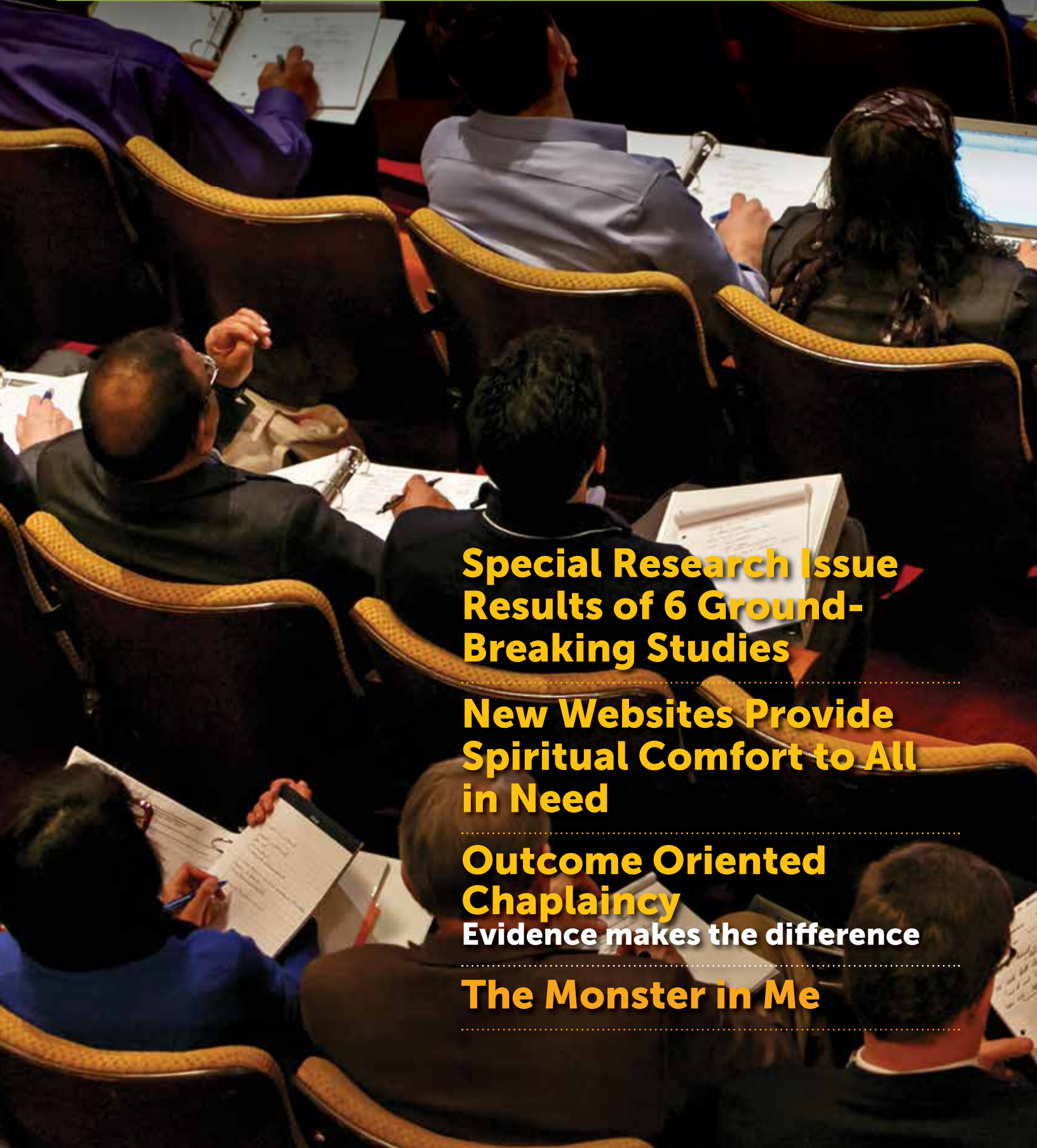


ADVANCING THE INTEGRATION OF SPIRITUAL CARE IN HEALTH CARE

# Caring for the Human Spirit™

SUMMER 2014 magazine



**Special Research Issue  
Results of 6 Ground-  
Breaking Studies**

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**New Websites Provide  
Spiritual Comfort to All  
in Need**

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**Outcome Oriented  
Chaplaincy  
Evidence makes the difference**

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**The Monster in Me**

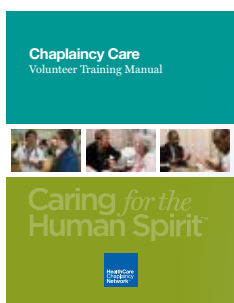
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Chaplains across the U.S. commend this valuable **Volunteer Training Manual**



**For health care institutions** that are committed to providing best practices in spiritual care



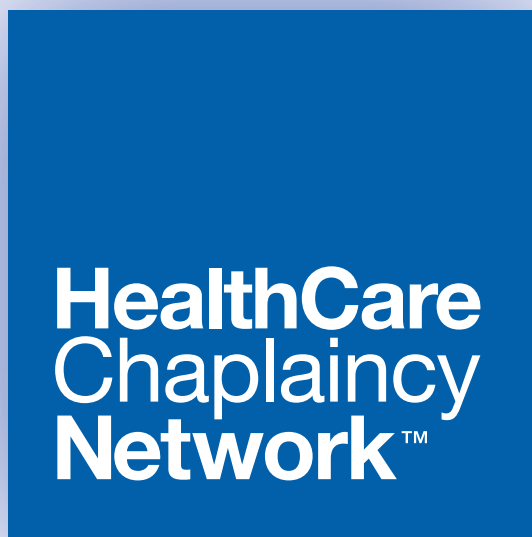
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Cover Photo And Other Conference Photos By  
AMESSÉ PHOTOGRAPHY

**Comments? Suggestions? Contact us at**

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Please share this magazine with your associates.

HealthCare Chaplaincy Network is a national health care  
organization that helps people faced with illness, suffering  
and grief find comfort and meaning regardless of religion or  
beliefs. ([www.healthcarechaplains.org](http://www.healthcarechaplains.org))

# WELCOME to this inaugural issue of *Caring for the Human Spirit*



Rev. Eric J. Hall, MDiv, MA  
President and  
Chief Executive Officer  
HealthCare Chaplaincy  
Network

**A publication whose time has come.** Now, more than ever, the inclusion of spiritual care as a standard of health care and the profession of chaplaincy needs a strong, clear voice.

The delivery of health care in the U.S. is changing faster than at any time in our history. In this environment, only services that can prove their worth will get a seat at the table.

With the increased recent research and subsequent data to substantiate the value, the spiritual care and professional chaplaincy community have a green light to advance the role of spiritual care in health care. Now is the time for us to make a difference.

