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### Comments? Suggestions? Contact us at

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HealthCare Chaplaincy Network™ is a national 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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Vol.2, No.1 Caring for the Human Spirit  $^{\circ}$  magazine is published semi-annually: spring/summer, fall/winter.

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Four major events have occurred since the beginning of this year that underscore the growing recognition of the importance of spiritual care in health care, and point to a vigorous future for professional chaplaincy in the U.S. and abroad.

In January, I was invited to be the keynote speaker at an international summit in Jerusalem to advance spiritual care in Israel's public health system. With a growing awareness of the lack of spiritual care in the medical and social services establishments in Israel, the sponsors of this summit are passionate about importing the field of spiritual care and advancing it as a recognized profession.

In April, HealthCare Chaplaincy Network (HCCN) held our second annual "Caring for the Human Spirit Conference," in Orlando, Fla. The 400 health care professionals who attended in person, together with the thousands who watched via webcast, read like a U.N. of health care, hailing from the U.S., Canada, the U. K., Belgium, Germany, the Netherlands, Austria, Switzerland, Israel, Saudi Arabia, Nigeria, Namibia, India, Australia and Singapore. They represented multiple disciplines, including physicians, nurse practitioners, chaplains and researchers. Clearly, the attendees, many of whom travelled thousands of miles, felt there was something important afoot here for the furtherance of spiritual care.

Then, in early May, HCCN expanded our annual Convocation Ceremony beyond the commissioning of our own chaplains to include a renewal of commitment to spiritual care for all chaplains, either in person or via webcast. In a hitherto fragmented chaplaincy community, this event ushered in a new era of inclusiveness.

And as you read this, we are excited to be introducing a powerful interactive tool for chaplains, The Chaplain Connection  $^{TM}$ . This first-of-its-kind resource enables chaplains the world over to connect with each other, access continuing education and other resources, and keep up to date with developments that affect the field.

Taken together, these events point to a newly-energized population of professionals who provide spiritual care.

This publication is doing its share as well. "Caring for the Human Spirit®" magazine was created to bring together important voices in the field of health care—to inform, to inspire, and to move the profession forward.

In this, our third issue, you'll read about helping veterans return to a "new" life, the telehealth revolution, a case study in chaplaincy care, and the integration of spiritual care in palliative care. Also in this edition, we introduce several new columns that will be permanent fixtures moving forward as well as video interviews with some of our writers to enrich your experience.

In addition to professionals like you, the beneficiaries of this invigorated sense of commitment to the importance of spiritual care in health care, both nationally and internationally, are the seriously ill, dying and grieving. This issue is dedicated to them.

Thank you for caring for the human spirit,



# The State of Professional Chaplaincy in the U.S.

By the Rev. Sue Wintz, M.Div., BCC

Professional health care chaplaincy in the U.S. has a rich history. Throughout, it has faced many changes and challenges, including what training encompasses, how to gather chaplains into membership groups, and how to respond to the evolving health care environment. While there is much to learn from chaplaincy's history, it is not only valuable but essential to look at the current state of the profession: its strengths, weaknesses, and outlook for the future.

### **STRENGTHS:**

Palliative care has recognized the importance of caring for patients' and families' spirits as well as their bodies, and has embraced chaplains as essential members of the interdisciplinary team for this specialty. This acknowledgement has occurred at the national level, and includes regulatory requirements that chaplains, like other disciplines, have education and demonstrated expertise in palliative care.

Guidelines call for chaplains who are part of health care teams to be board certified, ensuring that they have the appropriate training and credentials on par with other professional disciplines. These include guidelines created by the National Comprehensive Cancer Network (NCCN) and the National Consensus Project for Quality Palliative Care (NCP). Organizations that accredit health care entities are also recognizing and utilizing the expertise of board-certified chaplains in the development of their resources and requirements.

Research, in both the impact of chaplaincy care and the importance of spirituality and/or religion in the lives of patients and their caregivers, has begun to take its place as a new priority within

professional chaplaincy. More research is occurring now than ever before, and most chaplains want to increase their skills in reading, understanding and engaging in research with other chaplains as well as with other disciplines. In addition, chaplains are writing for both profession-specific journals and those of other disciplines.

Engaging members of Congress occurred for the first time in chaplaincy history. A petition that explains why and how professional health care chaplains cost-effectively improve patient and family experience and satisfaction with their health care was created and circulated to the health care community. Both chaplains and those who advocate for the provision of professional chaplaincy care that encompasses the spectrum of religious and spiritual beliefs and values signed on to make their voices heard. Sponsored by HealthCare Chaplaincy Network (HCCN), the petition and sign-on statement will now be disseminated to members of Congress.

Common Standards were written in 2004, which laid the groundwork for true professionalism within chaplaincy. The standards put into writing for the

first time a structure for professional chaplaincy certification and ethical practice. They consist of four documents: Common Standards for Professional Chaplaincy; Common Standards for Pastoral Educators/ Supervisors; Common Code of Ethics for Chaplains, Pastoral Counselors, Pastoral Educators and Students; and Principles for Processing Ethical Complaints.

Standards of Practice were developed for professional chaplains working in specific settings, first in 2009 for acute care settings, followed in 2012 for long-term care, and in 2014 for hospice and palliative care. As a set of guidelines for providing high-quality chaplaincy care and evaluating that care, standards of practice were the second big step forward for the profession.

### **WEAKNESSES:**

Inability for organizations to speak with one voice is the greatest weakness of the profession. There are numerous membership associations that operate independently of each other and have failed in attempts to collaborate to advocate for the profession, become one membership association, or agree on training methods, certification, or ways to provide education for chaplains.

### Holding on to the historical tendency to stay with what is known and familiar to the profession.

Chaplaincy training, methods of practice, ongoing education, and membership affiliations have been focused on "how it's always been done," and there is little indication that this is changing despite advances in other disciplines and the delivery of health care itself.

The 2004 Common Standards and the 2009 Standards of Practice have not been reviewed and updated. Since their publication, there have been significant changes within the profession, the delivery of health care, and the spiritual, religious, cultural and social transformations within society—yet the standards have not been revised to reflect these developments.

Minimal development of and advocacy for chaplaincy services outside inpatient settings has limited the reach of care to persons in spiritual distress. It is clear that much health care delivery—infusions, dialysis, Alzheimer's care, urgent care for illness or injury, doctor's offices, and home health, to name a few—is taking place at outpatient settings throughout communities. With this movement expected to continue, chaplaincy must address the need for spiritual care in these settings.

The profession is behind the

times in delivering chaplaincy care remotely. All health care disciplines are struggling with what the best approaches are to provide quality care remotely. However, chaplaincy has yet to even address the issue as a profession. HCCN's technology-driven services, particularly its websites for persons living with cancer, and active military and veterans, and its one-onone counseling by phone and email, have demonstrated demand for this mode of chaplaincy care, including among those who prefer the Web or do not have in-person access to a professional chaplain.

Chaplaincy training and certification models have remained essentially the same for decades. It is time to examine how to deliver training to persons who are not geographically near a clinical pastoral education site; as well as how to construct new models of training for both those who wish to become professional chaplain specialists, and persons from other disciplines who want to be generalists and add spirituality as a central element to their practice.

