rose from her pew. Her long-time spouse was just diagnosed with a life-threatening illness. Approaching the altar, this typically reserved woman buckled to her knees, and with uncontrollable tears, she prayed for God's intervention. "God, help him!" she cried out. She asked God to help her as well—to give her strength and comfort.

"Grief" is all in a day's calling for community clergy—perhaps even the most sacred and powerful aspect. While this intense suffering can result from various circumstances, including loss of a job, house or relationship, the grief that stems from health-related issues and end of life confronts us most often. In fact, 94 percent of clergy report making visits to people near death.

However, this can be challenging for many, especially for those clergy—who are not also chaplains—who have not received appropriate pastoral education. Training related to spiritual care in health care is largely missing from seminary education. Research studies show that only 60 percent of clergy visiting people at the end of life say they feel comfortable doing so; and two-thirds indicate the need for curriculum to help with spiritual and theological reflection related to serious illness, caregiving, end of life, and grief.

As health care increasingly moves to outpatient delivery, the role of clergy in providing care to their ill congregants across the continuum of care will expand and even become more complex. So, now more than ever, the need for clergy education is bubbling to the surface.

As part of our efforts to guide all types of spiritual care providers, this issue of *Caring for the Human Spirit®* magazine includes a special section on grief. It talks about the process, and it offers practical techniques to help people cope with loss.

These articles are just one effort that can further educate clergy. It's also time for seminaries to further incorporate pastoral education and/or more in-depth pastoral education into their curricula. Also helpful, training institutions and organizations should offer a greater portfolio of continuing education offerings that meet the needs of this sector. This is one of the gaps, among several, that the new Spiritual Care Association (SCA), an affiliate of HealthCare Chaplaincy Network, specifically addresses (see special supplement inside that announces SCA).

It is during serious or chronic illness or near the end of life that spiritual care, whether provided by community clergy, professional chaplains, or others, can be most wanted and most effective for people of all faiths or no faith. Having the appropriate education and, in turn, the comfort level to aid people who are suffering, dying or grieving goes a long way toward meaningfully providing them with healing and hope. We all need to join together in this effort.

Thank you for caring for the human spirit,

A handwritten signature in blue ink, appearing to read "Eric J. Hall". The signature is fluid and stylized, with a large loop at the end.

# The Field Continues to Grow

## *Welcoming New Spiritual Care Association*

By **Rev. Kevin Massey, M.Div., BCC**

Over the past couple of years, I have spoken and written in a number of venues about a topic very dear to me—namely, improving the process of training and forming persons for providing spiritual care. I have always clarified that the focus of my efforts on this topic is not that there is anything incorrect about what we as a field currently do in the personal and professional development of spiritual care providers, but rather that this preparation is incomplete in an emerging health care world that calls for objectively measurable outcomes and evidence-based practice.

Many have disagreed with me and others who have urged the spiritual care field to move in this direction, arguing that the foundations and premises of spiritual care provider formation are sound. I have always agreed that the classic foundations and premises of spiritual care formation are sound; however, I have emphasized that something more is needed to equip spiritual care providers with propositional knowledge and measurable objective techniques to improve the art of spiritual care.

From this perspective, for my

own part, I find the development of the Spiritual Care Association (SCA) exciting and welcome. First, this new organization is visionary because it is about much more than health care chaplaincy. Health care chaplaincy is just one segment caring for persons' spiritual needs. Faith community leaders worldwide will benefit from the educational tools and modules that SCA will offer. Additionally, innovative approaches to training and forming spiritual care providers of every kind can be shared, piloted, and compared to other approaches so that we as a profession can uncover new practices that may benefit the field.

I personally greet SCA not as a new competitor to the existing models and approaches to forming and equipping spiritual care providers, but rather as a welcome addition to that process—one that focuses on demonstrable best practice techniques, measurable outcomes, promotion of research on spiritual care, and advocacy for the pivotal role spirituality plays in healing and health care decision making.

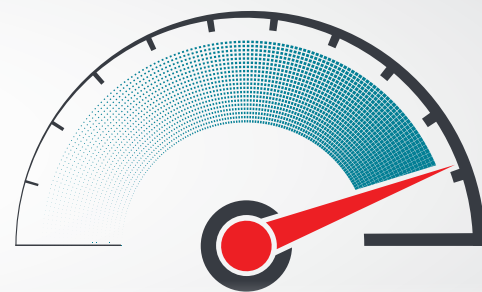
The advocacy role that SCA can play is especially urgent. Regarding just the U.S., the models

of reimbursement in health care can be expected to evolve continuously regardless of whichever political party leads the nation into the future. The role of chaplains specifically in helping guide health care advance planning conversations is essential, yet will need sustained uplifting among health care providers and payers. SCA's incorporation status helpfully positions it to be able to take a more direct and considerable role in that advocacy than other organizations.

I believe that the future is bright for spiritual care providers. As evidence-based practice expands and can be tested and measured, the benefits of spiritual care as part of the health care process will gain greater recognition. Our field will continue to grow and continue to enjoy increased acknowledgement for the unique role it plays in healing and health.

**Rev. Kevin Massey, M.Div., BCC,** of Chicago, Ill., is vice president-mission and spiritual care, Advocate Lutheran General Hospital, Park Ridge, Ill.

# New Evidence-Based Spiritual Care Quality Indicators, Scope of Practice Hold Great Promise



By **Carol Steinberg**

In a ground-breaking development that lands chaplaincy in the same class as other health disciplines that utilize evidence-based tools as a framework for care, two high-level panels recently developed both quality indicators and a scope of practice for spiritual care that are derived from evidence in current research and guidelines.

The panels were convened by HealthCare Chaplaincy Network (HCCN) and are composed of professional chaplains and health care providers of multiple disciplines from the U.S. and abroad. The consensus documents are intended to guide health care associations, administrators, clinicians, researchers, spiritual care providers, and others worldwide on the provision of optimal spiritual care in health care settings.

First, in February 2016, HCCN released the first comprehensive evidence-based indicators of high-quality spiritual care, the metrics that indicate such care is present, and suggested evidence-based tools that can quantify those metrics. The 18 quality indicators—structural indicators, process indicators, and outcomes—include spiritual care that reduces spiritual distress, increases client satisfaction, and facilitates meaning-making for clients and families.

On the heels of this, in March, HCCN unveiled the first evidence-based scope of practice for professional chaplaincy. Using the quality indicators as a reference point, the document articulates how chaplains can help their organizations meet these indicators, and effectively and reliably produce quality spiritual care.

The panel said this scope of practice “represents the first step in the development of an internationally recognized list of competencies for chaplains.” Further, it is intended

that this “will invite and inform the conversations around changes to chaplaincy education and training and become the basis for certification and credentialing processes with the ultimate goal of providing care recipients internationally with demonstrably reliable, high-quality care to help meet their spiritual needs and support their spiritual strengths.”

The significance for the field is multifold, according to panel members and others.

“Increasingly, all services are being judged (and funded) by the value of what they add to the system with value defined as Quality/Cost. In the U.S., the major quality goals are known as the ‘triple aims’—improved medical outcomes, reduced cost, and patient satisfaction,” said Rev. George Handzo, M.Div., BCC, director of health services research and quality at HCCN who chaired both panels.

“This inability to agree on outcomes has been especially problematic in spiritual care where the normal medical metrics of cure rates and readmissions seemingly do not apply. Further, the normal bar for proposing a quality measure or indicator is that it is ‘evidence-based.’ This evidence has been lacking for any indicator that would support spiritual care.”

Handzo expects these tools to “catalyze a wave of improvement initiatives progressively resulting in spiritual care that reliably identifies and meets the needs of clients and improves their ability to achieve health and healing.”

Betty Ferrell, Ph.D., M.A., a

member of the quality indicators panel, and director and professor, Division of Nursing Research and Education, Department of Population Sciences, City of Hope Medical Center, Duarte, Calif., called the quality indicators document “a valuable roadmap for the field.”

“The importance of chaplaincy in health care is undeniable,” she said. “Now all clinicians can advocate for the spiritual care we know is needed and be able to measure the outcomes.”

A member of the scope of practice panel, Rev. Frank Woggon, Ph.D., BCC, ACPE supervisor, believes that having evidence-based tools, like other disciplines, can help better integrate chaplains into interdisciplinary teams.

“Health care providers from other disciplines, too, will find this [scope of practice] document helpful in understanding better the work of chaplains and how it intersects with their own practice,” said Woggon, director of chaplaincy services and assistant clinical professor of medicine at University of Louisville Hospital/KentuckyOne Health, Louisville, Ky.

For chaplains out in the field like Mario DeLise, M.Div., BCC, this progress makes for an exciting time for the profession. DeLise, director of mission and community development, Sonora Regional Medical Center, Sonora, Calif., described chaplaincy as “coming of age,” with these developments “moving us down the road toward professionalism, best practices, and integration.”

**Carol Steinberg** is editor-in-chief of *Caring for the Human Spirit* magazine.

To read the documents on quality indicators, and how to use them, and on scope of practice, visit [www.healthcarechaplaincy.org/research](http://www.healthcarechaplaincy.org/research)



# Spiritual Care as a Driver of Patient Experience: The Critical Humanity of Health Care

By Jason A. Wolf, Ph.D., CPXP

At The Beryl Institute, we define patient experience as “the sum of all interactions, shaped by an organization’s culture, that influence patient perceptions across the continuum of care.” Central to this definition is “the sum of all interactions”; it represents a perspective that is much broader than the clinical realm in which we deliver care, reaching to the fullest experience that we have as human beings in health care. It encompasses our desire to maintain health and well-being, find healing, or live our remaining days with dignity, respect and peace.

Interactions are at the core of our work in health care and remind us that while this is a business based on science, it remains a practice grounded in our humanness, in our hopes and fears, vulnerabilities and strengths. At the heart of all we do and hope to achieve in health care we can never overlook that we are simply human beings caring for human beings.

The significance of this is that if we are to address the human needs in health care, we must look beyond simply the physical domains in which medicine is practiced to the whole person with whom we engage. This idea of person—of not just body, but also of mind and spirit—and of addressing patient experience with this awareness and breadth of intention reflects an enormous opportunity to have significant and lasting effects.

In our recent white paper and webinar “The Critical Role of Spirituality in Patient Experience,” we heard through the voices of our contributors and found in our own reflections as authors a critical consideration, bound both in science and experience. When we address the whole person in a health care encounter, we impact not just physical outcomes but the overall health of

## THE WHITE PAPER

The Beryl Institute in collaboration with HealthCare Chaplaincy Network released a white paper in December 2015 that explores the emerging focus of spiritual care and chaplaincy in patient experience excellence and provides central concepts for organizations to consider regarding spiritual care.

To download “The Critical Role of Spirituality in Patient Experience,” visit <http://bit.ly/1RehbdT> (at checkout, apply promo code: HCCN\_WP).

To listen to a webinar on the white paper, visit <http://bit.ly/22HRkB4>

each individual, and their families and support networks. Spirit in health care cannot and must not be left out from the conversation on driving the best in outcomes.

In the collective voices, we learned:

1) We must recognize that people are more than a diagnosis, disease, or simply a body. There needs to be an intentional commitment to holistic care to lead to the optimal patient experience.