In pursuit of that goal HealthCare Chaplaincy Network recently convened a ground-breaking research conference, funded by the John Templeton Foundation, dedicated to obtaining empirical data on the role and effectiveness of chaplaincy care interventions. You will find in this magazine reports on the very encouraging findings. Moreover, the gathering of hundreds in the field, and the dozens of sites attending by web cast and representing 8 countries, have made this conference transformative to the field.

The next step is for all of us...doctors, nurses, chaplains, social workers, hospital and nursing home administrators...everyone with a stake in the future of American health care...to join with us to make sure that the patients in our care have their spiritual needs attended to.

We plan this magazine to be the voice of our community. As such, we invite you who are professionals to participate by submitting articles on aspects of today's care that you'd like to see communicated to a wide and influential audience. We invite the global organizations in the fields of chaplaincy, spiritual care, medicine, social work, palliative care and hospice to consider this magazine an extension of your mission. Together, collaborating on this publication, we can make the field of spiritual care stronger, wiser and demonstrably effective.

We would like to dedicate the magazine to the leaders in our field who have blazed the trails that we now follow...pioneers like George Fitchett, Jimmie Holland, Ira Byock, Betty Ferrell, and many others. They've taught us that caring for the human spirit is as important as caring for the human body and mind. We also thank the visionaries who have gone before us at HealthCare Chaplaincy Network who for more than fifty years have tended to the spiritual needs of millions. May we collectively carry on the torch lighting the way to integrate spiritual care into the continuum of the health care system.

Thank you all.

A handwritten signature in blue ink, appearing to read "Eric J. Hall". The signature is fluid and cursive, written in a professional style.

# Spirituality, Health Care and Not Feeling Alone



By The Rev. Christine Davies

*"You're a what?"*

*The patient raises an eyebrow and looks at me suspiciously.*

*"I'm a chaplain. I'm part of the hospital team, to focus on your spiritual and emotional needs."*

*"But I'm not religious."*

*"That's ok. Neither am I!"*

*My retort brings relaxed laughter and then conversation flows.*

This is how many of my visits begin as a hospital chaplain. In making my rounds, I go to rooms, meeting patients and assessing their needs. Most have no idea what a chaplain is or why they need one.

The term chaplain may conjure up images of Roman Catholic priests, and as a woman I certainly do not fit that mold. People are afraid I want to convert them; I explain that I'm trained to support people of all faiths or no faith. My only agenda is the patient feels safe to express what's going on for them. Once we get over the initial hurdle of what exactly a chaplain is, I'm amazed at the trust people put in me and how quickly they open up and share their deepest fears or greatest joys.

Sue was a patient I met through a similar introduction. A former actress in her fifties, her wavy hair was a brassy red hue that matched her personality. She told me that she hadn't been to church in years, but she was bored so she might as well talk to me! "I don't really care about faith and all that junk," she admitted. "What is it you do care about?" I asked. Her response was a common one: "My family."

Theologian Paul Tillich wrote that faith can be defined as one's "ultimate concern." Sometimes my patients are concerned with typical religious issues, like where is God in their suffering. Often, people have "ultimate concerns" that society doesn't always see as religious, but when they ground a person's sense of self and being, how are they not spiritual?

Sue told me how she worried about her mother and felt guilty not being able to take care of her while in the hospital. With glee, she showed me pictures of her nephews. Through tears, she spoke of her grief of never having children of her own. She shared about her brother who had died a few years earlier and how much she missed him. As she contemplated her own mortality in the face of a cancer diagnosis, I asked what she feared most. "I don't want to feel alone," she said.

After an hour, I took my leave and Sue said, "Thank you for

helping me not to feel alone and for really listening. I feel so much better."

Chaplains create a sacred space for listening to "ultimate concerns," whatever they may be. Recently, HealthCare Chaplaincy Network, the organization I work for, launched a website, [www.Chaplainsonhand.org](http://www.Chaplainsonhand.org), where you can connect with a chaplain from the comfort of your home.

My hope is that more people will come to know the benefit of chaplains and feel, like Sue, as though they are not alone.

*The Rev. Christine V. Davies is a minister in the Presbyterian Church (USA) and is certified by the Association for Clinical Pastoral Education as an Associate Supervisor. She is the Manager for Chaplaincy Services at*



*NYU Langone Medical Center through HealthCare Chaplaincy Network. Christine earned her Master of Social Work degree at Rutgers University and her Master of Divinity degree at Princeton Theological Seminary.*

# Changing Roles of Chaplaincy



By David A. Lichter, D. Min.

As we all know, improving quality and driving down health care costs are pillars of the Affordable Care Act.

Health trends for 2014 center on change and innovate...new services with less money.

Accountable Care Organizations and Patient-Centered Medical Homes are developing rapidly. Health care chaplaincy is either a proactive player in this future health care arena or it will be another red-lined expendable cost that does not add evidenced-based value.

## Beyond acute care

As part of the change, health care services have extended far beyond acute care. One Catholic system reports that over ninety percent of patient contacts are in other than acute care settings. So where is the chaplain in these settings? What should the chaplain be providing?

The National Association of Catholic Chaplains (NACC) wanted to know if its members were working in other-than-acute-care settings. Where were they serving, and what further competencies, beyond those required from board certification, might be needed?

These questions aligned with NACC 2012-2017 Strategic Plan's Goal One: "to educate and support association members for the future of chaplaincy," with its first objective to "provide formation and resources for chaplains to be effective ministers and leaders,

especially in emerging settings and health care systems (both Catholic and other) and across the continuum of care."

## Survey suggests new training needed

In fall 2013, the NACC conducted a survey of its members to learn who was working in other than acute care settings. Nearly 40 percent of our full members replied, with 42.3 percent noting that they worked in some capacity and some time in other than acute settings. 17.6 percent identified themselves as working full time in such a setting.

The type of competencies needed in these settings included: training clinicians on screening and referral; time management; understanding and working within a clinic culture (less private, waiting room, brief visits); interdisciplinary care; referrals; triaging; training/utilizing volunteers; and relationship-building with patients for short sessions. This was very helpful information that NACC used to identify further types of training and educational programs for its members.

## Webinars stress innovation

Recently the NACC partnered with Catholic Health East Trinity and several other Catholic Health Systems to plan the CHE Trinity 2014-2015 Spiritual Care Champions Webinar Series. These webinars are addressing the diverse roles that spiritual care leaders and

chaplains are being called to embrace. They include becoming a change agent and innovator in the midst of significant transformations in the health care arena.

The chaplain will have to be an educator and trainer of other staff, helping them identify and screen for spiritual, emotional, and existential needs, and advocating for the value chaplaincy care provides.


## The road ahead

More than ever the chaplain will need to be an effective spokesperson for patient/family concerns as an integral member of the interdisciplinary team, as well as contributing value to the organizations overall quality initiatives.