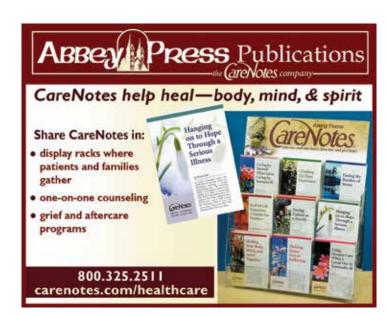
### THE OUTLOOK FOR THE FUTURE

Professional chaplaincy is at a crossroads. It has a strong foundation with highly-skilled practitioners who bring a unique and much-needed expertise to health care delivery.

Surveys demonstrate that persons wish to have clear communication with their health care providers and want their beliefs and values, including their sense of spirituality and times of spiritual distress, talked about and included in their treatment and decision making. Chaplains are crucial in ensuring that this happens, and the profession is poised to become more deeply integrated into personcentered health care.

Yet without acknowledging its weaknesses and working toward turning them into strengths, the profession is at risk, and along with it, the care of people who face spiritual pain and distress due to illness or injury. It is time for everyone—whether a chaplain, organization, or a person who values care for the human spirit—to act for the good of the profession.

**Sue Wintz, M.Div., BCC**, is the director of professional and community education at HealthCare Chaplaincy Network, and managing editor of "PlainViews," an HCCN publication for professional chaplains.







There are three things you should know about the future of chaplaincy in Europe.

By Anne Vandenhoeck, Ph.D.

First, we, chaplains in the Old World, do see a future for chaplaincy in Europe. "We" are representatives of professional associations for chaplains and of faith organizations that are members of the European Network of Health Care Chaplaincy (ENHCC).

Yes, there are constant challenges such as cutbacks, changes in health care that affect our jobs, the continuous lack of money, and the fast-changing ways in which people express their spirituality. But, despite this, we see a future because of our experiences, and, moreover, because we know the best spiritual care can contribute to the lives of human beings. So we are hopeful, and we continue to communicate the value and contribution of chaplaincy in various settings

Second, diversity in chaplaincy is a given in Europe. A few times a year I get emails from chaplains in the U.S. who are looking for a job in Europe, thinking we have a European central chaplaincy agency. Not so. There are 28 countries in our continent, each having a different way of organizing chaplaincy as determined by the country's cultural and religious history. That diversity is both our strength and our weakness.

Of course, the fundamental

principle of chaplaincy is always about listening to, and working with, the spiritual dimension of people. But the way chaplaincy is organized, the culture surrounding it, the training necessary to become a chaplain, and pay scales are very diverse throughout Europe.

We find great enrichment in exchanging and learning from each other, yet we are at different places on the road to the future. We did reach a consensus, however, in the last consultation of the ENHHC: Our Salzburg Statement 2014 (www.enhcc.eu) stresses the importance of working toward a profession that is research-informed "in order to improve the quality of care." Yes, evidence-based chaplaincy lives in Europe, too. We are happy the Association of Professional Chaplains (APC) endorsed our Salzburg Statement, making cooperation easier between European and American chaplaincy.

Third, we are determined to invest further in research on chaplaincy. We are aware that there is much interest and research in spirituality in health care by other professions, and we are convinced that we, as chaplains, have a unique perspective on spirituality. Chaplains and chaplaincy researchers in the U.K., the Netherlands, Ireland, Belgium, Switzerland, Germany, Cyprus and Finland, to name a few, are doing interesting and diverse research

into spiritual care and chaplaincy.

The ENHCC plans to gather this research at its next consultation, in Hungary in 2016, and to present new research during its consultation in France in 2018. We encourage representatives from the U.S. to participate in these meetings and learn from us, just as we learn from American research. It is necessary to spend our time and money on research wisely and strategically, so international cooperation is highly desirable. The multiplicity of languages in Europe surely plays a role in the fact that European chaplaincy research is less known across the Atlantic, but we hope to change that. At the same time we are looking for creative ways to implement research results into the education of chaplains and into their daily work. Here, too, we can learn from each other's good practices. Let's do it!

Anne Vandenhoeck, Ph.D., is professor of pastoral theology and pastoral care at the Faculty of Theology, Catholic University of Louvain, Belgium. She serves as coordinator of the European Network of Health Care Chaplaincy, which consists of representatives from churches, faiths, and national associations.

### Helping Veterans

### Return to a 'New' Civilian Life

By Richard E. Powers, M.D.

A veteran who fought in Vietnam had been a good soldier in many bad situations. He had returned home with Posttraumatic Stress Disorder (PTSD). Now, he was dying from cancer, and he carried many regrets in his soul. His most important desire was to have a final conversation with a family member who had been distant from him. The veteran's past mental health problem reduced his ability to maintain connections like that, and he wanted to correct that problem before he died.

A hospice treatment team that involved intense assistance from a chaplain helped him to achieve that goal. What greater accomplishment is possible than helping a man find peace after that veteran gave up so much in service to his country?

#### **Returning Home**

Few persons return from war unchanged. But the fact is that most veterans come back from war with great pride in their service as well as wisdom imparted by a demanding life experience. Most return to a delighted family and grateful community where they resume their lives without difficulty. It is a scenario that runs counter to common portrayals of veterans in the media and elsewhere.

Some, however, return wounded in different ways. Soldiers can sustain physical, neurological, psychological, existential and spiritual injuries.

Most Americans who fight overseas view themselves as protectors of our country and our way of life. Some wartime experiences conflict intensely with the soldier's desired role as a protector of the innocent, and compel troubling decisions or actions. And for some of these returning veterans, they justifiably feel stereotyped in the public eye.

The number of Americans who serve in the armed forces is so small that many veterans may have few comrades with similar experience in their community, producing a sense of isolation. A minority of returning veterans may experience PTSD or depression, and some will abuse alcohol or marijuana to lessen the anxiety.

### It Takes a Team

Whether male or female, young or old, veterans of all ethnicities, social backgrounds, and spiritual beliefs may need assistance in resuming their sense of normalcy following a deployment. Those who return with combat-related mental health problems may benefit from care that requires a commitment by the veteran to months of therapy.

Comprehensive health services for a returning veteran involve a multidisciplinary treatment team that can address all aspects of the veteran's physical, psychological and spiritual needs. Optimal health care outcomes require a team of equals that fully utilizes the talents of each member, whether physician, psychologist, physical therapist, social worker—or chaplain.

### The Chaplain as Facilitator

Regardless of how a veteran has changed upon returning from service or where he or she stands on the path of life, the chaplain can help with the journey home.

Community pastors rather than health care providers may be the first point of contact for a family struggling with the return of a loved one. Chaplains can play a vital role in educating their community colleagues about challenges that may confront veterans and their families as well as services that can benefit these congregation members.

Service members are trained to be stoic, self-reliant individuals who

focus on the well-being of their unit, but chaplains can promote a comfort level for seeking help or sharing hardships. The conversation should be optimistic as we expect treatment to improve lives. And it often needs to begin with the acknowledgement that we know that they are not "crazy."

The goal is to facilitate the transition to the normal rhythm of life, assist the veteran with defining his or her new normal, and support the family while these transitions occur. This includes helping veterans feel comfortable, valued, understood, and fully integrated into the family and the community; and assisting both veterans and their families to move on with their lives and enjoy the happiness that they have earned.

