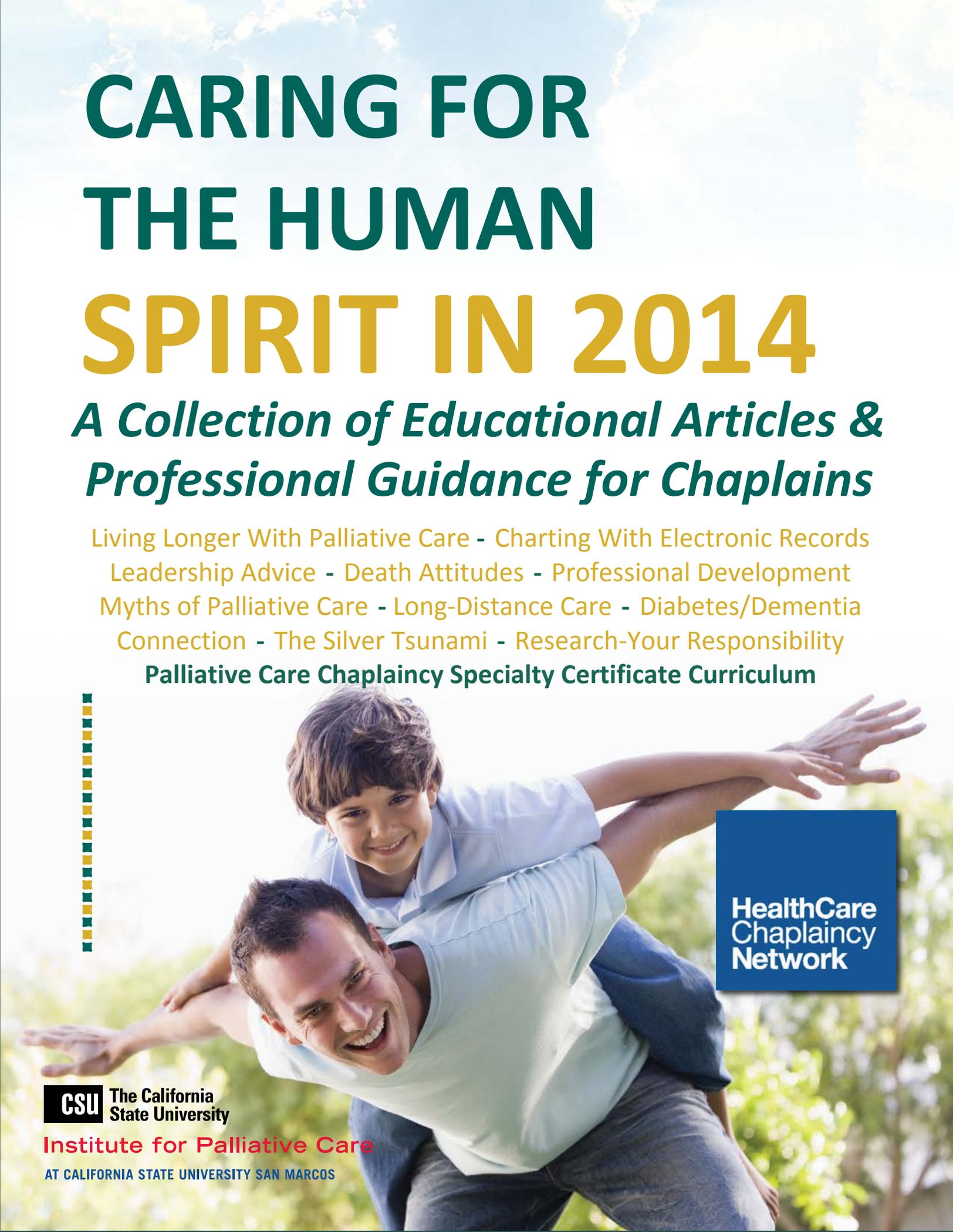


CARING FOR THE HUMAN SPIRIT IN 2014

A Collection of Educational Articles & Professional Guidance for Chaplains

Living Longer With Palliative Care - Charting With Electronic Records
Leadership Advice - Death Attitudes - Professional Development
Myths of Palliative Care - Long-Distance Care - Diabetes/Dementia
Connection - The Silver Tsunami - Research-Your Responsibility
Palliative Care Chaplaincy Specialty Certificate Curriculum



HealthCare
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Network

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State University

Institute for Palliative Care

AT CALIFORNIA STATE UNIVERSITY SAN MARCOS

Welcome!