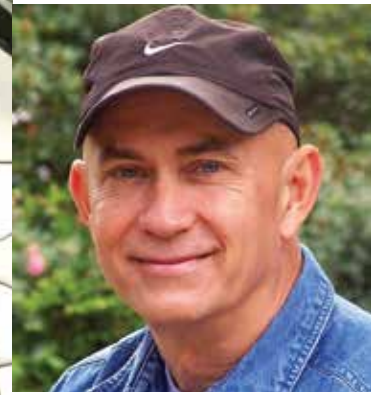
Grounding and guiding these services is a research evidence-based practice. The NACC is grateful for the pioneering work of HealthCare Chaplaincy Network's research initiative funded by The John Templeton Foundation. We also applaud the collaborative work of the Association of Professional Chaplains Research Task Force, especially the longstanding leadership of George Fitchett, DMin, PhD, BCC, Professor and Director of Research, College of Health Sciences, Rush University. These projects and efforts are exciting and critical to ensure the future of health care chaplaincy.

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David A. Lichter, D.Min. is the Executive Director of the National Association of Catholic Chaplains



"It's one piece of a big jigsaw puzzle that is today's health care system."



Rev. Malcolm Marler  
Director of Pastoral Care  
University of Alabama Medical Center

## Support Teams Network Aims to Reduce Hospital Readmissions

In order to help people be healthier, says Rev. Malcolm Marler, Director of Pastoral Care at the University of Alabama Medical Center in Birmingham, we need to partner with the community, train lay people. "It's one piece of a big jigsaw puzzle that is today's health care system."

During the recent Pastoral Care Week, Marler, who heads a 20-person department, held a workshop for Alabama chaplains about how the Support Team Network can help solve health care's "readmission puzzle" by building bridges in the community. "We're teaching the community how to care."

Marler first developed support teams in 1994 as chaplain for the HIV clinic at UAB. Care teams, then mostly from the faith community, provided help to AIDS victims

who did not have a family support system. When the new medicines became available, the care teams became support teams. This effort grew into a national movement, having trained teams in 37 states to help with any health issue. During the last two years, Marler says, they have focused on how to adapt to a huge new health care system to reduce readmissions and educate the community among faith groups, businesses, and other organizations.

The latest initiative at UAB is a pilot program to train students from the university's social work department. Thirty two students in five teams meet weekly, each student providing three hours of community service a week at the UAB Townhouse, an apartment building with 120 units for patients awaiting or recovering from transplants as well as others who need to spend one night or several months near the hospital.

Focus groups are held with patients and families as well as professors and students. Students help with activities such as game night and support groups, or

provide rides to the grocery store. "We are in the middle of downtown," Marler points out "and they have no transportation." He hopes to expand the program to all health professions on campus--medical, nursing and public health students. As he points out, "We have 18,000 students and all of this need."

UAB is a huge complex of 1,100 beds. By the end of the year Marler hopes to have a full-time patient navigator on staff – someone assigned to patients who are challenged in some way and predicted to have difficulty navigating the health care system. "It's a one stop call for the patient," he says.

Marler credits the medical center's leadership with being open to looking at new ways of helping patients and reducing costs in this "perfect storm of the new health care in our country."

# SPECIAL Research REPORT

## Forming an Evidence Base for Chaplaincy Care Effectiveness in Health Care

“This was not just  
a conference.  
This was a  
transformative  
experience.”

“The conference  
is a landmark in  
the progress of  
health care.”

**T**his goal was at the core of the recent ground-breaking global conference: **Caring for the Human Spirit: Driving the Research Agenda in spiritual Care in Health Care.**

The conference, sponsored by **HealthCare Chaplaincy Network**, was held March 31 – April 3 at the New York Academy of Medicine, and was the culmination of a three year long research and education effort funded by The John Templeton Foundation.

The conference drew 325 attendees, in person or by webcast, from throughout the U.S. as well as from the U.K., Australia, Belgium, India, Ireland, Canada, Kenya and Namibia.

Announced at the conference were the results of six research studies from major academic centers across the United States on the role of chaplaincy care interventions. The studies represent the first collection of empirical data on the contributions of chaplains in health care.

### Proving that chaplaincy interventions make a difference

For many years, chaplains have done their work with a well-trained basis of knowledge which has, with experience, become intuitive. But the health care world demands data. The six research studies presented at the conference launched a new field of research in spiritual care in health care. They represent a huge step forward in

describing what chaplains do, so that these interventions can be tested, measured, refined and applied to better patient care.

“This was not just a conference. This was a transformative experience.”

That was a direct quote from one participant, and the general consensus overall.

325 attendees  
from 9 countries  
in person and  
by webcast

“The conference is a landmark in the progress of health care,” said Charles F. von Gunten, MD, PhD, vice president of Medical Affairs, Hospice and Palliative Care for the Ohio Health System.

“The majority of Americans think their spiritual care is as important as their medical care when they are ill. That means we should be as careful and thorough in spiritual care as we are in medical care. This conference sets the field in the right direction.

“I predict that, in the future, we will look back on this conference as a watershed moment in the same way we look back at the Flexner Report and its effect on physicians.”



Attendees came from throughout the U.S. as well as from the U.K., Australia, Belgium, Ireland, Canada, India, Kenya and Namibia.



## Conclusions from the Principal Investigators

The Rev. George Handzo, BCC, CSSB and Linda Emanuel, MD, PhD were the co-principal investigators for HealthCare Chaplaincy Network. They oversaw the complex grant that funded the research, meetings and collaboration among researchers, and finally this conference.

Dr. Emanuel said: "In the evolution of living things, including collective thought, there are phase transitions. There is incubation, birth, development, maturation, impact and so on. The conference 'Caring for the Human Spirit' made a transition out of its three year gestation, and a new field was born. People who did not previously share a common language, culture or core assumptions came together with six groups who had worked for the last three years, creating as they went a common language and a new collective culture.

"Hundreds came from far and wide, and we streamed and tweeted and included questions and comments from yet more.

"We shared a model for the workings of human spirituality the group had worked on that used a mathematical formula and visual depictions. Chaplains and researchers alike had wonderful comments and a deep appreciation for its potential to help generate research questions.

"We shared research findings from the six groups. It was like an extended family caring for newborn sextuplets.

"Everyone seemed to have something special to offer; this new

community was investing in the future success of each of its investigators! We shared the stories about how we got to know one another and laughed. We shared a vision for the future. Could anyone have imagined a conference being a sublime experience? Well, no need for those of us present to imagine it, we experienced it!"

The Rev. Handzo said as he closed the conference: "This is a day a lot of us hoped for and dreamed about and thought it would never come.

"We're not there yet. But we're on the journey and we're not turning back.

"People call and email me asking what they can tell administrators what chaplains do and how to do spiritual assessment. Now we have a start, thanks to the John Templeton Foundation and the six research teams who are the heroes and heroines today.

"It's a new day.

"Now we've got to do more.

"I am convinced that because of what has been set in motion here more people will have their spiritual suffering reduced and their lives improved."