Veterans may identify many changes in family, work or community that occurred during their deployments. Chaplains can normalize the conversation about the aftermath of war and reassure the family that discussing solutions will help the situation. They can provide support and encouragement for the self-advocacy of the veteran during the transition from the familiar military life to a new civilian life.

### The Lasting Memory of War

Many veterans rely on their spiritual self to propel them forward in all aspects of life, and the chaplain can sustain or reinvigorate that inner energy.

The spiritual suffering caused by fighting in war can be intense and prolonged. Some younger veterans may be still trying to process the experiences of war. Older veterans may begin to focus on these events from earlier life as they retire and reflect on events of the past. Some Vietnam veterans may continue to grieve losses and regret actions that occurred 40 years ago.

Chaplains may offer the answers to many of the challenges that confront both recently-returned veterans and older veterans who continue to struggle with these concerns.

### **Encouraging Care**

In addition, chaplains can encourage veterans to get the medical and mental health services that they have earned through their honorable service.

Some veterans need encouragement to address chronic health problems like hypertension or injuries that require pain management, and to look after themselves at home with the same dedication that they looked after their battle buddies during deployments.

Veterans with traumatic brain injury often require specialized services to help regain full cognitive function, reduce psychiatric consequences, and manage common complications such as headaches or sleep apnea.

For veterans with PTSD, the psychological care often centers on changing the emotional or cognitive responses that may be disruptive or distressing, such as excessive vigilance and self-isolation. They often have disruption of sleep and may re-experience stressful events when triggered by sounds or smells. Medical care using medications that are not addictive can improve symptoms of depression or reduce symptoms such as nightmares, flashbacks and irritability.

Many Vietnam veterans did not receive effective treatment for common post-combat problems such as PTSD, but research conducted in the last decade has defined effective, evidence-based practices. Specific interventions such as those outlined in reports from the Institute of Medicine, an independent health arm of the National Academy of Sciences, support the use of antidepressants for mood and irritability, prazosin for nightmares, and specific psychological therapies such as cognitive processing therapy to reduce psychological distress.

Although medications are helpful for some veterans with PTSD, the cornerstone of care is specific psychological treatment provided by trained therapists who understand the military experience. Spouses, children and parents may benefit from inclusion in the care with the veteran's consent.

Just as the chaplain helped the Vietnam veteran who desperately wanted to reconnect with his estranged family member, a chaplain can play a major role in helping a veteran live life more fully and ultimately meet his or her maker with fewer regrets or burdens.

Richard E. Powers, M.D., of Mountain Brook, Ala., is a board-certified psychiatrist who has cared for hospice patients and persons with stress-related mental health conditions. He served in the U.S. Army as a doctor, and is a member of the board of directors of HealthCare Chaplaincy Network.

### **Get Help**

Here are some valuable resources for veterans and their families:

From HealthCare Chaplaincy Network

**Chaplain Care for Veterans** www.ChaplainCareforVeterans.org

Chat with a Chaplain one-on-one counseling 844-227-3483 (844-CARE4VETS) www.chaplaincareforveterans.org/chatchaplain-email

From the U.S. Department of Veterans Affairs

**Veterans Crisis Line** 800-273-8255

National Call Center for Homeless Veterans 877-424-3838 (877-4AID-VET)

"About Face" videos of veterans' stories about PTSD www.ptsd.va.gov/apps/AboutFace/ veterans.html

# Have You Joined the Telehealth Revolution Yet?

By Rev. Eric J. Hall

ow do I love digital technology? Let me count the ways. I can open my garage door remotely before I get to my driveway. I can do all my shopping online. I can deposit a check into my account by sending a cell phone image to my bank. I can hold an "in-person" meeting with global business leaders via webcast. And I can find out anything I need to know instantly through the Internet, including health care information such as researching a prescribed medication or a physician's background.

All that is just the tip of the iceberg, especially in the new age of health care. Increasingly, we want to take charge of our own health. And digital technology is allowing us to do just that—and more.

For consumers, telehealth is giving all of us great latitude to manage our own health care, conveniently and, especially for those in rural areas, gaining access to a wider level of care.

For providers, it's enabling clinicians and health care institutions to manage and expand their delivery methods, with an eye on facilitating interactions and reducing costs.

For both, the end goals are improved overall patient experience and improved quality of care—as they should be.

"The trend of consumers taking charge of their health care is going to accelerate," said Lisa Stockman, president of global public relations and medical communications at inVentive Health, in "The Holmes Report: 2015 PR Trend Forecast: Healthcare."

A Cisco Customer Experience Report in 2013 found while consumers still rely heavily on inperson medical treatments, given a choice between virtual access to care and human contact, 75 percent of patients would choose access to care and are comfortable with the use of technology for the clinician interaction.

Some form of telehealth is already in use in 42 percent of the nation's hospitals, according to a "Health Affairs" study in February 2014. As costs for health care continue to rise and patients spend less time in the hospital, good outpatient care is vital to continued recovery. For the homebound and rural residents who can't easily get to the hospital for checkups and monitoring after surgery, or where in-home visits aren't available, telehealth is a very important innovation.

As an example, diabetics can manage their health without having to leave home by uploading food and medication logs and blood sugar levels for a nurse who reviews them and responds electronically. Blood pressure monitors can be connected to the Internet or video equipment to allow face-to-face interaction with our doctors.

Mobile apps from smart phones and tablets already exist to allow radiologists to view images and for cardiologists to remotely monitor our hearts. We're using apps for health-related reminders, healthy eating and exercise, and chronic disease management.

No doubt, more health care apps are on the way. The Food and Drug Administration will be reviewing a record number of health-related apps to determine if they meet its standards for medical use.

As telehealth gains ground, it is touching more than just our physical well-being; it includes our emotional and spiritual care. An article in the January-February 2015 issue of "Health Progress," published by the Catholic Health Association of the United States (CHA), outlines ways that spiritual telehealth care has also arrived.

"Many people who are sick and in spiritual distress are turning to the Internet for help," wrote Brian Smith, the CHA's director of mission integration and leadership formation. "Many of these individuals do not have a spiritual home or anyone they can talk to about their emotional and spiritual needs in a time of illness."

He recommended two programs recently introduced by HealthCare Chaplaincy Network (HCCN) where such seekers—no matter what their beliefs—can obtain spiritual care: Chaplainsonhand.org and cantbelieveihavecancer.org, specifically for cancer patients and their families, are free spiritual support resources developed

by professional chaplains to educate and counsel patients and caregivers. Both sites include a "Chat with a Chaplain" feature that provides the opportunity to connect with a professional health care chaplain via phone, video call or email. There are also faith-specific and universal prayers, self-assessment tools, and other resources.

Thanks to digital technology, and bolstered by the growth in outpatient care, HCCN is also offering other on-the-go spiritual support services. In collaboration with VOX Telehealth, an industry expert in digital health systems, HCCN is developing palliative care and spiritual care telehealth modules to engage patients in their own care. And HCCN's new spiritual care TV network, HCCN-TV, inspires and informs patients and their families in hospitals, outpatient clinics, or at home via the computer or closed-circuit TV.