2) We must continue to elevate that sense of humanity by working to help people feel understood, heard and respected. This is not just patients or families, but caregivers in all settings as well. This cannot be left to chance. We must be purposeful and intentional in engaging the whole person—mind, body and spirit.

3) We must continue to expand and reinforce the dialogue on the outcomes that spiritual care itself can drive. The data on engagement, holistic care, and other aspects of care show us the power and impact of a focus beyond the body. The tougher choice is to find strength to invest both time and resources in having those types of interactions in health care today.

4) We must recognize that while spirituality can be aligned with organizational chaplains or religious affiliations, a focus on the human spirit is much greater and broader. If we believe experience is the sum of all interactions, then we have to recognize that everyone—all members of the health care team—play a role in addressing the spiritual nature of care.

In raising the implications of a focus on spirituality, or, simply, the humanity of all we do in health care, we have a significant opportunity. It moves the health care conversation from just medicine to meaning, from simple contract to covenant, from distinct encounters to a holistic human engagement. Through each of those points of focus we can and will drive the best in patient experience.

When we’re willing to see patient experience as something that encompasses all the health care encounters involving patients, family members, and care providers, we truly set the stage for a radical shift in our thinking. We can then trace back all of our desired outcomes in health care—from clinical and financial results to consumer loyalty and community reputation—to one foundation: the experience we provide or have. When we focus on the essence of humanity at our core, the very spirituality that encompasses the body in each and every interaction, we cannot help but achieve not just what is good for those in health care, but also what is right for all we care for and serve.

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**Jason A. Wolf, Ph.D., CPXP**, of Nashville, Tenn., is president of The Beryl Institute, the global community of practice dedicated to improving the patient experience through collaboration and shared knowledge. He is the founding editor of the *Patient Experience Journal*.

THE CEDARS-SINAI HYBRID LIAISON MODEL OF SPIRITUAL CARE:

# A Jewish Hospital Considers its Past to Move Into the Future

By Rabbi Jason Weiner, BCC,  
Rev. Pamela Lazor, M.Div., and  
Jonathan Schreiber, MSBA, MBA, MAEd



Cedars-Sinai Medical Center, Los Angeles, Calif., faced a crossroads six years ago: How can a medical center with deep roots in one religion both hold on to its past and accommodate a future that includes an increasingly diverse patient population?

In 2010, this Jewish hospital, located in an urban setting, began exploring whether it should grow its spiritual care services, and, if so, the best route to accomplish its goals. It initiated a comprehensive assessment of its current department and looked at the field's most successful, evidence-based models for chaplaincy care, while taking into consideration the institution's core values, needs and vision for the future.

In order to gather and analyze as much relevant data as possible, the institution hired an outside consultant and developed an internal task force led by two senior executives and composed of spiritual care advocates from 19 departments and disciplines within the hospital.

As a Jewish hospital, it was clear that this heritage had to play a key role in the model that would emerge. Underscoring this challenge was the deeper question: "What exactly does it mean to be a Jewish hospital in the 21st century?"

While there are many ways to answer this question, Cedars-Sinai applied two key considerations:

- As an institution that has a historical legacy of ensuring that Jewish doctors—who were excluded elsewhere because of their religion—would have an opportunity to practice, and that Jewish patients—who were also excluded or

mistreated elsewhere—would receive appropriate care, the first priority of a Jewish hospital is to remain a place that is welcoming to all people.

- Cedars-Sinai realizes that Jewish history has taught a critical lesson: religion cannot be coerced. Judaism has flourished when it is enabled, but not when it is enforced. As a Jewish hospital, Cedars-Sinai must be a place where faith, religion and spirituality are enabled and encouraged, but never imposed.

The medical center also confronted a second question: How can classic Jewish texts deal with questions of interfaith cooperation? This 950-bed urban hospital is exceedingly diverse, featuring a daily census of many international patients, hundreds of Jewish, Catholic and Protestant patients, many patients of various other faiths, and those who declare no specific religion.

In August 2011, the spiritual care task force's recommendations, with institutional acceptance, led to the implementation of a unique model for the provision of spiritual care, as well as the addition of seven new chaplains and initiation of a clinical pastoral education (CPE) program.

With a larger chaplaincy staff, the approach Cedars-Sinai developed to interfaith relations is actually one in which blending religions, whether in intense religious dialogue or worship, is discouraged in favor of maintaining each faith's particular distinctiveness. Indeed, instead of "interfaith," the Spiritual Care Department staff often refers to this department as "multi-faith" and believes that each religion flourishes best when

differences are not minimized.

Perhaps counterintuitively, this approach has enabled a diverse variety of religions at the institution to thrive authentically, from within their own traditions, side by side. For example, in addition to various Christian and some Hindu programming, the hospital offers weekly Muslim prayers that are attended by Muslim patients, staff and visitors from around the world. Similarly, it offers Jewish programming that appeals to Jews across the spectrum of belief and practice.

Taking into consideration Cedars-Sinai's definition of what it means to be a Jewish hospital and its approach to multi-faith collaboration, the medical center created the "Cedars-Sinai Hybrid Liaison Model" of spiritual care. It evolved out of a patient-centered focus and bases chaplaincy staff assignments on the advantages of both unit-based and faith-preferred practices.

In this model, patients receive a consultation from a chaplain who is the best "fit" for them. This usually means that the Spiritual Care Department sends chaplains to patients of the same religion. Sometimes, however, the department selects a chaplain on the basis of other factors of commonality with the patient, such as language or gender, when relevant. The goal is for patients to feel the best possible connection with their chaplain and to remove from the onset as many barriers as possible to building trust and meaningful connection.

This process is facilitated with the assistance of a central office



coordinator, whose job it is to determine the most appropriate chaplain for each referral. Cedars-Sinai has a diverse team of chaplains to help provide appropriate coverage to patients of all faiths, as well as those who have no declared faith tradition. CPE interns from many backgrounds help to supplement the robust staff chaplaincy team.

This model means that individual chaplains function throughout the entire hospital and must be very clear and intentional in their communication with other chaplains and interdisciplinary team members by being quick to chart in the electronic medical record.

Chaplains, however, do more than respond to their coreligionist referrals—hence, the “hybrid liaison” moniker. Each chaplain is assigned to a unit where they provide chaplaincy support for patients of no religion or of a religion for which a chaplain is not available. On the assigned unit, this chaplain also makes rounds to support patients who may never have even thought of contacting a chaplain; supports the staff; and actively participates in interdisciplinary rounds, often making referrals to chaplain colleagues based on a patient’s particular needs.

Chaplains also rotate on-call coverage. During this time, the hospital attempts to always have a rabbi and priest available, while the on-call chaplain supports all other patients in an interfaith manner.

In addition, the Spiritual Care Department assigns chaplains to cover entire units on an interfaith basis, since it is impossible to provide a chaplain of every religion in places such as the very busy emergency department and the heavily populated cancer center. Even in these areas, however, chaplains make referrals to appropriate faith-specific chaplains when necessary.

The hybrid liaison model has provided some challenges for training CPE interns. For example, there are many protocols to learn early on, and students who are uncomfortable providing care for patients of different faith backgrounds can more easily

avoid such patients in favor of tending to those with whom they feel more comfortable.

However, the model has also presented many unique benefits for CPE interns, such as learning to work as a member of the spiritual care team by following up on referrals on other chaplains’ units and referring patients on their own units to other team members. Students also get more opportunity to provide spiritual care to patients from their own faith backgrounds, which for students from religious minorities has proved to be very helpful in learning about assumptions and differences within their own communities.

As a result of this protocol, the department has heard many wonderful reports from patients who feel uniquely respected and welcomed at Cedars-Sinai, and from staff who finds the intense support for their patients and themselves to be invaluable.

While Jewish patients at a Jewish hospital expect to receive a visit from a Jewish chaplain, and are very appreciative of it, the department receives its best feedback from patients who are not Jewish and feel especially respected and comforted

by receiving a chaplaincy consultation from a chaplain of their own religion.

At Cedars-Sinai, this approach to chaplaincy care, combined with aggressive outreach and educational efforts across the institution, initially helped to increase monthly referrals for chaplains from approximately 400 in August 2011 to more than 1,100 one year later. Today, more than 20,000 total visits from the hospital’s 11 staff chaplains and 18 CPE interns occur annually.

Cedars-Sinai is proud of its rich tradition of spiritual care and has found great success in reenvisioning its model of chaplain deployment by balancing patient needs, contemporary best practice standards, and our ancient values.

**Rabbi Jason Weiner, BCC,**  
**Rev. Pamela Lazor, M.Div., and**  
**Jonathan Schreiber, MSBA, MBA,**  
**MAEd, all of Los Angeles, Calif.,**  
work at Cedars-Sinai Medical Center in Los Angeles. **Weiner** is senior rabbi and manager of the Spiritual Care Department. **Lazor** is ACPE supervisor. **Schreiber** is director-community engagement.

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## A CASE STUDY:

# Talking to Kids About Death and Dying

By **Martha Dimmers, M.Div., MSW, BCC**

The first time I met 16-year-old Isabella\* and her family, the teen had come to the hospital for a “brief” stay while tests were being run to confirm her ever-decreasing pulmonary function and to reconfigure her caloric intake needs. In that initial conversation, I learned that her mom, Marisol, was the pastor of a small Spanish-language Pentecostal church, and her dad, Mario, worked in finance. While Marisol had visited many hospitalized congregants in her years as a clergyperson, she spoke energetically about how different this was from her pastoral visits. She requested support for herself and her family.

Immediately, questions came to my mind: How to be a chaplain when there’s a pastor involved? How to be sensitive to these parents and their child despite our different theological backgrounds? I am a Presbyterian minister. How to engage a teenager? What does faith look like in the midst of a

hospitalization? How does being Latina and only speaking Spanish impact your experience?

Isabella was a bright, petite teenager who when feeling well would engage in conversation on a wide variety of topics; through this, I learned what was really important to her. When she felt terrible, she’d roll over in bed, cover herself with a handmade blanket, and be completely uninterested in anything outside of her immediate self. Occasionally, during these moments, she’d ask me to stay with her in silence.

Marisol was the parent most often at the hospital. Initially, she was rather stoic, taking things in stride and praying to God for protection for her daughter, herself, and their family.

Isabella was in and out of the hospital over the next few years. Each time Marisol would update me on how things were going for them. The family’s prayers were for Isabella’s health, better breathing,

and learning, as well as patience for themselves. During this time, Isabella continued to go to school when she could. Her parents stayed steady and true to her, to their faith, and to their life as it was.

A critical turning point came when Isabella became a candidate for a lung transplant. Would she want new lungs? What would their faith say about this? Isabella was curious about what it would be like and began conversing with people in person and on the Internet about their medical and personal experiences.

Her parents were immersed in the discernment process. They felt Isabella’s condition had reached the point they had always been most concerned about: where the choice seemed to be life or death. Their daughter’s health was precarious. They didn’t want her to die, yet they didn’t want her to suffer anymore. And they were sure God didn’t want her to suffer.

We talked openly about

Isabella's quality of life. They knew it was deteriorating quickly. She could no longer engage in her beloved youth group activities, and she seemed withdrawn, retreating into her shell of a body. Her prayers, once verbalized, were now more often internalized.