## Memorial Sloan Kettering Cancer Center salutes the HealthCare Chaplaincy Network



Memorial Sloan Kettering  
Cancer Center



KEYNOTE SPEAKER

## Workings of the Human Spirit in Palliative Care Situations: A Consensus Model



**Linda Emanuel, MD**, Director, Buehler Center on Aging, Health & Society, Institute for Public Health and Medicine, Buehler Professor of Geriatric Medicine, Northwestern University, and Senior Vice President for Research and Education, HealthCare Chaplaincy Network.

Dr. Emanuel outlined the 10 features of the consensus model, the definition of spirituality for palliative care chaplaincy research, explored ways in which researchers model the “physiology” of spirituality, and identified potential physiological measures of spiritual interventions.

### Highlights included:

- The time is right to bring together disciplines that have traditionally been separate.
- We are here to help patients benefit from empirically guided chaplaincy care.
- People will benefit from the spiritual care research presented at this conference.
- Spirituality is a human experience and can be studied. If we can feel it we can measure it.

## KEYNOTE SPEAKER

# Research in Spiritual Care and Palliative Care: A Global Perspective



**Kathleen Foley, MD**, holder of the Society of Memorial Sloan-Kettering Cancer Center Chair in Pain Research, Attending Neurologist, Pain and Palliative Care Service, Memorial Sloan-Kettering Cancer Center, Professor of neurology, neuroscience and clinical pharmacology, Weill Medical College of Cornell University talked about "Research in Spiritual Care and Palliative Care: A Global Perspective." Dr. Foley is identified as one of the 30 most influential leaders in hospice and palliative care today

Dr. Foley outlined the global issues which generate the current need for spiritual care in palliative care, discussed the major challenges and opportunities for spiritual care globally, and identified research questions for work both locally and globally.

### Highlights included:

- It is extraordinary that spiritual is included in the World Health Organization (WHO) definition of palliative care: Palliative Care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families.
- Palliative care is a public health issue. There is no question that it affects all people and has a potential to prevent suffering. If palliative care is a public health issue then so is spirituality as we seek to prevent and reduce suffering.
- Approximately 25 million people worldwide need palliative care - and therefore spiritual care, too.
- There is great importance in professionalizing those who provide spiritual care in addressing this essential part of palliative care.

KEYNOTE SPEAKER

## The Role of Research in building a New Discipline: Lessons from Those Who Have Done It



**Jimmie C. Holland, MD,**  
Wayne E. Chapman Chair in Psychiatric Oncology,  
Attending Psychiatrist, Department of Psychiatry  
& Behavioral Sciences, Memorial Sloan-Kettering  
Cancer Center.

Dr. Holland focused on the challenges of developing a research program and evidence base for interventions that depend on patient-reported outcomes of their symptoms.

Medicine has long favored physician observations as being more accurate. The barriers are difficult in areas that are regarded as “too soft for real data,” and research in spirituality faces these issues. In her talk, Dr. Holland helped the audience navigate through ways to gain knowledge about the development of a research base in psycho-oncology, learning the common barriers and supports for “soft science” areas, and how to apply practical suggestions for future efforts in research.

### Highlights included:

- The stigma in early end of life psychosocial research was similar to what is seen in research on spirituality in health care now.
- Distress, including spiritual distress, should be identified, documented, and treated according to clinical practice guidelines.
- Patient distress should be considered the 6th Vital Sign that is assessed and treated. The human side of cancer care - addressing distress - must be part of the future.
- There are many creative ways to modify a distress scale to be included in electronic medical records. Try them and share results.

KEYNOTE SPEAKER

# Emerging Horizons in Palliative Care Research: Special Focus on Spiritual Aspects of Care



**Charles von Gunten, MD, PhD,** Vice President, Medical Affairs, Hospice and Palliative Medicine for OhioHealth, Chairman, Test Committee, Hospice & Palliative Medicine, American Board of Medical Specialties.

At the top of the nation's policy agenda is helping health care move from volume to value. Palliative care has been demonstrated to deliver on the value equation: improved quality at lower cost. Continued research is needed in all areas in which palliative care delivers its generalist and specialist outcomes – improving the pain management, symptoms and stress of serious illness.

Dr. von Gunten used case studies and video clips to engage the audience in an interactive conversation about the “Emerging Horizons in Palliative Care Research: Special Focus on Spiritual Aspects of Care.” In doing so, he included the history of hospice care as developed by Dame Cicely Saunders, MD, who emphasized the importance of “total pain” management: physical, emotional, practical, and spiritual.

## Highlights included:

- Two big fear myths continue in pain management: medication tolerance and medication dependence. What are the spiritual components of pain management, and how can chaplains claim their role in addressing them?
- Spiritual care has been the weakest in the palliative care disciplines: we need to change this.
- Spiritual assessment and care are essential to effective pain management in order to identify sources of spiritual pain.
- We don't want physicians and nurses to be weaker; we want chaplains and social workers to be stronger as members of one team.
- Many palliative and hospice programs have enough chaplains on team to work with the large number of spiritual issues experienced.

**Project Director:**  
The Rev. Kevin Massey, BCC.

**Co-Principal Investigators:**  
The Rev. Marilyn Barnes, BCC,  
William Thomas Summerfelt, PhD.



## Developing a Taxonomy of Chaplaincy Activities

A groundbreaking study, “What Do I Do? Developing a Taxonomy of Chaplaincy Activities and Spiritual Care in ICU Palliative Care Patients,” was fielded by Advocate Health Care in Chicago. The research advocated a new approach to identify an inventory of chaplain activities through conducting a mixed-method exploration of chaplain thought and language. As a result, it created a new taxonomy of chaplain interventions, methods and intended effects.

Many people understand that chaplains do good things, but there hasn't been a sense of exactly how they do it. Among other things, the research showed that chaplains play a major role in helping patients express their wishes about end of life and advance care planning.

While the taxonomy can be seen as a general inventory of chaplain activities, the research focused on palliative care patients. It showed that chaplains are very active in helping the plan of care reflect a person's personal, cultural as well as religious values.

This study is groundbreaking because it has begun a process of putting words to what chaplains do. The study team has presented the work at the 3rd Annual Medicine and Religion Conference held March 2014 in Chicago, and will also present at the 2014 conference of the Association of Professional Chaplains in June and the 6th Annual Spirituality and Health Summer Institute at George Washington University in July.

### Study steps included:

1. Using a purposeful sequence of steps to generate and evaluate a comprehensive pool of items
2. Identifying a core set of chaplain activities and interventions aimed at meeting the spiritual needs of patients, significant others, and health care staff within palliative care provided in the ICU
3. Forming a standardized chaplaincy language geared towards:
  - Serving as a common frame of reference for chaplains to communicate actions with each other and interdisciplinary care teams
  - Providing the utility of uniformly portraying those actions for research and evaluation purposes

The study team used a variety of methods through its process, including literature review, retrospective chart review, focus groups, self-observation, experience sampling, concept mapping, reliability testing, and case studies.