For telehealth, as with any new delivery method, a big part of acceptance and growth weighs on the financial bottom-line and the added value. Telehealth could save U.S. companies \$6 billion a year, according to an analysis by Towers Watson, a global professional services company. Getting there requires "a shift in patient and physician mindsets, health plan willingness to integrate and reimburse such services, and regulatory support in all states," a senior consultant at the company explained.

Insurance coverage for telehealth is in the early stages, but it is included in the Affordable Care Act, many of the major insurance companies are already on board, and Medicare is reimbursing beneficiaries for some telehealth services, primarily in rural areas.

The "Health Affairs" abstract also pointed out that reimbursement rates for this new kind of health care will vary with individual state policy. "Policies that promote private payer reimbursement for telehealth are associated with greater likelihood of telehealth adoption, while

policies that require out-of-state providers to have a special license to provide telehealth services reduce the likelihood of adoption," it said

Among those providers on the fast track, the U.S. Department of Veterans Affairs (VA) is recognized as one of the world leaders in technology-driven health care. It delivers services using virtual linkages like video teleconferencing and home telehealth technology. The VA is also meeting a vital need to provide specialist consultation to remote sites via telesurgery, enabling diagnosis, care coordination, and pre- and post-op assessments for many conditions.

As health care continues to harness the power of technology, telehealth leaves us with no excuse for providers not to offer and for consumers not to find the help we need—for body and soul—no matter where in the world we are.

**Rev. Eric J. Hall** is president and chief executive officer of HealthCare Chaplaincy Network.

— MICHAEL L. LINDVALL

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### How Do You Picture Death?

By Donalyn Gross, Ph.D., LCSW, CMP

I am a thanatologist, studying death and working with the dying and their loved ones for more than 35 years. I've witnessed hundreds of deaths, good and bad.

My career path traces back to my teen years. In high school, I worked in a nursing home and saw so many residents abandoned by their loved ones and dying alone. I vowed I'd do what I could to change this. In my postsecondary education, I trained to become a a social worker with a concentration on death and dying.

Since, I've worked in hospitals, hospices, nursing homes, and correctional facilities, offering end-of-life workshops, teaching a course on "Death, Dying and Bereavement" at an area college, and creating an array of educational programs related to death. Believing in the power of music and as a certified music practitioner, I've also played therapeutic bedside harp for people approaching end of life, and released two CDs of music for the dying.

When I present my workshops or teach my classes, the first thing I do is ask the questions, "What does death look like? How do you picture death?" I give everyone paper and crayons and ask them to "draw death."

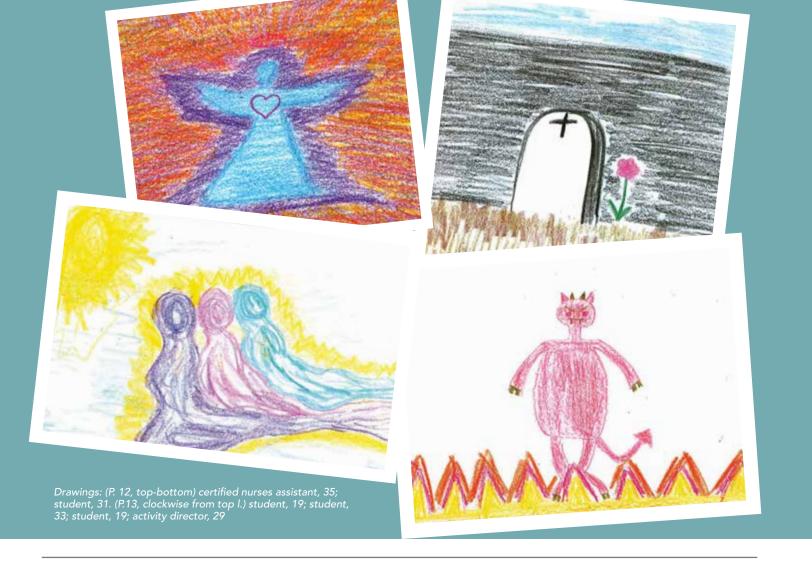
Through the years I've amassed boxes of beautiful and revealing pictures drawn by social workers and other health care professionals, students and others. I assembled 80 of the drawings into a book called "What Does Death Look Like?" Schools, libraries, clergy, health care professionals, and others are using this book to demonstrate how we view death.

No one likes to talk about death, but it's important to have the discussion. Being around someone like myself who is trained to discuss these issues makes it easier to release concerns regarding death. For those of us working in the health care field, death education and training is essential. In the event that a dying patient has no family or friends, you, as a health care worker, may be the last point of contact for this person prior to passing. As we learn to cope with our own issues regarding death we can better work with the dying as well as meet the needs of the bereaved.

#### Donalyn Gross, Ph.D., LCSW,

**CMP**, is an adjunct professor, Death, Dying and Bereavement, at Bay Path University, Longmeadow, Mass., author and professional musician. She is the author of "What Does Death Look Like?" (2010, Xlibris). The drawings that accompany this article are reprinted from her book with permission.







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Editor's note: This article is an excerpt from a chapter in "Spiritual Care in Practice: Case Studies in Healthcare Chaplaincy" (2015, Jessica Kingsley Publishers), edited by George Fitchett, D.Min., Ph.D., and Steve Nolan, Ph.D., and is reprinted with permission. See sidebar on page 16.

The following case unfolded several years ago during my time as a chaplain in a hospital in East Jerusalem. This is where I met David, a Jewish man in his mid-60s, brought up Orthodox in the Old City of Jerusalem. Like many children who consider the Old City their world, he barely ever left the city walls.

Yet David's early adult years were interrupted by one of the not infrequent street bombings. This time his mother was killed, and it was David, as the oldest son, who had to identify her and deliver the news to his family. Shortly afterwards, his father committed suicide. From then on, 16-year-old David became the head of the family, raising his younger siblings and taking over his father's business as a shoemaker. Eventually, his siblings grew up and left home. David, however, found himself unable to move on and realize his dreams. He married but never felt close to his wife. Eventually, they divorced.

When I met him, David had recently been diagnosed with stage 4 pancreatic cancer. He had been told that there was no curative treatment for him. Since he had had to face more physical pain than he could function with while living by himself, he had decided to come to the hospice part of our hospital, primarily for palliative and end-of-life care.

David clearly had an angry side to him. I witnessed several verbal fights he had with one of the doctors which demonstrated his wish to control his own medication and not follow their advice. Over time, he had grown to be both feared and pitied by the staff.

Late one evening, when I passed by his room, I heard someone moaning. Not knowing whether it came from him, I entered only to find the curtain around David's bed drawn shut. When I carefully peeked inside, I got a furious look that communicated very clearly, "Get out and leave me alone!"

Knowing I would not be able to connect with him during the

day, I started a different strategy. Due to pain and overmedication, David's nights were still the most complicated time of his day. I started staying longer into the evenings in the hospital, sitting just outside his room, close to the little coffee and tea station. I found that at least once every evening he would come and get a strong cup of black tea. After a few days of my being there, David actually began to take more time to make his tea, even accepting the sugar and spoon I had prepared for him on the little table so that, despite his shaking hands, he could go through his tea ritual without interruption. We never said a word, nor did we look at each other. It was as if evening by evening the language we used was the actions that went into preparing a cup of tea.