Marisol began to question her faith and where it was leading her. One night while on-call, I was paged to come back to the hospital to provide spiritual care to Isabella's family. As it turned out, it was really Marisol who needed the support. She'd begun to feel as if she were living on a different continent with her faith, and she wasn't sure how to live there. Through tears, she spoke with honest concern about how she'd changed; how the faith of her childhood and church where she pastored meant so much, yet she had bigger questions and bigger ideas about God's role in her life and the lives of others. She wasn't sure she could stay where she was in her pastoral role, but she didn't know where else she'd fit. These were moments when her faith life felt so fragile, like a newborn bird, hatched, yet not able enough to fly off.

Marisol spoke lovingly and openly to her daughter about her health, her life, and her decisions. She had opinions about the lung transplant—mostly favorable—yet she could see how it would not be easy at all—for any of them.

Marisol and I paced around the hospital and talked. At times, she'd moan, "God help me ... Martha, I need God to help me." We'd stop, cry a few tears, say a quick prayer, and be on our way—to the next topic and the next prayer. And this was how it went for a few months.

Meanwhile, Isabella was having doubts about getting a transplant. She didn't want someone else's organs in her own body. She wasn't sure what God would think. Together, sometimes with her parents present, and often alone with me, we explored all the possibilities: life as it was, life

post-surgery, life with new lungs, death without surgery. Although her family hadn't talked a lot about death, Isabella always knew it was a possibility with her medical situation.

After much soul searching, Isabella announced one day she believed God would bless the transplant and lungs if she'd go through with it. The only issue now was that she just didn't think she could do it.

**"KIDS ...  
HAVE  
SOMETHING  
TO SAY  
ABOUT THEIR  
HEALTH,  
THEIR DEATH,  
AND THEIR  
FAITH."**

In her conversations with her parents and with me, and even with her best friend, it was now clear that Isabella didn't want the lung transplant. On the day she made her declaration to the world, she asked her nurse to call me to come right away. Isabella lay back on her bed, with her mom and dad beside her, and we gathered with a prayer as we most often did and then dove into the most pressing topic: the decision.

Everyone was on the same page: no transplant. There were tears and hugs. Then, Isabella's parents left to get some air (or maybe it was because they knew Isabella needed to say a few more things without them there).

Isabella shared with me how much she loved her family and would miss them. But she felt life

would be better in heaven, and she didn't want to feel this terribly forever. She held on to my hand, as if for dear life, and I squeezed back. The intensity of the moment coursed through my body.

Why do chaplains talk with children and their families about death? Because death is part of life. It's difficult and hard, yet it's meaningful and important. Kids, like Isabella, have something to say about their health, their death, and their faith. Chaplains help guide the conversations with patients, their parents, and their families.

At the end of Isabella's life, her family clung to love, to their faith as they knew it in that moment, and to the entire experience of being present with one another through life, illness, lungs/no lungs, and death.

\*Names have been changed to protect confidentiality.



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# Living With Heartbreak: The Grief Process

By Kenneth J. Doka, Ph.D.

*Think about yourself for a moment: Focus on your first significant loss. How did you experience grief? How long did it take for you to begin to function at a level of effectiveness again? Do you still have surges of grief?*

Grief is a reaction to loss. Individuals can grieve many losses in their lives, such as the deaths of family members, friends, or even individuals they have never met such as celebrities or political leaders, as well as the loss of relationships or valued possessions.

Individuals can experience typical grief in varied ways. It most commonly surfaces as physical, emotional, cognitive and behavioral reactions. Grief has spiritual manifestations as well. Individuals may struggle to find meaning and to reestablish a sense of identity and assumptive order in their world. They may be angry at God or struggle with their faith. Different cultural, religious and spiritual beliefs, values and traditions bring different ways of understanding death, dying and grief, and various practices to be observed.

The reactions of persons to loss are highly individual and influenced by a number of

factors. These include the unique meaning of the loss; the strength and nature of the attachment; the circumstances surrounding the loss; and the individual's temperament and adaptive abilities, general health and lifestyle practices, support systems, and cultural and spiritual beliefs and practices.

There have been a number of approaches to understand the process or course of grief. Earlier ones tended to see grief as proceeding in stages or phases. For example, Elisabeth Kübler-Ross' stage theory, published in "On Death and Dying" (1969), has dominated popular thinking about the ways individuals grieve. Though Kübler-Ross' stages—denial, bargaining, anger, depression and acceptance—were originally applied to dying individuals, they were soon applied to the study of grief.

Contemporary grief theory has moved away from looking for universal stages to acknowledging the very individual pathways that persons use in coping with loss. Other changes include recognizing the continuing bonds with the deceased or loss object as well as acknowledging the opportunities for individual growth that can occur with loss.

The term grief can be defined as a type of stress reaction, a highly personal and subjective response that an individual makes to a real, perceived or anticipated loss.

This special section on grief explores the process, some techniques to help people cope with loss, and a heartfelt encounter.

Recent approaches have emphasized that grief does not follow a predictable and linear course, stressing instead that it often proceeds in a roller coaster-like pattern, full of ups and downs, times when the grief reactions are more or less intense. Some of these more intense periods are predictable—holidays, anniversaries, or other significant days; other times may have no recognizable trigger.

For example, Stroebe and Schut's (1999) Dual Process Model suggests that successful coping in bereavement means oscillating or moving between loss-oriented (reacting to the loss) and restoration-oriented (rebuilding a life now changed by the loss) processes. Persons who are fixated with restoration risk denying the reality of the loss, while those who focus only on the loss may be prone to chronic grief reactions.

The work of Robert Neimeyer (2001) emphasizes meaning reconstruction as a central process of grief. To Neimeyer, a significant loss challenges assumptions about self, relations, and the world. A significant process in grief then involves reconstructing meaning, asking in the face of the loss: Who am I now? What do I believe? How are my identity and relationships now changed by the loss?

Beyond stressing individual pathways in grief, both models reaffirmed that mourning was more than simply a series of essentially affective responses to loss. In addition, each of these newer models

asserted that mourning involved not only a response to the loss of another, but also an effort to manage life in a world now changed by significant loss.

These models offer much to counselors assisting bereaved persons. Stage models suggested a more limited role for counselors: interpreting the reactions of bereaved individuals and essentially assisting them as they moved through the stages. These newer models allow a more significant role: The counselor can validate a person's grief, assist bereaved persons in understanding what factors are complicating the completion of certain tasks or processes, and offering rituals and other interventions that can aid the grieving person in adapting to loss.

Indicative of individual pathways, some people may be highly resilient to loss—experiencing few manifestations and little loss of function. Others may undergo a more disruptive pattern of grief.

In addition, some people may be more intuitive in their experience of grief—with waves of affect such as loneliness, anger or guilt. Such individuals will express their grief in behaviors aligned with their emotion: crying, shouting or withdrawing. They will find solace in expressing and exploring these emotions. Others will be more instrumental in their grief. Such persons will experience grief in more physical or cognitive ways. They may express their grief in activities, or in sharing memories and stories.

While men are more likely to be toward the instrumental side,

and many women, at least in U.S. culture, on the intuitive side, it is important to remember that while gender influences a pattern (as does culture, socialization experiences, and temperament), it does not determine it (Doka & Martin, 2010).

Nor is there any inherent timetable to grief. Typical grief reactions can persist for considerable time, gradually losing intensity after the first few years. Recent research as well emphasizes that one does not "get over the loss." Rather, over time, the pain lessens, grief becomes less disabling as individuals function at levels comparable to (and sometimes better than) pre-loss levels. However, bonds and attachments to the lost object continue, and periods of intense grief can occur years after the loss (Klass, Silverman and Nickman, 1996).

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# MASCULINE GRIEF:

By Rev. Daniel R. Duggan, BCC

Mainstream grief theory begins with getting in touch with our feelings and sharing those feelings with someone. This may be a more feminine style. Often the way men go through the process looks very different than the way women grieve.

For many men in grief, the first reaction is often a movement inward into solitude. In solitude, they can express themselves, confront what has happened, deal with feelings, and begin to sort out their next steps. Typically, this process helps them to eventually move beyond their solitude and into relationships again, using storytelling and “doing” to help them grieve.

Most of us were not trained to see solitude as a positive response to grief or to appreciate that a man may not have to name and express feelings as a first step into the core of grief.

The challenge, then, is not only for us to learn new skills, but also to be willing to move beyond our own comfort zones. While keeping in mind that the grief process is highly individualized and that common reactions are not exclusive to either gender, the following approaches are ways to walk with men through grief.

## **Create Safe Places**

We all need to feel safe. If a man does not feel safe, he will not entrust another with his stories or feelings.

Practice gender inclusiveness. Know that some men name and express feelings. Accept it for what it is. Acknowledge and validate.

Do not rush to help men in grief if you are not willing, able or capable of being present with them on their own terms. They will see through your façade and turn away. If you are unsure about how to be helpful,

trust that most men appreciate being asked what would be helpful. Then follow their suggestions.

Finally, do not be afraid to step back and get out of the way if the man and his family are doing what they need to be doing for themselves during this time.

## **Be Realistic**

Ask yourself: “What can I realistically hope to accomplish?” You cannot do the work for a man. He has to go through the door that leads to the core of grief for himself.

Be mindful of your agenda. Each man is a unique individual with his own experiences and style of coping. In some people’s eagerness to help, they become impatient and forget to follow the lead of the person whom they are trying to support. Such enthusiasm can have the effect of making the other person feel unsafe.

## **Be a Witness**

Men will often report on what they have experienced. Do not interrupt when a story is being told. Men may not need to be understood, but they most often need or want their stories heard. In the end, say, “Thank you for telling me your story.”

Appreciate silence. It is not unusual for a man to use long periods of silence as a way to collect his thoughts before knowing how to frame a story. Being present while a man is thinking is also a way to witness. Men may use fewer words as well.

## **Trust Solitude**

If we are truly going to be helpful to men, we must value solitude. Men learn about relating to themselves, others, life, and the Holy as they enter their solitude. There, a man attends to his wounds, sorts through what has



happened, deals with feelings, trusts himself and others who are there with him, and learns how he wants to move beyond the cave and into the world of external relationships again.

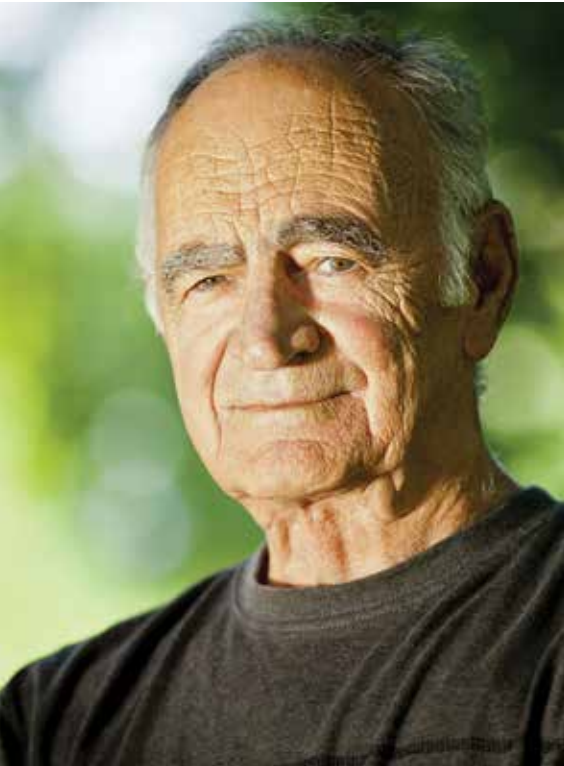
When a man needs to be alone to deal with what has happened, important healing work may be going on. By being comfortable with the man’s need for space, we are showing that we trust his ability to know what he needs to do for himself. Just as importantly, we are showing respect and building the bridge between us.