Terms emerged during the Literature Review phase and continued in the Focus Group phase. These included:

- **Intended Effect:** the desired purpose, goal, and outcome of chaplain action(s).
- **Method:** the manner by which a specific gesture, action or activity supports a purpose, goal, and outcome.
- **Intervention:** any ministry gesture, action, or activity by a chaplain.
- **Pathway:** the assemblage of an Intended Effect – Method – Intervention.
- **Spiritual Care Plan (SCP):** the intended effects, interventions, and methods selected in response to the identified spiritual care needs surfaced in the spiritual care assessment.

**Project Director:**  
Tracy Balboni, MD, MPH

**Project Chaplain:**  
The Rev. Angelika Zollfrank, BCC



## How Chaplain Care Influences Well-Being and Decision-Making for People Facing Serious Illness

The data collected for the study by the Dana Farber Cancer Institute in Boston, "Hospital Chaplaincy and Medical Outcomes at the End of Life," focused on the presence and helpfulness of chaplaincy visits for advanced cancer patients. Project director was Tracy Balboni, MD, MPH and the Rev. Angelika Zollfrank, BCC was the project chaplain.


Over half (52.4 percent) of the 250 respondents reported not being visited by a chaplain. Of those who were visited by chaplains, 88 percent of patients said the chaplaincy visit was at least helpful to a small extent. The study also collected qualitative data in response to the question: "Please explain why your time with the chaplain was helpful or not helpful." Several patients said that the chaplain was "comforting," noting that the discussion, support, and prayer with the chaplain were helpful. Though this data is still in the process of being collected, some preliminary conclusions indicate that though chaplaincy visits may not be as frequent as desired, when they do occur, they are generally helpful to patients.

One dramatic outcome on the chaplaincy end of the research involved the clinical pastoral education for health care providers at Massachusetts General Hospital, led by Angelika Zollfrank and other members of the research team. They have created one potential educational method designed to develop health care providers' expertise in spiritual caregiving.

The findings show that clinical pastoral education for health care providers is an effective educational method to help caregivers gain confidence in addressing patients' religious or spiritual needs. The majority of the research focused on the provision of spiritual care at the end of life, but the project began with the goal of supporting field-advancing research aimed at furthering the understanding of chaplaincy care within palliative care.

The research is expected to aid in furthering the understanding of how chaplaincy spiritual care influences patient well-being and their medical decision making at the end of life. In light of these important potential research advances, the study findings hold key implications for improving the availability of chaplaincy services to patients and to deepen chaplaincy's involvement on medical teams, particularly in the setting of end of life care.

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**Project Director:**  
Tammie Quest, MD (not shown)

**Co-investigators:**  
Molly Perkins, PhD  
The Rev. George Grant, PhD, ACPE  
Ellen Idler, PhD



## The Chaplain’s Role Goes Beyond Spiritual Care When Testing the Seriously Ill

The goal of the study from Emory University in Atlanta, “Impact of Hospital-Based Chaplain Support on Decision-Making During Serious Illness in a Diverse Urban Palliative Care Population,” was to understand the impact of hospital chaplains on end-of-life (EOL) decision-making in a diverse urban population. Findings showed that a chaplain’s primary role was to relieve spiritual distress, ease guilt and provide comfort. Key barriers to EOL planning were low health literacy and misperceptions about palliative care and hospice care.

The Emory study focused on the use of palliative and hospice care in the African-American community, which is well documented as underutilizing these services and also the largest population served in the project area.

Chaplains provided data on nearly 500 hours of visits with more than 700 patients across 1,100 visits just during the 10-month data collection period. This represents only a portion of their work during this period, as many visits with less seriously ill patients were not recorded for the study.

More than half of chaplain visits did not focus specifically on spiritual issues, but were concerned instead with physical symptoms, existential and emotional matters, family concerns, life reviews, medical issues and advance directives.

Health literacy and understanding of their disease was remarkably low among patients who were interviewed.

A majority of chaplain encounters resulted in the patients and

families relaxing and expressing positive emotions. In about 9 percent of cases the patient developed new coping skills.

The chaplains rated the patient’s familial support as problematic in only 8.7 percent of cases, so the chaplains perceived families to be overwhelmingly supportive.

The spokesperson at the conference for this study was Ellen L. Idler, PhD, the Samuel Candler Dobbs Professor of Sociology, Director, Religion and Public Health Collaborative in the Department of Epidemiology at the Rollins School of Public Health.

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**Project Director:**  
John Lantos, MD

**Associate:**  
Chaplain Dane Sommer, BCC  
(not shown)



## Understanding Pediatric Chaplaincy in Crisis Situations

For many families, their child's critical illness was a time of spiritual crisis. Many of the parents in a study by Children's Mercy Hospital in Kansas City, reported that, with the help of the chaplains, their own relationship with God changed. Most of these changes were for the better - or, at least, the parents were grateful. A few parents were alienated from God and church as a result of their child's illness. This study describes and documents what chaplains do, which will allow testing for the first time of chaplaincy interventions.

Chaplains are often caught in the middle - they are both representatives of the hospital to the family and representatives of the family to the hospital. Thus their work takes place in a limited space - in the doorway, as it were, from where they look in both directions.

This place in the doorway leads the chaplains to think seriously about the notion of hospitality. They think about it in two ways. First, they see themselves as offering hospitality to patients, welcoming them to the hospital environment and serving as their guide and chaperone in the emotionally and spiritually troubling world of tertiary care pediatrics. Second, they are guests in the family's space and, as such, effectively convey to the families that the hospital is now, at least temporarily, the family's home, and the chaplains are visitors or guests there only with the permission and through the hospitality of the families.

The research team presented the results of this observational study of pediatric chaplain interaction with families of critically ill children. It focused on the ways chaplains introduce themselves to families in crisis; on ways they help families find solace in prayer and the ways in which chaplains minister to members of the health care team.

### The research team:

- Assessed the challenges chaplains face when intervening in crisis situations
- Analyzed the role of prayer, penitence, and psychology in discussion about the meaning of a child's illness
- Considered the ways in which chaplains balanced their conflicting obligations—to themselves, to other patients and families and to different members of a child's family.

The researchers completed seven detailed case studies of chaplain interactions with parents of children admitted to the hospital with life-threatening illnesses. They learned that most health professionals have little or no understanding of what chaplains do. They fly under the radar. When asked about specifics of what chaplains do, or whether it was beneficial, most professionals were utterly at a loss to provide any detailed responses.

Their project didn't focus on palliative care, per se, but on children with life-threatening illnesses.



**Project Director:**  
 Laura Dunn, MD  
 (Far Right)

**Project Chaplains and  
 Lead Investigators:**  
 Rev. Will Hocker, MDiv, MSW  
 Allison Kestenbaum, BCC ACPE,  
 Michele Shields, DMin, BCC, ACPE



## UCSF Researchers Take “Spiritual AIM” at Advanced Cancer

“Spiritual Assessment and Intervention Model (AIM), in Outpatient Palliative Care for Patients with Advanced Cancer” is one of very few studies to provide an in-depth picture of what chaplains do in their work with patients. The study at University of California, San Francisco, was designed to address a major gap in chaplaincy research: defining the nature of spiritual care.