After one long weekend that I had spent away from the hospital, the first message I got from one of my nurses was, "David is waiting for you; you must come to the balcony right away."

He stood up and went to the

edge of the balcony. He pointed toward the Old City.

David: This is where I am from ... over there. Have you been to the Old City yet?

Chaplain: Yes, I have, many times. David: Ahh, but you don't know it ... not the way I do.

Chaplain: Then why don't you tell me about it?

I was incredibly relieved; he had given me an opening into his world. For the next hour, David talked and started to share his story with me—parts in Hebrew, parts in Arabic, a few English words in between.

Over the next few weeks, I spent more time with David, sometimes talking, sometimes just sitting with him

I started to realize that when David spoke about events that hurt him, his voice rose—his anger and feelings of abandonment found a very loud way out. His life experience had been one of being alone—feeling abandoned by his parents, siblings, wife, God, country, and now finally by his body, which was slowly succumbing to cancer. He had experienced a lifetime of hurt to which he reacted with anger.

At first, the staff kept their distance from us, only briefly interrupting at medication times; however, as the days went by, the male staff members especially started approaching carefully. Slowly, he grew closer to some staff members as I helped him share some of his story in a safe space with them.

Over the last few weeks of his life, David's pain was out of control; however, during our time together he would demand not to be under too much pain medication so that he could converse and think straight. He shared that when talking about what really mattered to him, his physical pain would seem to ease.

During his final hours, he was surrounded by the staff and volunteers to whom he had grown closer. He was minimally sedated upon his own wish; the mere presence of people who now genuinely care for him was enough to ease his pain of dying and loneliness.

### **Discussion**

From the first time we met, David's presence seemed to be filled with anger, hurt and frustration that went deep and beyond words. It was clear to me that it was not with words that the first connection needed to be formed. It was through the simple intentional coexistence of two presences in one space.

Wondering where in his life this amount of anger and hurt came from, I hoped that giving David a chance to tell his story and to do a life review would be a successful intervention. Telling his story became not just a

### New Book Highlights Chaplain Case Studies

### **Grooms Professionals for Actual Encounters**

Case studies have an important role to play in the development of a research-informed approach to health care chaplaincy. However, until now, only three chaplain case studies have been published.

That has changed with the recent publication of a collection of chaplain case studies, "Spiritual Care in Practice: Case Studies in Healthcare Chaplaincy" (2015, Jessica Kingsley Publishers, http://www.jkp.com/uk/spiritual-care-in-practice.html). The book is edited by George Fitchett, D.Min., Ph.D., professor and director of research in the Department of Religion, Health and Human Values, Rush University Medical Center, Chicago, Ill., and Steve Nolan, Ph.D., a palliative care chaplain at Princess Alice Hospice, Surrey, U.K.

The book features nine chapter-length case studies from chaplains practicing in pediatrics, psychiatry, and palliative care in hospitals and hospices in the U.S., Canada, the U.K., and Israel. Each case study includes background information on the care recipient(s), the chaplain, and the institutional context in which the care was provided. This is followed by a description of the spiritual care,

including selected verbatims; an account of changes in the patient/family during or after the chaplain's care; and each chaplain's own critical review of the spiritual assessment, interventions and outcomes.

A distinctive feature of the book is critical reflections on each group of cases by a chaplain and a health care professional.

The publication of this book will advance health care chaplaincy in three ways. First, since there is little literature about what chaplains do, these case studies will provide data about chaplains' actual spiritual care interventions and, thus, a foundation for further research into the quality and efficacy of chaplains' spiritual care.

Second, these case studies can play an important role in both training new chaplains and providing continuing education to experienced chaplains.

Third, by providing detailed descriptions about how chaplains care for people, these case studies can help educate health care colleagues and the wider public about the work of health care chaplains.



**WATCH INTERVIEW** with the book's co-editor George Fitchett www.healthcarechaplaincy.org/magazine

life review, but an exploration into his emotional and spiritual history as he relived the emotions of his past. Helping him step out of this loneliness and see that a caring connection could be possible, without losing himself or feeling abandoned again, was one of my first goals for the pastoral relationship.

His prevalent anger, grief and despair were the first emotions I addressed. Being forced to grow up at a very early stage in his life, he survived by being fiercely independent, yet subconsciously he longed for companionship. Seeing that this was not possible by simply inviting him with words, I demonstrated it by being present and insistent, silently showing that I would not be easily scared off by his behavior.

Our "tea ritual" helped him ease into a safe space. I hoped my presence would communicate a simple message: "I am here. I will not be scared off, either by pain or by anger. I will not force you to talk or engage, but I can wait until you are ready to reach out." Knowing how precious these few moments were, that a silent connection and initial trust was being established, I left the initiative of how and whether he wanted to proceed in David's hands, and just a few days later, he did reach out, actively and with words.

After our first conversation on the balcony, I could feel his need to talk and, at the same time, his fear of letting someone into his story. I decided to check in with him whenever we ran into each other, keeping my greetings casual but offering him the possibility to talk. When he did talk, I initially only asked factual questions so as to show my real curiosity about him, but without pushing him to reflect, feeling that he first needed to get his story out in his own way.

David lived in a country that is filled with tragedy on an everyday basis—a country whose people are worn out by war and conflict. He lived in a sociopolitical situation where similar things happen to so

### "He was able to experience that not only was his story heard, but also that he was accepted as a whole person ..."

many people that his story was not even recognized as tragic.

By the standards of his traumatized society, he was comparatively normal, but it was not "normal" in the way he needed to be. His terminal cancer diagnosis eventually just confirmed what he had experienced all his life: tragedy, isolation and hopelessness, with the only difference being that now, all of a sudden, his body had "betrayed" him and he could not fight through it. This triggered anger and fear. Recognizing this lifelong dynamic showed me the importance of helping him with his life review—making sure that what he went through was recognized as traumatic and deserving of attention and healing.

### **Outcomes**

Even before being able to tell his story, the most important outcome of our connection was that David was able to make a connection beyond his anger. I experienced David's ability to allow himself to enter this safe space as an initial success on which we could build. It was a first sign that, despite all the hurt, he had not yet lost the ability to trust. Building a basis of trust, first without words, and then testing this trust by telling his story and finding the trust reaffirmed, was important to David's regaining of trust: first a trust in himself; then a trust in others.

He was able to experience that not only was his story heard, but also that he was accepted as a whole person, with his strengths and weaknesses. It was not surprising to me that David started with telling me about his home. He started his story from a place of strength and safety: the memories of his home and his early childhood. Only after that did he allow himself to share more hurtful memories.

The life review we did helped him struggle with the inevitability of his imminent death, given that being recognized in his sadness, grief and trauma took away some of his edge to fight everything and everyone just to get attention. Sharing some of his story with staff, through me and by himself, helped him connect and experience a few caring connections, even if they were only short term.

His loneliness had been alleviated to a substantial degree, and his worst fear of dying as lonely as he had lived was not realized.