## **Help Restore Self-Esteem**

Recognize that a loss may have struck a blow to a male’s self-esteem because he could not protect or prevent the loss. The rush of feelings may be more than he can handle.

Here, again, accepting and respecting the man’s need for solitude while he collects himself is a way to help him restore his self-esteem. When a man moves into his solitude, he learns to use his inner strength to deal with life. For all of us, self-esteem comes when we see ourselves doing what we need to do for ourselves.





# A QUIET HEALING

## Support the Family System

Work to provide a safe space for family members to cope with their loss in their own unique ways. Then, step back and get out of the way. The family system will often rise to the occasion and do what only it can do for itself, using both feminine and masculine gender characteristics to help them cope.

Men are often viewed in negative ways when they are misunderstood or not accepted. Destructive or harmful behavior cannot be tolerated. Yet, we need to recognize that our judgments and biases are not helpful.

## Invite Ways to 'Do' Things

Do not assume that because men are less demonstrative with their feelings they lack a need to express their grief. "Doing" is a way of expressing emotions. Help men to think about ways they can do things to give meaning to their loss and grief, and that serve and nurture others. Rituals can help express grief since they embody meaning and give honor.

## Accept Anger

Do not assume that when a man shares anger with you that it is about you. It may be more about feeling unsafe or feeling too vulnerable. Let him have his feeling of anger. You may be the only anchor that he has against harming himself or someone else.

If you are concerned, let him know what the limits are, but acknowledge that you hear his pain. Ask him if there is anything you can do to help him with his anger.

## Provide Space

Remember that men often get to their feelings by storytelling, doing, and the conversations and searching they do in their solitude.

Avoid asking, "How are you feeling?"—at least until you sense that the man has words for feelings. Instead, ask, "How are you doing?" He can tell you that.

Give men space to go into their emotional cave. Do not blame or become resentful when they do so.

## Know the Importance of Stories

Men eventually get to feelings once they have entered their grief and begin telling their stories. Once a story is told, the grief work may be done. In other words, the feelings were expressed in telling the story.

This may be all that is necessary. It is like peeling the proverbial onion. Healing takes place when one is ready to peel away that layer. If you are in doubt about whether or not the story is done, ask something like, "Is there more?" or, "Do you feel done?"

## Recognize the Importance of Honor

Help men to have honor in their grief. Death often confronts men with a

sense of failure because they feel they have not ultimately protected their families. Honor them by giving them space to go into their caves without being judged. Trust that their silence may be sacred to them.

Encourage men to do their best. If you sense a feeling of helplessness, you might ask, "What is going to be the most helpful thing for your family or friends?" Let them hear they are okay, loved and accepted. Speak their names aloud in conversation or prayer. Listen quietly when they begin to tell their story. Doing so honors their sharing.

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Finally, openness to gender differences in grieving styles allows us to learn from one another. It also allows us to bless the many natural ways of healing we have, rather than assume there is only one way for men or women.

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**Rev. Daniel R. Duggan, BCC**, of Alexandria, Va., has ministered with men and women in grief for more than 40 years as an ordained Presbyterian minister and a board certified chaplain. An ACPE supervisor, he currently serves as director of chaplaincy at Goodwin House Bailey's Crossroads, and director of CPE at Goodwin House CCRC, Falls Church and Alexandria, Va. This article is excerpted with permission from his book, *Men, Grief, and Solitude—A Different Perspective* (2014, Solitude Publishers LLC).

# *Another Form of Healing:* **Using Art Therapy in Bereavement Groups**

By **Laura Trachtenberg, M.A.**

As the group members stared down at the sopping wet clump of tangled wool in front of them, I asked, "So what did we create?"

"It's ugly," laughed one woman.

"It's wet," another member remarked.

"It's our grief," said a third person.

This was a six-week bereavement support group for people who had lost a loved one and were trekking through the grieving process. Each week, the hospice chaplain who served as the group's facilitator introduced new themes to help members navigate through their grief; and on several occasions, I was given the chance to introduce art therapy interventions and facilitate small group discussions.

As the group progressed from week to week, the participants, who had identified losing a father, mother, husband, or other close family member, began to give strength and empathy to one another and gain in return an understanding of themselves and validity in their grief.

Then, as the final session neared, the impending loss of the special relationships that had formed during the group's existence loomed overhead. The loss experienced by the members would no longer be solely in relation to the death of a loved one that had precipitated their enrollment in the group, but would now encompass the expiration of

the formal group itself. Just how this experience would terminate was of the utmost importance.

So as the members of the bereavement group entered the meeting room on the sixth week, they were greeted with tufts of colorful wool roving, piles of stones, and bowls of soapy water. As the initial excitement of reconvening, this time for the last time, settled among the group, I led them in a wet felting task. Each group member was instructed to choose a stone and add a layer of wool to it, and then pass that stone to their neighbor—forming a pattern of layering and passing, laughing and talking, and occasional concentrated silence.

After two go-rounds and about 30 minutes, I informed the members that the object in front of them was in fact theirs. There was a burst of laughter, followed by much interest in the disparity of end products that had been created. This led to the question about creation.

Once the members shared initial, superficial observations, a deeper and richer context and understanding of the task emerged. Indeed, this was another look at grief.

In the ensuing discussion, some members commented on the many layers that formulated their unique, felted object, much like the layers that made up their unique experience of grief. Others shared that each object looked very different, mirroring

how grief and the grieving process play out differently for people.

Another conversation emerged around each group member's contribution to one another's final product, with the suggestion that the object represented the group and the building of knowledge and relationships that occurred over the six-week time span. Other members vocalized joy and pleasure in being able to take a piece of each other home through the work of art. This observation was further strengthened with the knowledge that once the object was rinsed and dried, the layers of wool roving would become fused together.

Among the Ethical Principles for Art Therapists outlined by the American Art Therapy Association (2013), art therapists have a duty to foster creativity. Creativity guides art therapists in "cultivating imagination" to help clients understand "self, others, and the world" while also supporting "creative processes for decision making and problem solving as well as meaning making and healing."

With the principle of creativity in mind, art therapy in the context of the bereavement group served to help members understand themselves, one another, and the process of grief. Members also utilized creativity to foster healing and make sense of the group's lessons and conclusion.

"Even the [art therapy], which at

first I did not embrace, had a wonderful purpose," expressed one participant. "Hearing laughter and bantering [during art making] showed how close we had become."

At the end of the day, this exercise revealed the usefulness of, and expression possible in, art therapy.

Group members utilized the process of art making as an outward expression of their inner selves. The project provided a space for the bereaved to use their hands, hearts, minds and intuition to create something that represented the culmination of the many layers, themes and experiences offered through the sessions. Furthermore, creating art



together and allowing participants to make contributions to one another's art resulted in the formation of a transitional object for members to take with them as a physical reminder of the work accomplished throughout the group's existence.

As the art therapy task and discussion came to a close, the participants smiled down at their felted grief and felted representations of the group as well as smiled and nodded at one another. The wet tangled mess of wool in front of them was no longer a foreign object, but a dear memento of a group that offered healing and growth for all.

**Laura Trachtenberg, M.A.**, of York County, Pa., is an art therapist at an alcohol and drug rehabilitation center in Pennsylvania. She was an art therapy intern at Lighthouse Hospice, Inc., Cherry Hill, N.J., during the 2014-2015 academic year while attending Drexel University, Philadelphia, Pa., to earn her Master's in Art Therapy and Counseling.

# It's Just Not Fair

By **Rev. Dr. Judith Craik**

The death of a loved one is always painful. But the pain that is suffered from the death of a child is in a category all by itself. One of the many reasons that the loss of a child is so painful is that it seems so unnatural. It just feels wrong when a child of any age dies before his or her parents. No wonder a grieving mother or father raises a fist to God and cries out, "It's just not fair."

This accusation against God speaks volumes about the innate, human need for fairness, for justice. We demand justice. We demand that rules must be obeyed. And one of the rules that we, as 21st century Americans, hang on to is that children must not die before their parents. Nowadays, the vast majority of American children do outlive their parents. This is the standard that we take for granted. It is a standard that, like many standards, has become a rule. When this rule is broken the grief-stricken parent has suffered an appalling injustice—it's just not fair.

But the kind of justice that is based on rules is just one category of justice. Theologian Paul Tillich

suggests that there is another category of justice, the kind that can at least begin to bind up the wounds of those who suffer from injustice (Tillich, P., 1954). Tillich calls this "creative justice," which is the only kind of justice that can actually meet our demands for justice. He describes the elements of creative justice as listening, forgiving and giving.

This form of justice can provide some comfort to those who have suffered from the death of a child or any other kind of injustice.

That's what a grief support group held at the First Baptist Church of Newfane, Newfane, N.Y., for example, has found in using this concept as a way to ameliorate the perceived injustice they've experienced.

Most of the participants in this group are mothers who have lost a child. At their meetings, they share their feelings and their stories. Their wounds are certainly not healed. They do not expect any real closure to their grief. But they do find some comfort. Their wounds are a little less painful because they





experience the nurturing power of a group that practices creative justice.

This category of justice begins with a willingness to listen. And the participants in the support group often exhibit a special kind of listening.

One time, a mother spoke about her ongoing need to take care of her son's grave. She clears away the leaves from his grave, and when it's cold outside, she puts a blanket on the grave. She said that it's the only way she has now of taking care of him.

The other mothers knew that this was not the time to point out that putting a blanket on his grave does not actually take care of her son. Instead, the group members simply nodded their heads; they understood. They heard the terrible emptiness in her need to keep her dead son warm. They felt, with this mother, her need to nurture a son who could no longer experience her nurturing.

In applying this special kind of listening, the participants are able to hear the emotional content of

each other's messages. They provide creative justice by listening to and accepting each other's feelings.

In addition, the support group members actually put into practice the prayer "... forgive us our debts as we forgive our debtors." They forgive those who do not come regularly to the meetings even though their absence does weaken the nurturing function of the group.

Does their very real empathy for each other help them to forgive others? Or is it that they just don't "sweat the small stuff?" The answer is not important. What is, is the group's willingness to forgive; it is an essential part of what makes them provide the comforting power of creative justice.

These broken-hearted mothers also are so very generous in their giving to each other. Each one shares with the group her own profound feelings of grief. Sometimes they talk about the horrible loneliness they experience. Some speak about feeling guilty because they were unable to

save the child who died. Some feel guilty because they are still living while their beloved child is not. In revealing themselves to each other, the women give to each other a gift of unspeakable beauty.

The people in this grief support group practice creative justice. They do not expect closure to their grief, but they do find comfort in the group. The injustice of the death of a child before his or her parents is made a little less painful because they listen to each other, they forgive each other, and they give themselves to each other.