Spiritual AIM posits that individuals have core spiritual needs in the areas of meaning and direction, self-worth and belonging to community, and reconciliation (to love and be loved).

The study was able to characterize in detail, using both qualitative (audio taped, transcribed sessions) methods, the nature, process, and outcomes of chaplains’ spiritual assessments and interventions with patients with advanced cancer.

This is one of the few studies to provide this in-depth picture of what chaplains do in their work with patients. While this has been described in case reports and overviews, having verbatim transcripts of chaplains’ sessions with patients is providing a wealth of information about the important and unique contributions of chaplains to the care of patients with serious illness.

A remarkable outcome of the project was that even three sessions with a chaplain seemed to have important effects for patients. In other words, this

research raises the possibility that chaplain interventions should be studied as a potentially powerful, yet brief, intervention for patients with various serious illnesses, not just cancer. Anyone facing a life threatening or chronic illness has spiritual needs, and chaplains are uniquely positioned and qualified to address these. More research is needed that uses in-depth, rigorous methods to examine the content, process, and outcomes of chaplains’ provision of spiritual care.

Even those patients who did not describe themselves as religious or spiritual found that they had important spiritual concerns and that they benefitted from meeting several times with a chaplain. Many expressed surprise at learning that the chaplain was a resource who could provide a novel perspective and unique insights.

Patients were, on the whole, quite welcoming and appreciative of their meetings with chaplains. Some patients reached new self-awareness, found a deeper

sense of purpose of meaning, or made important steps toward reconciling with important people in their lives.

While palliative care has long been committed to providing interdisciplinary care, evidence has been limited for the feasibility and added value of board-certified chaplains as uniquely important, vitally necessary members of the palliative care team. This research demonstrates the key contributions of chaplains to the care of outpatients facing advanced cancer.

Chaplaincy’s perspective is vital to a full understanding of patients receiving palliative care and enables the team to provide truly comprehensive care.

**Project Director:**  
Karen Steinhauser, PhD

**Project Chaplain:**  
Annette Olsen, BCC



## Even Non-Religious Caregivers Feel Supported by Chaplains

The goal of “Caregiver Outlook: An Evidence-Based Intervention for the Chaplain Toolkit” from Duke University Medical Center (Durham, NC) was to conduct a pilot test of the feasibility and acceptability of the Caregiver Outlook intervention. Since this was a feasibility trial, it doesn’t show whether it works. It shows that The Caregiver Outlook intervention is feasible (doable) and acceptable to caregivers of those with advanced life-limiting illness. The study demonstrates the acceptability of the first chaplain-led intervention from a manual.

Both religious and non-religious participants found conversations with the chaplain meaningful and without an agenda. Non-religious participants did not feel that there was a religious or spiritual agenda. Religious participants found that they were supported in their worldview. This is very important for chaplaincy. This study establishes that patients and families can benefit from a low-cost, standardized chaplaincy intervention by phone, is measurable and can be taught.

Research shows that caregivers with a higher sense of meaning report lower subjective caregiver burden. In palliative care, two important tasks of the caregiver role are preparation and completion, which include reviewing one’s life, addressing relationship conflicts and forgiveness and identifying wisdom gained and future goals.

These tasks are crucial to patient and family definitions of quality and central to the goals and skills of health care chaplaincy:

- Analyze the feasibility and acceptability of a manual intervention to improve the well-being of caregivers
  - Analyze the feasibility and acceptability of a manual intervention for chaplains
  - Integrate such an intervention with spiritual assessment and other approaches to chaplaincy and spiritual care.
- Unexpectedly, a lot of caregivers of those with ALS were enrolled in the study.



### What is Clinical Pastoral Education?

Clinical Pastoral Education is multifaith professional education for ministry. It brings theological students and clergy into supervised encounter with persons in crisis. Out of an intense involvement with persons in need and the feedback from peers and teachers, students develop new awareness of themselves as persons and of the needs of those to whom they provide care. From theological reflection on specific human situations, they gain a new understanding of their role and their vocation. Within the interdisciplinary team process of helping persons, they develop skills in interpersonal and interprofessional relationships.



[www.acpe.edu](http://www.acpe.edu)

# Outcome Oriented Chaplaincy is Key to Effective



## Spiritual Care

By The Rev. Sue Wintz, BCC,  
Managing Editor, PlainViews® online professional journal



The concept of “outcomes” is certainly not new to health care.

Traditionally outcomes have been linked to disease management (such as appropriate medications to prescribe or surgical and other treatments to pursue) and short- and long-term disease indicators (such as controlling a patient’s hypertension or working towards remission and survival.)

In recent years, medicine has moved from a disease-outcome-based model to a more patient-centered model where care is focused on what patients want and need based on their values. The patient-centered model encourages patients and their families in making decisions about their treatment options. It designs a patient experience that focuses on good communication, respect, an environment that encourages trust, and ultimately, their satisfaction with care.

True patient-centered care encompasses a patient’s cultural background, emotional needs, deeply held beliefs and values, and spiritual and religious needs. By far the most effective approach is “outcome oriented chaplaincy,” which was created by chaplains Art Lucas and Larry VandeCreek in 2001.

### Three components comprise it:

- **Spiritual assessments**, where professional chaplains are uniquely able to hear and identify the patient and family’s spiritual distress and spiritual/religious strengths and needs in a reliable and standardized way. This assessment can then be communicated clearly to the health care team via a standardized note in the medical record, in conversations with nurses, physicians and others, and through participation in interdisciplinary team meetings.
- **Interventions**, which are guided by what’s learned in the spiritual assessment, and are what chaplains do to provide care to patients or families. Interventions range from assisting a patient into exploring their spiritual and/or religious belief system, to their image of the Divine to identifying spiritually or religiously-based coping resources.
- **Outcomes**, which are the observable results of the care and interventions that the chaplain provides. They are based on what the chaplain can see, hear, or feel as, according to Art Lucas, outcomes are “sensory based.”

The use of outcome oriented chaplaincy is a global imperative. In fact, five attendees of the International Consensus Conference on Improving the Spiritual Dimension of Whole Person Care held in Geneva, Switzerland last year issued in May of this year in the academic Journal of Health Care Chaplaincy an international call to action “to support the development of evidence-based outcomes that allow professional chaplains to demonstrate how we meet the expressed spiritual needs of patients, family caregivers, and staff.” They assert, “This development will increase both the quality and quantity of spiritual care in health care and enable those who commission and procure health services to understand and have confidence that chaplains add value to health care.”