### **Conclusion**

One of the most striking elements in the pastoral care relationship with David was how it seemed to influence his pain levels. Almost every pain comes with suffering, and I differentiate here between pain as the physical experience and suffering as the emotional and spiritual response to physical pain and other life-disrupting circumstances.

When David told me that he had never had a pain-free life (meaning free of physical pain), looking at it from an existential point of view, I was not surprised. Yet, when speaking about some of his deepest feelings and fears, his body would react, his stomach pain would come back—but he would not ask for medication, claiming that his physical pain was "bearable and important." It was important pain for him to go through in order to start healing.

Nina Redl, BCC, currently works at Bryan Medical Center, Lincoln, Neb., where she specializes in palliative oncology, trauma and intensive care chaplaincy for patients of all ages. She has worked as a chaplain in the U.S., Germany, and the Middle East.

### SPECIAL SECTION: Palliative Care







"Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social and spiritual needs and to facilitate patients autonomy, access to information, and choice."

— "Clinical Practice Guidelines for Quality Palliative Care," issued by the National Consensus Project for Quality Palliative Care, 2013

# Hearing our Patients' Voices

By Rabbi Edith M. Meyerson, D.Min., BCC, and Diane E. Meier, M.D., FACP

The patient, Mr. L, was a Hispanic man in his early 80s, who lay in his hospital bed surrounded by his children and grandchildren. When our palliative care team walked into the room, it was clear that he had been the protector and patriarch in his family, and now they were struggling to figure out how to protect him from his metastatic cancer of unknown origin that had spread to his liver and bone and was progressing rapidly.

In response to concerns expressed by his children prior to entering the room, the team promised to follow Mr. L's lead, talking only about issues he was comfortable addressing, never pushing the conversation

in a direction that felt too overwhelming. The family did not want Mr. L to be upset by information about how advanced his disease was, but they were also craving his opinion about what he would want. They hoped that he could make decisions for himself because it was too difficult for them to make decisions on his behalf.

Mr. L was able to clearly express himself and his wishes. He stated that he understood that he had an advanced cancer, and that "it was found too late." He understood that there was no cure for this metastatic cancer, and that any treatment would be palliative.

When asked about treatment, he said that the most important thing to him was his family, and that his family is "good medicine." He designated a health care proxy (who was also present during the meeting) and voiced that he wished to be comfortable and surrounded by his family during his remaining time.

Mr. L then became very tired.

The team asked him if we could continue the conversation with his family, and he agreed. His family expressed understanding of his poor prognosis. They didn't want him to suffer, and were grateful and relieved that they heard what he wanted.

The essence of palliative care is understanding who the patient is as a person—what matters most to that person. This—the search for meaning—is also the essence of spiritual care.

This medical specialty focuses on patient- and family-centered care, operating within the construct of an interdisciplinary team comprised of physicians, nurses, social workers, chaplains, massage and yoga therapists, and other health care professionals, and provided across all health care settings to assist patients and their loved ones navigate serious or lifethreatening illness.

Eligibility and appropriateness for palliative care is based on need and not prognosis. It is appropriate for people pursuing cure (for example, head and neck cancer or acute myeloid leukemia); living with long-term chronic but debilitating illness like chronic obstructive pulmonary disease (COPD), dementia, or congestive heart failure; and approaching the end of life as a result of a progressive disease (e.g., stage 4 lung cancer metastatic to brain and liver). Patients can be receiving both curative chemotherapy and palliative care.

As palliative care clinicians, we empower people who are navigating serious illness to make decisions that are right for them in the context of the reality of the illness. We hear our patients' voices and ask them important questions. Tell us about your life. Who are you and what is important to you? What are your greatest

hopes and concerns? Tell us about your family. We all have one life to live, how do you want to live yours?

Too often in the treatment of serious and chronic illness, patients and families struggle to voice a great many things, and things are left unsaid even at the end of life. The palliative care team, trained and expert in communication skills, helps patients and families express their true feelings, questions and concerns. They work to ensure

"We hear our patients' voices and ask them important questions."

that those involved have the appropriate information about the diagnosis and have a space to express how they would like to proceed — keeping the patient's priorities and goals at the center.

When there are discrepancies in a family's wishes, the team helps the parties assert their opinions and needs, and then attempts to mediate, bringing the conversation back to what matters most to the patient. For patients, for their families, for consulting providers, for all human beings, to be known and understood, to be heard, is the basis for spiritual care.

Our patients and their families so often are grateful for

the infusion of authenticity the palliative care team provides. Patients will say, "This is the first time anyone has sat down with me or with my family to ask us who we are, how we're doing, and to have a conversation about the big picture." Within the fragmented, time-pressured, health care system, the team approach that characterizes palliative care permits skilled staff the time and attention necessary to do just that.

Sadly, Mr. L's disease progressed faster than the doctors had predicted, and within a few days he died on our palliative care unit. He died with full knowledge of his disease, surrounded by family as he had desired. The burden of making decisions was lifted from the family because they had heard his voice, knew what he wanted, and were able to honor his wishes in a pure form.

Who are you and what is important to you? This is the basis for palliative care and for spiritual care

Rabbi Edith M. Meyerson, D.Min., BCC, is director, pastoral counseling and bereavement services, the Hertzberg Palliative Care Institute, and clinical instructor, Brookdale Department of Geriatrics and Palliative Medicine, Icahn School of Medicine at Mount Sinai in New York.

Diane E. Meier, M.D. FACP, is director of the Center to Advance Palliative Care (CAPC), a national organization based in New York. She is vice-chair for public policy, professor of geriatrics and palliative medicine, and the Catherine Gaisman Professor of Medical Ethics at the Icahn School of Medicine at Mount Sinai in New York, and was the founder and director of the school's Hertzberg Palliative Care Institute.

## Integrating Spirituality

# Into Palliative Care Education and Research

By Betty R. Ferrell, RN, Ph.D., MA, FAAN, FPCN, CHPN and Tami Borneman, RN, MSN, CNS, FPCN

A critical need exists to integrate spirituality into professional education and research projects. Enhancing professional knowledge of spirituality and advancing the evidence related to spiritual care are priorities so that patients and families receive spiritual care during serious illness.

Over the past 25 years, the City of Hope Medical Center in Duarte, Calif., has attempted to integrate spirituality into its research and educational efforts. This commitment to spiritual care is based on the hospital's Quality of Life (QOL) model, which has been the foundation of this work (see diagram).

It has been important in this research and education to advance the center's belief that spiritual care is an essential—not optional—aspect of quality care. Many organizations have confirmed this belief, including the National Consensus Project for Quality Palliative Care<sup>1</sup>, which identifies spirituality as one of the eight domains of care.

The End of Life Nursing

Education (ELNEC) project<sup>2</sup> is a good example of the City of Hope's educational efforts. Initiated in 2000, the ELNEC project has trained more than 19,000 nurses and other professionals throughout the U.S. and in 85 countries, providing participants with the resources to train others. Spirituality is integrated throughout the various ELNEC projects, including ELNEC Core, Pediatrics, Critical Care, Geriatrics, and other curricula; and is addressed through lectures, role plays, case studies, and all other teaching methods.

Spirituality has been included in the City of Hope's Pain Resource Nurse Training Course, now in its 24th year. Training nurses in pain management provides an ideal opportunity to focus beyond physical pain and pharmacology, and address such topics as spiritual pain, existential distress, and suffering.