**Rev. Dr. Judith Craik**, of Williamsville, N.Y., is the former interim pastor of the First Baptist Church of Newfane, Newfane, N.Y., where she facilitated a grief support group that was initiated by a member of the congregation. A retired American Baptist pastor, she continues her ministry as a pastoral counselor and is a fellow of the American Association of Pastoral Counselors.

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# Love in Liminal Space

**A Hospice Social Worker Helps a Grieving Family Express What's on Their Minds and Hearts**

By **Scott Janssen, M.A., MSW, LCSW**

Rick's\* eyes were fixed on the gray sky as he glared angrily out the kitchen window. Everyone was giving him a wide berth. A physically powerful man, he's intimidating on a good day and with his 27-year-old daughter Jen's lifeless body upstairs, this was one of the worst.

I cleared my throat to let him know I was standing behind him. As I approached, I made sure he could hear each footstep. I stood beside him silently, hardening my eyes, and we glared together at the autumn sky.

After several minutes I softened my face and looked at him. He swallowed hard, forearms and shoulders clenching as though bracing against a wave of unspeakable pain. When he looked at me, his eyes glassy with tears, I visualized sending him a silent pulsation of courage and love. Spontaneously, he began telling me a story about the day Jen was born.

"When the nurse brought her

in, my wife held her in her arms repeating the words, 'I love you' over and over. I asked what the hell she thought she was doing," he recalled.

Tears welled in the corners of his eyes as he cleared his throat, explaining, "She told me she wanted the very first thing Jen ever heard to be a message of love."

"What'd you do?" I asked.

"I picked her up and said 'I love you' over and over," he replied.

He returned his gaze to the window, his face lost in remembering. After a few minutes of silence he said he needed to get some air and disappeared out the kitchen door.

\*\*\*

This time I had not followed him. After years as a hospice social worker I know that not everyone who is suffering wants to talk about it. Sometimes people want silence; sometimes they want space.

Though aware of the blueprint hospice professionals often use

to help people prepare for such moments—encouraging them to say and do all the right things—I've come to believe that there really is no "right thing"; there are only imperfect, often frightened human beings with human hearts doing their best to deal with painful situations and, however awkwardly, express love.

Not all messages of love are as clear as the one Rick delivered to Jen the day she was born. Sometimes love is expressed in barely recognizable gestures: a momentary softening in the eyes, a pause to catch one's breath rather than respond with frustration, the touch of a hand, an unspoken prayer.

Such expressions are easily missed or mistranslated amidst the stormy surface of difficult events, swallowed beneath the tempest of intense emotions, stress and fatigue.

One of my jobs as a hospice social worker is simply being attentive to the ways love gets overshadowed or goes unrecognized, and finding ways to call people's attention to these messages even as physical decline and impending separation press down on the nerves. Helping patients and their families connect with what some clinicians call their deep or core selves, what others call their souls, and to express this felt sense of love has become a central part of my practice.

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As I watched Rick light a cigarette and kick his work boots against the brick foundation of the carport, I thought about the visit I had with him and Jen a couple of weeks earlier. She was declining rapidly and had asked both of us to come at the same time.

When we were all there, Jen straightened her back, raised her voice, and told Rick she was fed up with his bullying anyone who tried to speak honestly about her decline. She'd had it with his denial. Rick

## Ode to Chaplain Friends

Since chaplains are an indispensable part of any hospice team, I have worked with quite a few over the years. And I have learned from my chaplain friends more than I could ever articulate.

Chaplains have helped me understand that every person, whether having religious faith or not, has a profoundly spiritual dimension; and that this dimension may be transformative during times of struggle such as often occur at the end of life.

They have sensitized me to the deep self, the spirit, within each individual, and reminded me to listen closely for the inner voice of this deep self, whatever pain or suffering may be roiling the surface.

And they have helped me learn to cherish the mystery of life, accept that some things are unknowable, and trust that love, after all, really is more powerful than death.

—Janssen

responded defensively, accusing her of surrendering to negativity and giving up without a fight. It was a rough and heated conversation.

When things had settled, I asked him to tell Jen what he'd been trying to communicate by shutting down any conversation about her dying. Tears washed down Jen's face as he told her that he'd been trying to protect her and motivate her to fight harder to live.

"Why is it important to you that Jen fight?" I asked.

He started crying, and then, in an unusually soft voice, declared, "I don't want you to die Jenny-bear."

He leaned forward as if in physical pain, his shoulders shaking, and sobs erupting from his massive frame. Jen reached out for one of his hands as he balled the other into a fist.

Beneath Rick's ferocity had been an impulse to protect. Beneath his intimidating behavior had been the fear of a father whose heart was breaking and whose anger masked deep sadness.

When Jen had tried explaining what it was like to be in a body battered by metastatic cancer, why she was tired of fighting, it was too much for him. He raised his hands and demanded she stop, launching into a discourse on why she shouldn't feel the way she felt—always a recipe for disaster.

I interrupted him mid-stride and asked to him to be quiet, to leave his thoughts and let himself feel, however scary, what was going on inside him at that moment.

"What's the bottom line Rick?" I whispered, tapping the center of my chest. "From the heart this time."

\*\*\*

Outside in the morning cold, Rick flicked away his spent cigarette and put his hands in his pockets, anger chiseled into his face.

I thought about how he had told Jen he loved her, how he would have traded places with her if he could have, how ashamed he was that he

couldn't keep her safe. I remembered how he had asked for her forgiveness, the way they had hugged. In my mind's eye I can still see the look in Rick's eyes as she said, "I love you, Papa-bear."

I left the kitchen and walked upstairs to Jen's room. The room was packed with friends and family. When they saw me everyone fell silent and, as if on cue, quickly filed out, leaving me alone with Jen's husband, Steve, who was sitting on the bed next to Jen's body.

Mindful that the funeral home was going to arrive soon, I asked Steve if he would like me to leave too so he can have a few final moments alone with his wife. He motioned for me to sit next to him.

As he held Jen's hand he shared a few simple memories, which contained deep, eternal truths. I asked what he thought she would most want him to remember now and in the days ahead. In a breaking voice, he said, "She'd tell me I did enough. I did my best."

He said he knew she was dying. The hospice nurse had gone over the little blue book that outlines the signs of approaching death, but he hadn't needed the book. He knew.

"I held her hand for I don't know how long," he said. "I just kept saying, 'I love you.' I said it until her heart stopped. It was the last thing she heard."

*\*Names have been changed to protect confidentiality.*

.....  
**Scott Janssen, M.A., MSW, LCSW**, of Hillsborough, N.C., has been a hospice clinical social worker for more than 20 years and currently works at Hospice and Palliative Care Center of Alamance-Caswell, Burlington, N.C.



SPECIAL  
SUPPLEMENT



# SPIRITUAL CARE

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## ASSOCIATION

JOIN NOW

MAKING SPIRITUAL CARE **A PRIORITY**

# Introducing the **Spiritual Care Association**



HealthCare Chaplaincy Network (HCCN) has been an organization in the spiritual care and chaplaincy field since 1961. Throughout our history, we have been committed to excellence in spiritual care through our direct clinical care, our clinical pastoral education (CPE) and continuing education programs, and our extensive research and consensus statements. We have been an ongoing financial and resource provider to other organizations over the years, enabling them to carry out myriad projects. There is no doubt HCCN is a part of the fabric of spiritual care in America.

My arrival as HCCN's chief executive officer in 2013 brought me face to face with many like you. The staff at HCCN educated me on our history. Thought leaders, chaplains, and other health care professionals challenged me to better integrate spiritual care into health care, to address the gaps, and to look to the future. HCCN's dedicated board sought action to contribute significantly to the field.

That's why the Spiritual Care Association (SCA), an affiliate of HCCN, has been born. SCA, with its vast resources and services, is the product of years of research and discussion. It is the culmination of HCCN's experience, and the thought and insights of respected leaders as well as the daily providers and interested parties in spiritual care and chaplaincy. It engages chaplains and other health care professionals from multiple disciplines, community clergy and religious leaders, and organizations and institutions in common purpose. It looks at the real needs of providers, patients and their families, and the important role of chaplaincy. It standardizes a fragmented profession, and makes education and preparedness a fundamental necessity. And it commits to raising a loud voice for the spiritual care agenda by providing the opportunity in the U.S. and across the globe to speak up and lead to change and transformation.

A passionate vision, isn't it? Some may say it is impossible. Others may say we have never done it like this before, and so may deride the prospect. Still others may express concern, fearing that which is new. But what about *you*? What do you think? Isn't it time for spiritual care to be better accepted, respected and valued? Isn't it time to ensure that the whole person – body, mind *and* spirit – is cared for? Isn't it time to do everything we can to reduce the pain and suffering of those we serve? Isn't it time for more to be done, for more support and better guidance to be provided? This is an opportunity to get involved, an opportunity to make a difference. No, it's not just a passionate vision: it is the vision of our future.

Sincerely,

A handwritten signature in blue ink, appearing to read 'Eric J. Hall'. The signature is fluid and stylized, with a large initial 'E'.

Rev. Eric J. Hall  
President & CEO  
Spiritual Care Association

# About the **Spiritual Care Association**

**The Spiritual Care Association (SCA) is the first multidisciplinary, international professional membership association for spiritual care providers that establishes evidence-based quality indicators, scope of practice, and a knowledge base for spiritual care in health care.**

As health care providers emphasize the delivery of positive patient experience, SCA is leading the way to educate, certify, credential and advocate so that more people in need, regardless of religion, beliefs or cultural identification, receive effective spiritual care in all types of institutional and community settings in the U.S. and internationally. SCA is committed to serving its multidisciplinary membership and growing the chaplaincy profession.

The nonprofit SCA is an affiliate of HealthCare Chaplaincy Network™ (HCCN), a health care nonprofit organization founded in 1961 that offers spiritual-related information and resources, and professional chaplaincy services in hospitals, other health care settings, and online.

As a lead-up to the establishment of SCA and to transform the field, HCCN released in 2016 evidence-based quality indicators and evidence-based scope of practice.

## **WHAT SCA OFFERS MEMBERS:**

- **Engages and unites multiple interest groups so more people in need receive effective spiritual care**
- **Opens access to new evidence-based knowledge base: Online Learning Center**
- **Offers new paths for chaplaincy credentialing, board certification, and clinical pastoral education**
- **Provides valuable resources to contribute significantly to career development**
- **Creates a powerful voice for spiritual care**



# Spiritual Care Association Membership

“When we touch on the essence of humanity at our core – the very spirit that accompanies the body in each care encounter, we reveal boundless opportunities to positively impact the overall health of each individual and the communities we serve.”

— Jason A. Wolf, Ph.D.,  
President, The Beryl Institute

Source: “The Critical Role of Spirituality in Patient Experience,” The Beryl Institute and HealthCare Chaplaincy Network, 2015

## Spiritual Care Association membership is open to:

**All individuals and organizations committed to the delivery of optimal spiritual care, as a vital component of whole person care and the overall patient experience. We offer three categories of membership:**

- Health Care Professionals, including but not limited to:
  - Physicians
  - Nurses
  - Social Workers
  - Chaplains
  - Patient Advocates
  - Administrators
  - Volunteers
- Community Clergy and Religious Leaders
- Organizations and Institutions



# SCA Addresses Crucial Needs Raised by Thought Leaders

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## › The Demand for Outcomes

- “Health care in industrialized countries is increasingly focused on outcomes (Department of Health, 2013) ... Whereas chaplains have generally been exempt from this economic focus, increasingly the value of chaplaincy care is being evaluated on these criteria.”