# European Chaplains Endorse Research in Spiritual Care

For some time, there has been a debate within the professional health care chaplaincy community worldwide about the role of research in chaplaincy practice. Questions have been raised about whether what chaplains do can be measured at all, and if so whether the intrusion of science into chaplaincy practice will somehow change the essence of the patient-chaplain relationship that makes chaplaincy effective and unique.

The other side of the argument, which has been gaining ground, is that research does not replace the chaplains' training and intuition as drivers of good care but adds another dimension to it. Moreover, research gives chaplains increasing ability to determine how effective their care is, enabling them to improve it.

### An integral part of chaplaincy activity

Recently the European Network of Health Care Chaplaincy (ENHCC), consisting of representatives from churches, faiths and national associations throughout Europe, has endorsed this latter view of research.

Meeting recently for their 13th consultation in Salzburg, Austria, the ENHCC issued a statement

calling for the active promotion of research as an "integral part of chaplaincy activity". The statement, endorsed by representatives of more than twenty countries, calls for health care chaplains in Europe to incorporate current research into their practice, and to participate in research that measures the outcomes of spiritual care.

As the beginning of a partnership, the Rev. George Handzo, HCCN Director of Health Care Research and Quality, was one of the three plenary speakers at the Salzburg Consultation, and Dr. Anne Vandenhoeck, Network Coordinator of ENHCC, attended the recent HCCN research conference.

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He's capricious.  
Willful.  
Utterly unpredictable.

# The MONSTER in Me

By Chaplain Holly Gaudette

**P**lease allow me to introduce the monster that lives inside of me. He's a chimera: three heads, breathes fire, lots of claws. Also, I think he may be teething.

Until the monster took up residence, it was just me. Me and my body. And we were a pretty good team. Over the course of 32 years together, we had learned one another's needs and habits. I could tell when it needed rest and when it needed to push through. I could tell when I was getting a cold, and I could fight it off with Vitamin C, exercise, and sleep. I could tell when it was getting dehydrated, when it needed quick sugar, and when it just plain needed a burger. And together, we accomplished things. We climbed mountains. We paddled rivers. Last year we pushed it to a new level, training and riding the Pan-Mass Challenge — a 192 mile bike ride across the state of Massachusetts.

**AND THEN,  
THE MONSTER MOVED IN.  
AND ALL BETS WERE OFF.**

My monster has a mind of his own. He's capricious. Willful. Utterly unpredictable. He wants what he wants, when he wants it. He wakes, unpredictably, with a vengeance. Some days, he wakes with a fury, raking claws, snapping, and biting. Other days, he wakes ravenously hungry, threatening to gnaw off my arm unless he gets food immediately. But... just as frequently, upon being fed, he throws his food at the walls, and collapses in full toddler meltdown mode, gnashing his teeth and breathing fire. And, then, without warning, he curls up and goes to sleep, leaving my body and I alone, spent, and wondering what just happened.

When the Monster first took up residence, I was furious. I was angry. My peaceful, embodied existence had been shattered. My familiar body was a stranger, and I was angry with it. Stupid stomach, I thought, can't I even eat breakfast in peace?! I recalled so many patients expressing similar sentiments, and remembered how often I had suggested the word "betrayal" as a name for their feeling. It was a feeling to which I could not relate at the time, but could easily

imagine. For surely, there are times that our bodies do betray us. Hearts stop pumping. Legs stop carrying us around. Minds no longer make sense of what we see. Bodies we once took for granted decline with age. I recalled Arthur Frank's perfect phrase, and resented the fact that I was living "at the will of the body."

But something about that language wasn't quite right. In those quiet moments, when the Monster had settled down, I could feel my body. Even as I waited for the next outburst, I tentatively listened to my body, surprised to discover that it felt more or less familiar. The Monster had attacked my skin, his fiery breath leaving it scaly and sunburnt, but there, I could see where it was beginning to heal itself, just like I would expect it to. My eyes, too, were dry and angry, remnants of another Monster meltdown, but I could feel pinpricks of hot tears behind my eyelids. My weakened body may have been exhausted from the onslaught, but I realized it hadn't betrayed me. It was under siege. Thus, the Monster was born.

These days, we talk, not about living at the will of the body, but about living at the will of the Monster. Sometimes, the conversation is tongue-in-cheek. Sometimes, I name the monster. Sometimes, the Monster is a caricature, and I picture trying to put a leash on it and take it for a walk. Other times, I rage against it, placing all my anger onto its vicious, ugly form. And freed from being angry at my body, I can once again focus on recovery, despite the presence of the Monster.

I would like to suggest, therefore, that you consider adding the language of the Monster to your toolbox as chaplains. It won't ring true for everyone, but I have to admit, I was surprised at how helpful the image has been for me. For some, the Monster may be the disease. For others, the symptoms. To be honest, I'm never entirely sure which of those things my Monster is, but that's okay.



If the image works, the possibilities for transformative conversation are endless, especially with regard to hope. What does hope look like for life with my Monster? I haven't quite decided. Some days, I think I ought to go read *How to Train Your Dragon*, and hope to make peace with him. Others, I think I ought to wage war against him, fight with equal ferocity to reclaim my body. Still others, I think that my Monster might one day become a sign of strength — an integrated part of my being, rather than an enemy.

And since this is still a live question for me, I would like to

invite you, dear chaplains, to join the conversation. How shall we approach this Monster?

I welcome your comments, insights, and questions, as I continue this journey.

Editor's note:

Holly Gaudette is a staff chaplain at NYU Langone Medical Center in New York City, a HealthCare Chaplaincy Network partner institution. She is currently on medical leave for treatment of Hodgkins lymphoma. An exceptional diarist, Holly has been documenting her experiences on her blog: <http://hollygaudette.wordpress.com/>

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By Rev. Eric J. Holl

# Dying to Be Heard

**If you were diagnosed with a serious illness, would you hide it from your friends, share it with a small select group, or tell the world?**

There was a time when patients kept the details of their illness to themselves and their family, but recently we've seen a proliferation of blogs documenting the experience of living under a potential death sentence.

Social media has made it easier to share the details of this day-to-day struggle, but the motivation to do this in the first place taps into a very old and deep emotional need.

People diagnosed with progressive chronic illness face two basic choices: They can conclude that their life is over and retreat into a shell of detachment from the world of the healthy, or they can choose to stay connected to their pre-illness existence by sharing their experiences.

Those who choose isolation may be missing a profound area of support. Blogging creates community. Suddenly strangers become a new circle of friends, sharing their experiences, and rooting for you. As Pamela Katz Ressler put it in her recent post in *Cognoscenti*, "For many patients the process of blogging shifted their relationship with their illness, decreased their sense of isolation,

brought meaning to their lives, and linked them back to the outside world."

One of my professional chaplain colleagues at HealthCare Chaplaincy Network has observed:

Why share the intimate details of illness with a wide audience? Partly because serious illness is isolating. When we're seriously ill we live separate and apart. We observe the bustling of the quotidian world, the goings to and fro, but we occupy space outside that world. We stand alone, in what might as well be a separate country.