The medical center has also integrated spirituality into its National Cancer Institute (NCI)-funded R25 training programs, including two projects on Cancer Survivorship

training.<sup>3</sup> The NCI-funded course entitled "Improving Quality of Care for Family Caregivers"<sup>4</sup> emphasizes the importance of assessing and responding to the spiritual needs of the family caregiver, in addition to those of the patient.

One of the more recent trainings has been in the area of communication.<sup>5</sup> Elaine Wittenberg, Ph.D., joined the City of Hope's nursing research and education research staff in 2013 and has introduced interdisciplinary communication training that includes spirituality.

The research projects have also included spirituality as a key domain. Over the years, the medical center has moved from descriptive studies of spiritual needs to testing interventions related to spiritual care. Studies have included a NCI-supported project on "Eliminating Barriers to Pain and Fatigue Management" in which spirituality was included as a key area of pain management.<sup>6</sup>

With funding from the Archstone Foundation, the City of Hope was





able to host a national conference to create guidelines for improving spiritual care in palliative care, and later lead a demonstration project in which nine hospitals integrated these guidelines into practice. This project demonstrated that clinicians are eager to improve spiritual care and to have outcome data to support their efforts.<sup>7-8</sup>

In 2014, the medical center concluded a 5-year project funded by the National Cancer Institute on Palliative Care for Patients and Families with Lung Cancer. This study tested an intervention to support patients and families, with spiritual care as one of the key intervention aspects. The study also serves as a model for current research in other disease groups in which spiritual care is integrated into supportive care interventions and the outcomes evaluated.

The key message of this education and research has been that quality care for patients and family caregivers is not possible without quality spiritual care. Education and research are central in the efforts to achieve that goal.

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### By Ronit Elk, Ph.D.

Beaufort, S.C., is located in the state's Lowcountry—a mixture of agricultural areas, small towns on the mainland, islands along the coast, and recreational areas along Hilton Head. Established in 1711, it is now one of the fastest growing areas of the state.

A large part of the region's newly-expanding population is affluent white retirees who have relocated to Hilton Head and communities surrounding Beaufort. Its African-American residents, on the other hand, have been there for generations. Referred to as "the Gullah people," they are direct descendants of slaves who, because of their geographical and cultural isolation in rural areas and former plantations on islands, have preserved and continue to live by their rich African cultural heritage.

While many African-Americans still live on the more isolated St. Helena Island, others have moved into the small historic town of Beaufort. Sadly, poverty and all that accompany it, including joblessness, low literacy, and health disparities, are common; 15 percent of this population lives below the poverty level and the median household income is less than \$50,000 per year.

It is within this area of cultural and economic contrasts that a unique Community-University Partnership Research Program to develop a community-generated, culturally-tailored palliative care program for rural elders has been taking place.

Studies indicate that the kind of care a patient wants to receive is strongly influenced by their race, ethnicity and culture. At no time is this more apparent than when someone has a terminal illness. Palliative care programs consisting of interdisciplinary care focused on relief of pain and other symptoms in support of the best possible quality of life for patients have proven extremely effective.

Yet, to date, no palliative care programs have been developed in the U.S. that take into consideration the unique cultural needs and preferences of multicultural groups of patients living in rural areas.

To address this gap, a research team developed a 2-year study funded by the University of South Carolina in Columbia, the Medical University of South Carolina in Charleston, and the National Institutes of Health (NIA). The goal: to develop the first palliative care program culturally tailored to both African-American and white elders living in rural Beaufort who have a terminal illness—and to do so with full community participation.

The researchers assembled a Community Advisory Group (CAG), consisting of 14 community members representing various segments of the African-American and white community, including spiritual and business leaders, community gatekeepers, those who recently lost a loved one, and other representative community members. The CAG guides all three phases of the study.

### **Phase One: Focus Groups**

In Phase One of the study, the aim was to poll family members of elders who had been ill and died in the previous year about the care their loved ones received during their illness. The team conducted separate 15-person focus groups for African-Americans and whites.

The results pointed out both similarities and differences between the groups. Both sets of family members deeply appreciated it when doctors treated the patients with compassion. Similarly, participants in both groups commented that their pastor was the one who helped them accept the reality of the end of life of their loved ones.

Among the many differences, the African-American family members expressed a strong preference and responsibility for taking care of their loved ones at home according to their stated wishes, with extended family members taking turns in care taking. This was also one of the reasons cited for why African-American family members did not want hospice staff to come to their homes to help. Although several members of the white group also expressed the desire to care for their loved ones themselves, many felt unable to do so, and reluctantly and often with feelings of guilt placed their family members in nursing homes.

Another key difference centered on religion and spiritual issues. Although church and religion were important to both groups, the African-American group expressed that religion was the key and central source of comfort to the patients and families.

In keeping with the principles of full community participation, the team presented the results on separate occasions to both focus groups and the CAG for their feedback.

### Phase Two: Program Development

The goal of the second phase is to develop a palliative care program that is both evidence-based and culturally-tailored to African-American and white elders of this rural community, by carefully reviewing all the results of the focus groups.

In order to do so, a 10-member CAG, comprised of members of the first CAG and four members from each of the two focus groups, work in full collaboration with the research team and a palliative care doctor to provide culturally-sensitive input on the multiple facets of the program.

As an example, a theme that emerged in Phase One concerned the doctor's sharing of a patient's terminal prognosis with the family. African-Americans did not want the doctor to provide a date and exact time for the patient's passing, believing that only God can determine that. The program development team members made several recommendations related to discussing a prognosis with African-Americans, including that the palliative care doctor should always involve the family, make time to get to know the patient and the family, never provide an exact date and time for passing other than to cite what is in the doctor's experience, and always indicate that the exact passing is up to God or a power higher than the doctor.

The process of reviewing the results and developing culturally-appropriate recommendations has been ongoing for nearly one year; it will require at least six more months to fully develop the study program protocol.

### Phase Three: Program Implementation and Evaluation

In the final phase, terminally-ill elders in the hospital in Beaufort will be invited to participate in the study. Those who agree will receive the culturally-tailored palliative care program. They will meet with volunteers in person and connect with a palliative care consultant via

telemedicine. Patient and family satisfaction with this program will be evaluated.

The community input has been an integral part of this study. All CAG members have been attending monthly meetings "religiously."

When the team asked members why they felt it was important for area residents to be involved in this process, a common theme of "community" emerged. Among the comments: "Our community is very tight-knit ... Everybody knows everybody ... You can't come in ... with the Lone Ranger approach where you come in to save the world. We know that attitude won't work; it won't be effective in our community."

Ronit Elk, Ph.D., is a research associate professor, College of Nursing, University of South Carolina, Columbia, S.C., and the lead researcher on the Community-University Partnership Research Program.

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### **Inspiration ... Pass it On!**

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

"Keep your face always toward the sunshine and shadows will fall behind you." — WALT WHITMAN



### Putting Your Heart on the Page

By **Deborah Shouse** 

"What is this, dear?" my 75-year-old mother asked, holding up an avocado. It was early Thanksgiving Day. As usual, my mom and I were in the kitchen. But this year my mom was more of a distraction than a head cook; she is in the early stages of Alzheimer's disease and her memory had been slipping for months. Simple things, like the location of my silverware drawer and the existence of this oval-shaped scaly green vegetable, confounded her. And her confusion rattled my composure, catapulting my emotions into a maelstrom of sadness and anger.