Source: George F. Handzo, Mark Cobb, Cheryl Holmes, Ewan Kelly & Shane Sinclair (2014) Outcomes for Professional Health Care Chaplaincy: An International Call to Action, *Journal of Health Care Chaplaincy*, 20:2, 43-53, DOI: 10.1080/08854726.2014.902713

## › The Demand for New Methods for Professional Education and Certification

- “Greater engagement with chaplaincy certification competencies is one of several approaches to improvements in chaplaincy education that should be considered to ensure that chaplains have the training needed to function effectively in a complex and changing healthcare environment ...”

Source: George Fitchett, Alexander Tartaglia, Kevin Massey, Beth Jackson-Jordon & Paul E. Derrickson (2015) Education for Professional Chaplains: Should Certification Competencies Shape Curriculum?, *Journal of Health Care Chaplaincy*, 21:4, 151-164, DOI: 10.1080/08854726.2015.1075343

## › The Demand for a New Professional Spiritual Care Membership Organization

- “The current system in professional chaplaincy is not sustainable, and we must develop and embrace a different mode ... Without an empirical base that validates the outcomes of their professional work, chaplaincy as a profession will remain on the margin of health care, and not be able to justify further investment of limited health care dollars to support its professional endeavors ... Chaplaincy still lacks an organized, strong, unified, proactive and representative national voice.”

Source: The Rev. Walter J. Smith, S.J., Ph.D., from his 2012 COMISS Network (The Network on Ministry in Specialized Settings) Forum Address upon receipt of the COMISS Medal, its highest recognition. At that time, Father Smith was HCC President and CEO, a position he held from 1991 to 2013.

## For Health Care Professionals

### SCA Is a Vital Resource

- While professional chaplains are the spiritual care specialists on the interdisciplinary health care team, there is growing recognition that delivery of spiritual care requires the **participation of all members of the team.**

- “**In the medical field we’ve got to teach people from all types of disciplines** how to listen and engage people comfortably and care for them spiritually and emotionally.”

Source: Malcolm Marler, D.Min., BCC, Director of Pastoral Care, UAB Medicine, in “The Critical Role of Spirituality in Patient Experience,” The Beryl Institute and HealthCare Chaplaincy Network, 2015

- SCA delivers **for health care professionals a unique and comprehensive combination of benefits:** evidence-based education in the Online Learning Center, Spiritual Care Grand Rounds webinars, the online resource and community of The Chaplain Connection, publications and updates, and more.

# For Community Clergy and Religious Leaders

## SCA Is a Vital Resource

Community clergy and religious leaders are often unprepared to provide spiritual care to individuals with chronic disease and/or nearing the end of life because this training is largely missing from seminary education.

There are more than 350,000 spiritual leaders and community clergy in the U.S. The time is now to enlist their full participation in providing spiritual care.

### RESEARCH EVIDENCE:

#### From Clergy

- Although **94 percent** of clergy report making visits to people at the end of life, only **60 percent** are very comfortable making these visits.  
(Source: "Questions and Answers about Americans' Religion," Gallup 2007)
- **Two out of three** clergy indicate a desire to receive and provide education to tend to the seriously ill or dying.  
(Source: Duke Institute on Care at the End-of-Life survey, 2007)

#### From Patients They Serve

- **83 percent** of survey respondents indicated that their faith would be most important to them in facing long-term illness and end of life.  
(Source: Faith & Health Care, Transforming Lives and Communities through Health and Wellness—One Person at a Time, Henry Ford Health System, 2012)
- **Almost 70 percent** of patients felt their spiritual leaders were not prepared at all or very little to help them face the practical issues surrounding death.  
(Source: Ibid)
- **42 percent** of those facing life-terminating illness report little or no support of spiritual needs from their religious community.  
(Source: Balboni TA 2007, 25.555ff).



# For Organizations and Institutions

SPECIAL  
SUPPLEMENT

## SCA Is a Vital Resource

- Complements or supports **your mission and objectives**
- Gives you **access to high-value resources and benefits**, including:
  - \$200 discount on each online professional education course – applicable to all W-2 employees (\$295 fee per course for members vs. \$495 for non-members)
  - No charge for one exhibit booth at the annual Caring for the Human Spirit® Conference (\$500-\$750 value)
- Offers **communications opportunities about your programs** to SCA's diverse membership
- Provides a venue to become part of the grassroots, national and global, **multidisciplinary advocacy effort** to advance the integration of spiritual care in health care

## Gain a Powerful Voice for **Advocacy**

**SCA is leading the grassroots, national and global, multidisciplinary advocacy effort that:**

- **Is uniting the voices of individual and organizational members** to advance the integration of spiritual care in health care so that more people receive the help they need
- **Empowers** chaplains
- Gives chaplains **a seat "at the table"** when major decisions are being made about policy and reimbursement for inpatient, outpatient and home care
- **Thanks Chaplains** and other involved members of the interdisciplinary health care team for their extraordinary work by creating and publicizing the new annual Spiritual Care Day (May 10)

# Types of Membership



## Health Care Professionals:

Low \$95 annual membership fee offers an annual value of more than \$500



## Community Clergy and Religious Leaders:

Low \$50 annual membership fee offers an annual value of more than \$280



## Organizations and Institutions:

Low \$500 annual membership fee offers an annual value that can be unlimited with the discounted member pricing on online professional education courses for all W-2 employees

## Benefits

Benefits	Health Care Professionals	Community Clergy and Religious Leaders	Organizations and Institutions
The Chaplain Connection – Online Resource Center & Community			
\$200 Discount for Each Online Professional Education Course			
Free Spiritual Care Grand Rounds Webinars	3	2	
Discounted Registration for Annual Caring for the Human Spirit® Conference			
One Exhibit Booth at the Annual Caring for the Human Spirit® Conference			
Electronic Subscription to Journal of HealthCare Chaplaincy			
Subscription to Caring for the Human Spirit® Magazine			
Monthly Spiritual Care Updates			
Membership Directory			
Networking Opportunities			
Online Membership Dashboard			

# Grow With the Online Learning Center for Professional Continuing Education

- The curriculum is based on new, standardized evidence-based scope of practice and evidence-based quality indicators developed by two interdisciplinary panels of experts, convened by HCCN, from the fields of chaplaincy, medicine, nursing, psychotherapy, palliative care, social work, research and policy in the U.S. and overseas.
- The center uses a state-of-the-art learning management system.
- Each course was written by a subject matter expert.
- You can take each course at your own pace.
- Earn a certificate of completion and continuing education hours for each course completed.
- Individual course price for SCA members is \$295 and \$495 for non-members.

## Partial Course List

### › WHAT WE HEAR AND SAY: SPIRITUAL ASSESSMENT AND DOCUMENTATION

Brent Peery, BCC, Chaplain Director, Memorial Hermann Healthcare System

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### › THE CHALLENGES OF MEMORY: ALZHEIMER'S AND OTHER DEMENTIAS

Doug McNair, M.D., Ph.D., President, Cerner Math

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### › LIVING WITH HEARTBREAK: WORKING WITH GRIEF

Ken Doka, Ph.D., Professor of Gerontology, Graduate School of The College of New Rochelle

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### › FAR TOO SOON: THE ANGUISH OF PERINATAL LOSS

Joanne Cacciatore, Ph.D., Founder & Chairman, MISS Foundation

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### › CARING FOR THE SMALLEST: PEDIATRICS

David Pascoe, M.A., BCC, Manager of Palliative Care, Spiritual Care and Bereavement Services, Primary Children's Hospital

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### › WALKING THROUGH THE MAZE: PAIN MANAGEMENT

Richard Payne, M.D., Esther T. Colliflower Professor of Medicine and Divinity, Duke University

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### › CARE FOR ALL: CULTURAL COMPETENCE, INCLUSION AND VULNERABLE POPULATIONS

Sue Wintz, BCC, Director of Education, Spiritual Care Association

See the full course list and register at [www.SpiritualCareAssociation.org](http://www.SpiritualCareAssociation.org)





- › Virtual curriculum and didactics online and via video combined with on-site/in-person clinical work overseen by a Clinical Pastoral Education (CPE) supervisor
- › For anyone interested in CPE but whose work, personal or other responsibilities have prevented them from taking conventional CPE units, including:
  - Those interested in chaplaincy as a first career
  - Those pursuing a second or third career
  - Seminarians
  - Community clergy
  - Volunteers
- › Follows Association for Clinical Pastoral Education, Inc. standards
- › CPE.org is offered by HealthCare Chaplaincy Network (HCCN), through its affiliate SCA. HCCN is an Association for Clinical Pastoral Education, Inc.-accredited CPE center.

## SCA Offers Chaplain Credentialing

### Credentialed Chaplain

**Anyone currently working as a chaplain but is not board certified and meets these requirements merits the title of Credentialed Chaplain (CC):**

These include a Bachelor's degree from a Council for Higher Education-accredited (or international equivalent) institution in a content area relevant to chaplaincy, at least 400 hours of clinical training in spiritual/pastoral care (such as Clinical Pastoral Education), proof of working a minimum of 1,000 hours as a chaplain since completion of clinical training, and five more requirements. Find the full requirements list at **[www.SpiritualCareAssociation.org](http://www.SpiritualCareAssociation.org)**

*Equivalences will be offered and are subject to review on an individual case-by-case basis.*

## The Value of Credentialing

**For Chaplains:** The title of Credentialed Chaplain (CC) will attest to your level of competence in the profession.

**For Institutions:** A Credentialed Chaplain (CC) has demonstrated the competencies to perform normal chaplaincy tasks in non-complex settings, or under the supervision of a BCC in complex settings.

# SCA Offers Two Paths to Board Certification

## PATH 1

**Anyone who holds a current board certification or its equivalent from a recognized U.S. or international professional chaplaincy organization (See list at [www.SpiritualCareAssociation.org](http://www.SpiritualCareAssociation.org))**

## PATH 2

**A chaplain who meets these requirements:**

- A Master's degree from a CHEA-accredited (or international equivalent) institution in a content area relevant to chaplaincy. Concentrations include but are not limited to theology, study of sacred texts, medical or professional ethics, psychology, sociology, family systems, counseling, social work, nursing, world religions and belief systems, organizational development, gerontology, communication, and the relationship of spirituality and health
- Within or beyond a Master's degree, one credit in at least three of the following areas:  
1) quality improvement 2) research 3) spiritual assessment, care planning, and documentation 4) cultural competency/inclusion 5) end of life 6) grief/bereavement 7) ethics 8) religious faith systems 9) communication, or 10) basic pathophysiology
- At least 800 hours of clinical training in spiritual/pastoral care, such as CPE
- Employer letter verifying current employment
- Proof of working a minimum of 2,000 hours as a chaplain since completion of clinical training
- Three letters of recommendation from 1) health care administrator where you are employed 2) BCC or director of spiritual care at your place of employment, and 3) non-chaplain health care professional colleague
- Demonstration of competency by verbatims or standardized patient encounter
- Accountability for Ethical Conduct
- SCA's online, multiple choice, on-demand test of knowledge/understanding of evidence-based scope of practice

*Equivalencies will be offered and are subject to review on an individual case-by-case basis.*

## The Value of Board Certification for Chaplains and Institutions

A Board Certified Chaplain (BCC) has demonstrated competence to perform all of the normal tasks within the scope of practice of chaplains.