In *Illness as Metaphor*, Susan Sontag wrote:

*"Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. We communicate to bridge the chasm. Every blog post is another stamp on our passport."*

I believe in the transformative power of storytelling, which has cathartic value for the teller. When someone is present to hear that story a connection is made. The question is whether that connection can be made via "impersonal" media like Twitter, or whether one

needs a real human sitting with you. Ironically, in our fragmented age, social media seems able to bridge distance and bring a community to the sufferer, wherever they may be.

Because of the interactive nature of the blogosphere, readers and bloggers often feel a sense of connectedness, becoming more than strangers. Referring to the feedback that she had been getting, one blogger who wrote about her mother's illness noted that, "One of the best parts of blogging was the comments people left. Even though we had never met any of them, we felt like we had a little community rallying around us."

While many patients detail their experiences in order to stay connected, some blog for convenience and immediacy. Rather than having to muster the energy to call every single friend and family member, they simply update the blog, link to it on Facebook, and call it a day. Their friends read the update, and often will send texts or emails immediately, so they get messages of support with minimal effort.

Whatever the reason for blogging, as more and more Boomers move into the years where illness is more likely to strike, we're going to be reading many more profoundly personal and deeply moving experiences about the fight for life.

Note: This article was reprinted from The Huffington Post.



# New Websites



## Provide spiritual comfort to all in need

**HealthCare Chaplaincy Network is dedicated to fulfilling our mission of multifaith chaplaincy care, education, and research.**

In this spirit, we are pleased to introduce two new initiatives to serve patients and caregivers who are in spiritual distress:

**Chaplainsonhand.org** and **Cantbelievelhavecancer.org**.

Serious illness, trauma, or grief can create the spiritual distress that arises when one struggles with thoughts such as “Why is this happening to me?” “What do I have to live for?” “Has God abandoned me?” “What now?”

Professional health care chaplains created the content for Chaplainsonhand.org to respond to the big issues people in spiritual distress face due to illness and grief. The counseling, information and resources provided come from first-hand chaplain experience to help in the healing process.

The free support and resources of Chaplainsonhand.org is meeting a need for those turning to the internet for support. Launched in January, the site has had more than 45,000 visits worldwide through June, with 85% unique visitors.



**Chaplainsonhand.org**

One third of the visits have come from smart phones and tablets, which is higher than average for most nonprofits and reflects the work done to make the site user-friendly across device types. The resources of Chaplainsonhand.org provide counseling to anyone seeking help – regardless of religion or beliefs. To the best of HCCN’s knowledge, this is the first service of its kind specifically geared to health care.

The Chaplainsonhand.org site includes the Chat with a Chaplain feature where people can connect with a professional health care chaplain by email through the web site or by phone at 844-CHAPLAIN (844-242-7524) to get spiritual comfort and support. Another feature of Chaplainsonhand.org invites users to Submit a Prayer Request through which chaplains and colleagues of HCCN will pray for you or loved ones.

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[CantbelieveIhavecancer.org](http://CantbelieveIhavecancer.org)

Modeled after the success of [Chaplainsonhand.org](http://Chaplainsonhand.org), [CantbelieveIhavecancer.org](http://CantbelieveIhavecancer.org) is a site dedicated to providing spiritual support and care for everyone facing cancer. The resources are aimed at serving the newly diagnosed, those in treatment now, survivors, those who are not finding it going well, and caregivers. Through exploring spiritual issues, painful feelings, chronic pain, grief and loss, and information on planning ahead, we hope this site will be a resource for people and their loved ones

in their cancer journey. Like [Chaplainsonhand.org](http://Chaplainsonhand.org), [CantbelieveIhavecancer.org](http://CantbelieveIhavecancer.org) will offer chaplain support through Chat with a Chaplain and Request a Prayer.

These free services provide person-to-person assistance and in-depth resources to those seeking spiritual comfort and meaning in the face of a health crisis, grief at the loss of a family member or friend, and other challenges for which they seek counseling and support, whoever they are and whatever they believe.

While hospitals and other institutions have professional chaplains on staff who are trained to help those in spiritual distress, countless other members of the community don't have access to professional health care chaplains. Physicians, nurses, social workers, and chaplains say that [Chaplainsonhand.org](http://Chaplainsonhand.org) and [CantbelieveIhavecancer.org](http://CantbelieveIhavecancer.org) meet a large and important need, and people who have chatted with a chaplain have welcomed the help.

## PlainViews

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*PlainViews*® is an online journal published twice monthly by HealthCare Chaplaincy Network that provides chaplains, spiritual care providers and others involved in spiritual care with information and resources on contemporary issues, topics and interests relevant to their profession.

*PlainViews*® is also an online community where professionals can share information, dialogue with peers, submit articles and learn about ongoing educational events, conferences and symposia hosted by the HealthCare Chaplaincy Network.

Cost is \$40 (USD) for a 1 year subscription; \$75 (USD) for 2 years and \$95(USD) for 3 years. Group subscriptions are also available.

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Visit [www.plainviews.org](http://www.plainviews.org) for more information and to view a sample and special open access issues.

# Certificate Courses that Enhance Skills and Improve Spiritual Care

2 user-friendly, online certificate courses from the California State University Institute of Palliative Care & Health Care Chaplaincy Network

## Register online at [spiritualcareeducation.org](http://spiritualcareeducation.org)

### Mental Health Fundamentals for Spiritual Care Providers Certificate Course

#### Online 6-week Course

Those providing spiritual care for those with serious or chronic illness and their families frequently encounter mental health issues that can be challenging. This course provides chaplains and others providing spiritual care with essential knowledge of prevalent mental health issues and the opportunity to build their skills and confidence working in these situations.

#### *This course teaches:*

- The relationship between spirituality and mental health
- Common mental health conditions and the impact on spirituality
- Spiritual-care practices to improve patient's quality of life and reduce suffering

Cost is \$799 + \$30 technology fee

### Palliative Care Chaplaincy Specialty Certificate Course

#### Online 9-week Course

This course strengthens the quality of palliative care by providing a foundation of knowledge and practice built on applicable areas of the National Consensus Project's Clinical Practice Guidelines for Quality Palliative Care and the National Quality Forum's National Framework and Preferred Practices for Palliative and Hospice Care Quality.

Additionally, the course addresses the requirement for chaplains "with specialty training in palliative care as core members of the team," as mandated by the Joint Commission for health care institutions that are seeking advanced certification in palliative care.

#### *This course teaches how to:*

- Explain palliative care to others so that informed decisions can be made for patients, family members and other caregivers
- Become effective and articulate administrators of spiritual care programs in palliative care and hospice settings.
- Create and sustain programs that meet both human and institutional needs.

Cost is \$799 + \$30 technology fee

Each course is asynchronous, allowing participants to complete the coursework on their own time (6-8 hours/week). Students are expected to complete one module a week.

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