"An avocado." My voice sounded harsh and impatient, and I took a breath, reminding myself that my mother was not trying to irritate me; she was just hoping to understand an increasingly complicated and incomprehensible universe.

"Thank you dear." Mom sounded so grateful and so lost that I put down my potato peeler to hug her.

"I love you, Mom."

"I love you too, dear," she answered.

She'd been calling me "dear" instead of "Debbie" for the three days she'd been visiting; I wondered if she actually knew who I was. But I was not ready to test her and find out.

I returned to the potatoes, but the peeler was missing. Not resting atop the peels, not fallen onto the floor, not thrown into the sink. My throat tightened: Was it already happening to me? Was I losing my mind too?

"What's this, dear?" my mother asked, holding up the peeler.

Later that evening, after our Thanksgiving feast, when my parents were settled into the guest bedroom, I curled into a small cocoon and cried. My life partner, Ron, held me, smoothing my hair as I sobbed out my sorrows.

"Poor Mom,"I wailed.

I could not bear to think of all she must be going through. Her face seemed to freeze when I asked her a question; she gripped my hand when my father was not around to anchor her, as though I could save her from the confusion. Her vulnerability and helplessness scared me; she had always been independent, a woman who had served as an Army nurse in World War II, who had relished snow skiing and buzzing around in small airplanes. She had been no-nonsense and competent, always present to bandage scrapes and nurse ailing friends and relatives. I didn't know this woman who stood before the bathroom sink, rubbing her hands together, and saying, "I don't know which knob to turn." I was numb with the loss and also prickly with the fear that this could also happen to me.



"Have you considered writing about this?" Ron said, when I finally wiped my tear-laden face.

I'm too depressed to write," I answered.

But the next night, Ron's words came back to me. I worked as a writer; I had always kept a diary or journal. What if writing down my feelings could help me manage my grief?

After everyone had gone to bed, I went to my computer, opened a new file, and spilled my emotions over the page. I forgot about spelling, punctuation and grammar. I forgot about complete sentences and coherent paragraphs. I poured all my worries, fears, anger and heartache onto the page. My hands hurt when I had finished, but I felt a bit lighter and more hopeful.

I kept writing. Within months, my parents moved from their Memphis home of 40 years into a retirement community near me in Kansas City.

"Doesn't your mother look beautiful?" my father said several weeks after their move.

I sat across from them at the small table in their new apartment. My mother could no longer manage the stove, so I had brought in lunch. Mom stared vacantly across the room; her hair seemed greasy and a spot of potato soup splotched her cheek. I looked carefully, trying to understand what my father saw. At that moment, I couldn't see my mother's beauty, but I wrote down the encounter.

I documented our visits, jotting down my father's philosophies on love, the constant way he showed his caring for my mother. I wrote down my mother's behaviors, mannerisms, odd pronouncements, and bits of wisdom.

As my mother moved more deeply into dementia, she showed me ways to stay connected without words. Mom often smiled sweetly when she saw me; she held my hand when we walked together. She gazed into my eyes with such innocence and openness that I felt like I'd experienced a spiritual breakthrough. Without knowing exactly who I was, she welcomed and accepted me. And I began to accept her as she was.

Through these observations, I began to see there were actually some gifts in my mother's odd behaviors and receding memory. I wrote down my actions and feelings, as well as the lessons I was learning and the blessings I found in my new relationships with both Mom and Dad. Then I worked to make these encounters into stories and dug deeper, seeking to understand the rich meanings in my experiences.

Writing helped me during every aspect of my mother's journey through Alzheimer's disease. As I read my scribbles and rants, I began to see the meaning in our new lives.

Instead of being swamped by the sense of loss, I documented my new relationship with my mom, one without so many words, without so many rules—a relationship that was fueled by the heart and by the soul. I captured the little moments of joy and discovery, so instead of mourning that Mom didn't know my name, I could call Dad and report, "Mom held my hand." Or "Mom laughed."

As I connected with myself through writing, and ultimately shared these stories with friends, literary colleagues, and other caregivers, I was able to connect with others. The more I shared my stories and my journey, the closer I felt to those around me, to my parents, and to my true self.

**Deborah Shouse** writes about Alzheimer's disease and is the author of "Love in the Land of Dementia: Finding Hope in the Caregiver's Journey" (2013, Central Recovery Press).

# Writing Your Way From Grief to Insight

How do you take a challenging part of your life and bring it to the page?

Here are a few simple tips:

### Pour Out Your Feelings Give yourself time to feel your emotions, whether it's through writing, art, music or another creative expression.

### Notice the Details

Write down the particulars, noting simple concrete facts. You are a researcher collecting data.

Uncover the True Story

Look for the universal meaning in your specific experience. What is the larger message huddled inside your experience? How have you changed? How will the reader change through reading your words?

### Seek Feedback

Read the story aloud and see how it sounds. What's working and what's missing? Ask writing colleagues for a critique. Think over their advice and decide what is right for you.

### Share Your Writings

When you're ready, share your writings with family and friends and then reach out to a wider audience, using your experiences to connect with others and share information and insights.



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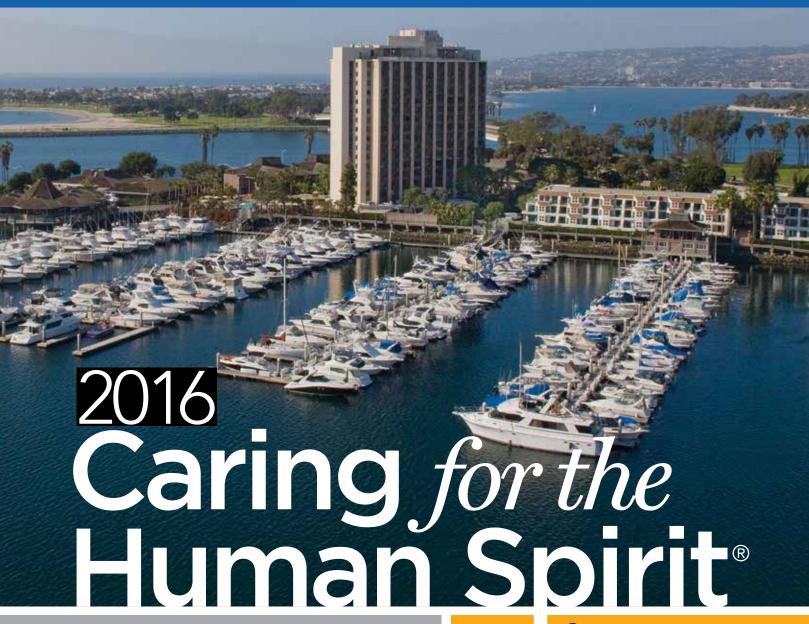
VITAS celebrates our partnership with the HealthCare Chaplaincy Network. We honor the chaplains across the country who address and advocate for patient needs.

### **VITAS Chaplains Care for the Human Spirit**

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