## NEW CLASSIFICATION:

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## NEW DEPRESSION SCREENING GUIDELINES:

# Implications for Health Care Chaplains

By Jason A. Nieuwsma, Ph.D.

Earlier this year, the U.S. Preventive Services Task Force (USPSTF) issued an updated recommendation for screening depression in adults aged 18 and older. The recommendation, published in the January 26, 2016 online issue of the *Journal of the American Medical Association (JAMA)*, updates a 2009 USPSTF recommendation on depression screening.

At first read, the two recommendations appear highly similar. And they are. At the same time, a careful inspection of how the recommendation has evolved from 2009 to 2016 suggests certain progressions within health care that have potential implications for health care chaplains.

The new USPSTF guidelines endorse depression screening in primary care settings for the general adult population and for the first time specifically recommend screening of pregnant and postpartum women. The recommendation states that “screening should be implemented with adequate systems in place to ensure accurate diagnosis, effective treatment, and appropriate follow up” (Siu et al., 2016).

This maps closely to the 2009 recommendation, which used the phrase “staff-assisted depression care supports” instead of the newer

“adequate systems” phrase, and which previously included an explicit recommendation against screening when such care supports or systems were not in place.

Although the newer recommendation no longer explicitly includes this caveat against screening in certain situations, it continues to imply the caveat by virtue of recommending that screening be done in a particular fashion: “with adequate systems in place.”

It is worth briefly describing what is meant by this very loaded phrase of “adequate systems.” In the *JAMA* article, the authors describe what at a minimum an adequate system looks like and then provide a number of examples of systems that go above and beyond. Their example of a system that meets the minimum requirements consists of a nurse who advises physicians of the positive depression screen and is able to facilitate referral to an evidence-based behavioral treatment. Their examples of systems well exceeding the adequate bar include different combinations of: providing trainings in evidence-based depression treatment approaches to staff; more intensive engagement by trained nurses; ongoing support for medication adherence; and different ways of facilitating evidence-based

psychotherapeutic treatments like cognitive behavioral therapy (CBT). Multidisciplinary teams that take a collaborative approach to caring for persons with depression received particular praise.

For health care chaplains, there are three subtexts to the new USPSTF guidelines that merit awareness and ongoing attentiveness.

### 1. Adequate Systems in Place

The first subtext is the retention of the recommendation that screening be done with adequate systems in place. Although the 2009 warning against screening in certain circumstances is no longer included in the 2016 update, it is still implied. And that is because the evidence suggests that while screening may increase detection of depression, screening in-and-of-itself does not result in better clinical outcomes (Gilbody, Sheldon, & House, 2008; Gilbody, Whitty, Grimshaw, & Thomas, 2003). When a positive screen occurs, the system needs to know what to do with it. The nurse needs to know how to make a referral. The physician needs to know how to prescribe medication at an adequate dosage. The health care professionals involved in caring for the person need to know what

are and are not evidence-based approaches to care, and how to facilitate access to such care.

This principle, though basic, has tremendous consequence for chaplains looking to more intentionally integrate themselves into various health care systems, mental health or otherwise. If a chaplain is going to encourage health care professionals to be more attentive to spiritual issues among patients—potentially even to somehow screen for such issues—those professionals need to know what to do with a positive screen. What care services are they going to recommend for this patient?

Presumably, if they are thinking of recommending chaplaincy services, the health care professional needs to have a basic knowledge of what these services are, and how to facilitate access to them. Importantly, they need to be confident enough in their own understandings of chaplaincy services to be able to describe these services to patients, to dissuade patients of any potential misconceptions about chaplaincy, and to articulate to patients why a referral to chaplaincy makes sense in a particular case.

## 2. Behavioral and Psychotherapeutic Approaches

The second suggestion embedded within the new USPSTF depression screening recommendation that has implications for chaplaincy is the greater emphasis on behavioral and psychotherapeutic approaches. The increased warming toward these methods of care for depression in primary care settings reflects an acknowledgement of the substantial literature on their efficacy (Cuijpers et al., 2013) as well as the relative lack of harmful side effects entailed by psychotherapeutic approaches in comparison to psychopharmaceutical approaches.

Though vague on the evidence to assert its claim, the

USPSTF suggests that its updated recommendation incorporates an awareness of mental health care services being more “widely available” and integrated into primary care settings. Indeed, there have been many efforts to more intentionally integrate mental health care services into primary care settings (Zeiss & Karlin, 2008). These efforts, and the fact that the USPSTF acknowledges them to some degree in the depression screening recommendation, can be viewed as evidencing a growing embrace of biopsychosocial conceptions of health.

Such a trajectory paves the way for biopsychosocial-spiritual perspectives and the inclusion of well-equipped health care chaplains. Psychologists and other mental health professionals have had to advocate their way into primary care settings, and no doubt chaplains will need to undertake similar advocacy efforts, but at least there are some encouraging signs that such efforts may prove fruitful.

## 3. Multidisciplinary Care Teams

Relatedly, the third implication for health care chaplains has to do with the USPSTF’s highlighting of multidisciplinary care teams. The 2016 language shift to “adequate systems” in place of the 2009 verbiage of “staff-assisted depression care supports” embodies a certain broadening of thinking about both systemic issues pertinent to the care of depression as well as who might be involved. In such a climate, chaplains are in an excellent position to make the case for their systematic inclusion as part of multidisciplinary health care teams, even in primary care settings.

There is research literature that indicates meaningful interrelationships between spiritual variables and depressive symptomatology (McCullough & Larson, 1999), which should not be simplified to suggest that religion

# GUIDELINES AT A GLANCE

- Primary care practitioners to screen for depression in all adults aged 18 and older regardless of risk factors
- Includes screening for depression in pregnant and postpartum women, subpopulations that were not specifically reviewed for the 2009 recommendation
- Issued the recommendation with a Grade B—reflecting “a high certainty that the net benefit is moderate or there is moderate certainty that the net benefit is moderate to substantial”
- No specific guidelines on how often to screen, stating “more evidence for all populations is needed to identify ideal screening intervals”
- Cites commonly used screening instruments: Patient Health Questionnaire, the Hospital Anxiety and Depression Scales in adults, the Geriatric Depression Scale in older adults, and the Edinburgh Postnatal Depression Scale in postpartum and pregnant women
- Notes multidisciplinary team-based primary care that includes self-management support and care coordination as effective in management of depression
- Cites antidepressants or specific psychotherapy approaches among effective treatment of depression

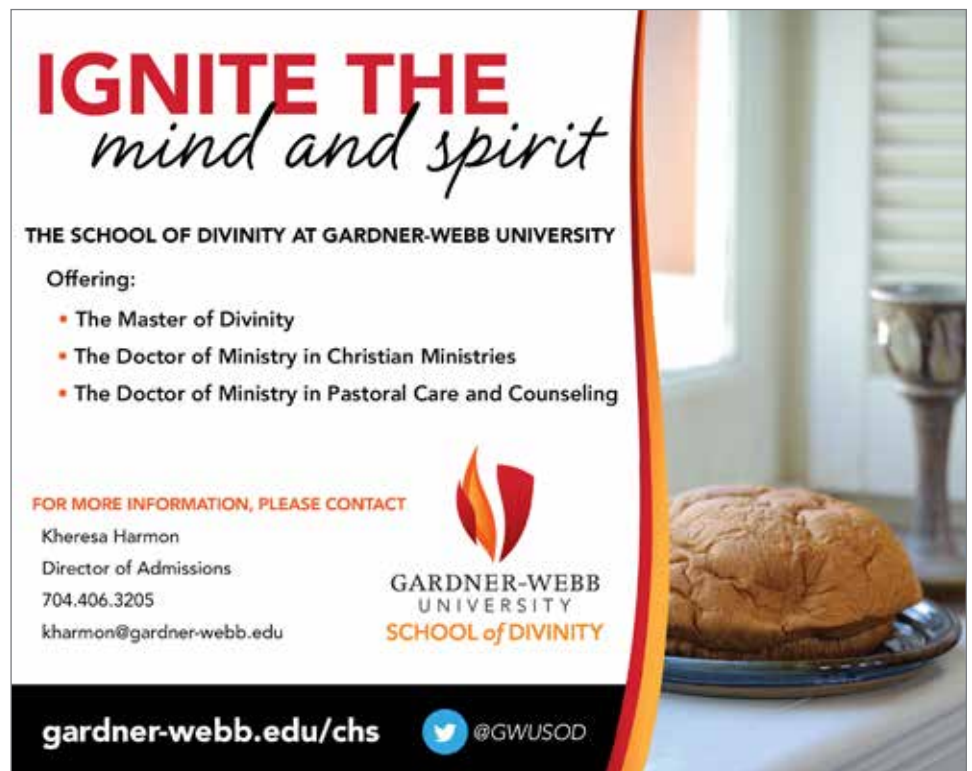
is good or bad for mood and yet which also indicates the importance of intentionally attending to spiritual issues among persons with depression. Such literature certainly helps to make the case for including chaplains on multidisciplinary teams.

It is not sufficient, though. To be optimally effective in the health care settings where depression is being screened for—such as in primary care settings—chaplains also need to be prepared. Optimally, they need to be well-equipped to function in health care settings, to have a solid familiarity with mental health issues, to be versed in evidence-based care approaches that are synergistic with chaplaincy, and to be ready to take on systems-level health care issues.

The latter may require chaplains to have a greater degree of readiness than even other health care professionals, as chaplains may be charting new integrative territory and will need to be prepared to think about issues such as how providers should implement screening and referral procedures related to chaplaincy services.

Substantial work remains to be done with respect to optimally integrating chaplains as part of multidisciplinary care teams. However, as some of the subtexts in the new depression screening guidelines may suggest, there are also promising signs of openness to the kinds of psychosocial-spiritual care that chaplains can provide. These signs of openness are encouraging—for chaplains, for affiliated health care professionals, and for patients with depression who stand to benefit from improved care services.

**Jason A. Nieuwsma, Ph.D.,** of Chapel Hill, N.C., is associate director of the Veterans Health Administration's Mental Health and Chaplaincy, a national initiative that aims to achieve a more collaborative system of care for the benefit of veterans and their families. He is also an assistant professor in psychiatry and behavioral sciences at Duke University Medical Center, Durham, N.C.



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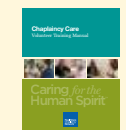
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# INSIDE MONGOLIA: *Progress in Palliative and Hospice Care*

## EDITOR'S NOTE:

*Mongolia caught the attention of the health care community last fall when it ranked 28 out of 80 countries on The 2015 Quality of Death Index, published by The Economist Intelligence Unit. The index uses quantitative and qualitative indicators related to the palliative and health care environment, human resources, the affordability and quality of care, and the level of community engagement. Among its findings, rich nations, like the U.K. in the top spot and the U.S. in the ninth, tend to score highest.*

*How then did this low-income, sparsely populated country of 3 million people in Asia find its way to the upper tier of the ranking? Cited by the authors as an "impressive case," Mongolia has come quite the distance: before 2000, palliative care was an unknown term here. Then, Odontuya Davaasuren, M.D., Ph.D., took up the cause. Inspired after attending a European conference on palliative care and recalling memories of suffering by patients and their families as well as her own family members, Davaasuren has been leading the country's rapid growth in palliative care and pain management programs, hospice facilities, patients' rights, and professional education for physicians and social workers.*

*"The knowledge gained from palliative care courses and [World Health Organization] WHO guides gave me the strength, faith and wings to fight for establishing a palliative care system in Mongolia with policy, education, drugs and services," she has said.*

*We invited this pioneering physician, who is hailed as "the mother of palliative care in Mongolia," to look back and look ahead at palliative care in her country.*



Photo: Palliative care advocates Dr. Odontuya Davaasuren (r.) and Ajaa Geegen

## By Odontuya Davaasuren M.D., Ph.D.

### History of Spirituality and Religion

Mongolia was a country of Buddhists in the beginning of the 20th century; 100 percent of the population was of the Buddhist religion, and more than 50 percent of men were monks. Since monks had no family and no reproductive activities, as a result, the population of Mongolia in 1918 was just 647,500. Mongolia had no hospitals and health organizations. It was a dying population in the world.

A revolution in 1921 made Mongolia an independent country after 200 years of Manchurian dictatorship. Religion was seen as "opium for people." During communist rule, Buddhist monks were persecuted and thousands were killed, and almost all 700 Buddhist monasteries were destroyed.

But, while all religions were suppressed, the development of sciences, medicine, education, and government policy under the Ministry of Health and Ministry of Education

began with the support of the Soviet Union. In 1945, the National University with medical faculty was established; it developed into the Medical Institute in 1961, and now it is the Mongolian National University of Medical Sciences.

With the transition to a more democratic regime beginning in 1990, Mongolians were able to practice all religions without persecution, and Buddhism started blossoming again in the country. We began celebrating the Mongolian New Year according to the Buddhist calendar; on this day, every spiritual Mongolian goes outside in the early morning to do a New Year ceremony. We see many new monasteries in Ulaanbaatar, the capital city, and other provinces. There, people always come to pray, sometimes having to stand in long queues to get to the monk ceremony. While the Mongolian population is not as religious as in the past, still today, 53 percent identify as Buddhists and 38.6 percent as not religious.

### History of Palliative Care

When we started establishing palliative care in Mongolia in 2000, the Mongolian Palliative Care Society organized several conferences and courses, and we included presentations on spiritual care. I told attendees about examples in other countries, such as the University Palliative Care Service in the Academy of Medical Sciences in Poznan, (Poland), with an in-patient unit and a home care team, which was built after direct communication with the Catholic Church; the Palliative Care Department of the National Cancer Center in Bratislava, Slovakia, which has a big prayer hall in the building; family health centers in Leeds, U.K., which have chaplains on staff who help family doctors by providing spiritual support, especially for palliative care patients; and the participation of many chaplains in the European Palliative Care Association's conference in Sweden in 2000, which was the first palliative care conference I attended.

These were my brief experiences with spiritual care in palliative medicine, which I gained from other countries. But, then, advances began taking place in my own country. In 2002, hospices began emerging with the support of Christian organizations; the hospices have their own spiritual care workers and nice spiritual rooms.

There was the establishment of the Green Home Hospice, with the support of Korean Saemmul Christian Hospice, in 2002; Hope Hospice, with the support of Mongolian Christian medical workers, and Grace Hospice, a ministry of the United Methodist Church, in 2005; Tiloba Hospice, a Buddhist center, in 2006; and Omega Hospice, with the support of the Mongolia Campus Crusade for Christ, in 2008; the latter two are no longer operating.

Multiple people from various disciplines have helped accomplish this. I want to express my gratitude to Pastor Lee Keon Huan, a director of Green Home Hospice; Helen Sheperd, a nurse who was a director of Grace Hospice; Pastor Altankhuyag Lkhagvagiin, for establishing Hope Hospice; Pastor Ankhbayar Jigjidiin, who was a director of Omega Hospice; and Monk Badamkhand Luvsangiin, who was a director of Tiloba Hospice, for their great work in developing spiritual care for hospice patients in Mongolia.

Beginning in 2008, Buddhist centers started to support palliative care activities. The head of the Department of Palliative Care of the National Cancer Center (NCC) of Mongolia, Gantuya Tserendorj, M.D., established a spiritual room for palliative care patients there. Monks from the Javzandamba Khudagt Center voluntarily provide spiritual care for palliative care patients.

In 2013, Ajaa Gegeen, a high-level Buddhist, established a children's center for cancer and blood diseases with a pediatrics palliative care ward inside. This center includes a modern hospital and a separate, beautiful building with a big, golden Buddha inside; children and parents of palliative care patients use this house for spiritual care.

These developments in palliative care prepared the foundation for establishing spiritual care as a part of health care.

In 2010, the First Lady of Mongolia, Khajidsuren Bolorma, established "Hope"-Cancer-Free-Mongolia National Organization, a non-governmental organization, and established palliative care wards—each with four to five palliative care beds—in the 21 provincial or secondary level government hospitals throughout Mongolia's 21 provinces, and in the nine district secondary level governmental hospitals, one in each of Ulaanbaatar's nine districts. The Mongolian Palliative Care Society has been educating doctors and nurses who work there.

Today, just slightly more than 15 years after the terminology became known to Mongolia, there are more than 166 palliative care beds in the country: 120 in government hospitals and 16 in NCC, all supported by government funding; and, with non-government funding, 32 in hospices plus those in private hospitals.

### **Spiritual Care on Horizon**

But spiritual care and spiritual care workers do not exist in these palliative care departments because the health budget and health insurance do not support spiritual care. Now even in the medical university most teachers could not differentiate psychological pain and spiritual pain, or the differences in assessment.

When I began studying palliative care in 2002, I did not know the differences, either. I thought that spiritual care is just religious support. I understood this difference after attending a palliative medicine fellowship program at San Diego Hospice from 2007 to 2010. I implemented an assessment form for spiritual pain based on the work of my teacher, Shannon Moore, M.D., now the hospice's clinical medical director. She is a very beautiful women with special light aura.

Now I teach the assessment of spiritual pain, and our medical students try to help patients. I saw many cases in which spiritual support helped patients—sometimes better than drugs. I think that research and studies will improve spiritual care in medicine. We are very hopeful that soon the Ministry of Health of Mongolia will understand

that spiritual pain is a part of health care.

Currently, I am facilitating a study on spiritual pain and will release the results shortly; I hope it will be a drop in the ocean of spiritual care research.

### **The Power of Spiritual Medicine**

Hundreds of years ago in the Zavkhan province of Mongolia lived nine hubilgans (monks with extrasensory ability and power to treat by spirit), and they said, "If people will use more than 10-15 percent of [their] brain, they can control [their] own body and spirit. It will be real high-level medicine without chemical medications and surgery." Thousands of years ago, Mongolian traditional medicine had spiritual medicine as a part of medicine, too.

Modern medicine is very primitive, low-level medicine because it enjoys chemistry and surgery. The highest level of medicine is spiritual medicine, when the person controls his or her own body and soul—when a person driving a soul can remove a bullet from his body, quickly heal a wound, or prevent having cancer.

While people now do not believe in spiritual medicine and do not accept spiritual care as part of medicine, I have confidence that the intensive growth of the sciences will develop the power of our brain, and spiritual medicine will be accepted by the world population as a highest level of medicine.

In the days ahead, our goal is better, permanent and flexible integration of palliative care with government and health care policies, and health education, social welfare, and spiritual care systems in Mongolia.

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**Odontuya Davaasuren M.D., Ph.D.,** of Ulaanbaatar, Mongolia, is a family doctor, and a professor in the General Practice and Basic Skills Department, Mongolian National University of Medical Sciences, Ulaanbaatar. She is the founder and president of the Mongolian Palliative Care Society and established the Palliative Care Resource Training Center in Mongolia.

Editor's note: This column is all about inspiration—to pass along to your patients and colleagues.

## Grandma's Life Lesson: Gratitude

By **Anne Kertz Kernion**

My Irish grandmother was a ball of fire who exuded warmth and love through many life challenges. Widowed in her 40s, she worked as a nurse and single-handedly raised six children, finally retiring at age 76. Although life was difficult, she knew how to enjoy the moment. I have many fond memories of our time together, like making peanut brittle, watching forbidden scary movies, and pondering beautiful sunsets in a nearby field.

I didn't realize until I was much older that the best lesson Grandma had taught me was to be grateful. She lived each day with a heart filled with thankfulness.

Brother David Steindl-Rast, a Benedictine monk known for his teachings about gratefulness, encourages us to live as Grandma did: grateful in one's life situation even if we aren't grateful for the situation. He reminds us that no matter how difficult life becomes, if we are still breathing, we have something for which to be grateful.

For example, when I have an exercise-related injury, I try to remind myself of all of the ways I still can exercise, instead of what I can't do. Being thankful turns a disappointing situation into an appreciation of different blessings.

Steindl-Rast also recommends that we use the ordinary moments during our day to open our eyes and be grateful. A gratitude practice teaches us to pay attention and notice the gifts right in front of us. For example, every meal can be an opportunity to slow down and truly experience the flavors and textures on our plates.

Gratitude also keeps at bay



Artwork by Anne Kertz Kernion

hedonic adaptation—a theory that humans' happiness remains at a relatively stable level despite major positive or negative life changes. This happens after we get a new car, a new house, or a new job. We adapt to these positive circumstances, and they don't feel new or exciting anymore. If we can continue to be thankful for all of these gifts long after the newness has worn off, we will not take them for granted.

When we are grateful, we cease comparing ourselves with others and block negative emotions like envy, resentment and regret. We can't be grateful and jealous at the same time. In addition, several studies show that grateful people are more resilient and respond better to stress, trauma and adversity; they are better off physically,

psychologically and socially.

So how do we jump on the gratitude train? Here are some ways:

- Write down "What Went Well" at the end of each day (or even each week). Find new things to be grateful for. This exercise not only keeps track of all of those good things happening every day, it prompts you to not take things for granted.

- Send cards or write notes of thanks to others. Just a few sentences will do. It no doubt brings joy to the recipient and the sender as well. It doesn't have to be a big deal. In fact, just yesterday I wrote to my sister, thanking her for buying the "good" baggies the last time she visited our family's condo. (I usually opt for cheaper ones, and it was a treat having the better ones to use.) No big deal, I know, but she was glad I expressed my gratefulness.

- Pause first thing in the morning, over your coffee or drive to work, and set an intention of gratefulness for the day. This will prime you to be alert and find "the good" all day long.

Finally, remember that as we exercise our gratitude muscle, we strengthen it. With that, more gratefulness will come to us naturally. Then we'll have more joy and happiness in our lives, no matter what life throws at us. Grandma would approve!

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**Anne Kertz Kernion**, of Wexford, Pa., is the author of *"A Year of Spiritual Companionship: 52 Weeks of Wisdom for a Life of Gratitude, Balance and Happiness"* (2016, SkyLight Paths Publishing). She is also the owner/artist of *Cards by Anne*, Wexford, Pa., an international greeting card company specializing in inspirational, hand-calligraphied cards with philosophical messages.



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