The CSU Institute for Palliative Care and the HealthCare Chaplaincy Network have created this collection of chaplaincy and palliative care articles along with a dose of career advice for any chaplain seeking to improve their palliative care skills and their impact on the organizations and people they serve. Some of the articles to follow come from HealthCare Chaplaincy Network's newsletter PlainViews®, the preeminent online professional journal for chaplains and other spiritual care providers. Other articles come from the staff of the Institute.



The California State University Institute for Palliative Care offers a vital mix of courses designed to enhance the palliative care skills of today's health care professionals. We frequently partner with health care organizations to provide specialized offerings to enable them to educate all their staff about palliative care.



If you are engaged by what you read here, [The California State University Institute for Palliative Care](#) and [HealthCare Chaplaincy Network](#) – two leaders in their fields – have created an online-certificate course to support chaplains and other spiritual care providers with the delivery of palliative care to patients and their families in hospitals, hospices, long-term care facilities, and elsewhere.

Created by a team of national experts, the nine-week curriculum strengthens the quality of palliative care by providing a foundation of knowledge and practice built on the 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. There are more details toward the end of this eBook.

Please consider deepening your knowledge of palliative care and enhancing your career by earning a Palliative Care Chaplaincy Specialty Certificate from The California State University Institute for Palliative Care. In the meantime enjoy the reading!

Sincerely,

Helen McNeal

Helen McNeal,
Executive Director
CSU Institute for Palliative Care

Gary E. Myers

Gary E. Myers, Ph.D., M.Div.
Senior Director of Continuing & Professional Education
HealthCare Chaplaincy Network

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Dispelling the Myths About Palliative Care

By Helen McNeal, Executive Director of the California State University Institute for Palliative Care at CSUSM

Almost everywhere you turn today in the media, there is some reference to palliative care. Therefore, it is surprising how much confusion exists within health care in general but particularly amongst physicians about what it is, why it's important, when to refer, etc. And, generally, I see much more of an ostrich-like posture about the response to this confusion on the part of many health care providers than one would expect.

Given our aging population and data that demonstrates that palliative care increases longevity, reduces readmissions and improves outcomes, if this were a drug, everyone would be prescribing it. Instead, for many patients and families, getting a referral seems like hand-to-hand combat.

For palliative care teams, education and building a referral base is a strategic, needlessly time-consuming one-on-one relationship building process. Isn't it time we all got on the same page?

Let's make a start by debunking some of the popular myths heard in health care circles about palliative care.

It all begins with the idea that **palliative care equals hospice**. Quite simply, it does not. Nor is palliative care only for terminal patients, a frequent corollary. Palliative care is appropriate for any patient with a serious or chronic illness and their family, from point of diagnosis onward, regardless of the patient's age or prognosis.

To be crystal clear, palliative care improves the quality of life for patients and families facing serious or chronic illness — whatever the diagnosis or prognosis. It prevents and relieves suffering by addressing pain as well as the physical, emotional, psycho-social and spiritual problems associated with serious and chronic conditions.

This is the fullest, most inclusive definition of palliative care. If one looks at palliative care as a continuum from diagnosis to death and then bereavement, hospice is part of the palliative care continuum. It shares the same interdisciplinary, holistic focus and philosophy. What is different is that hospice patients must be within six months of death

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This is a very popular and successful course so new cohorts are being started frequently. Check our website for details.

“The most valuable part of the course was my group and all the interactions we had. People responded to one another then responded to the responses. There was much learning that was involved in all this for me. I also liked all the readings!”

if the disease follows its normal progression and must give up curative treatment. To be honest, in some settings, a narrower definition of palliative care is used. Most frequently, this occurs because palliative care staffing is limited, or it is viewed as an expense rather than as means of reducing cost while improving outcomes and satisfaction. But even in settings with resource constraints, palliative care works with patients who are not within the “less than six months” window.

Another corollary of this is that **palliative care is only in hospitals and hospice is at home**. In California and across the nation, this is changing. Between the concepts of the Accountable Care Organization, the Patient Centered Medical Home and CMS’ drive to reduce readmissions, there are a number of initiatives focused on providing both outpatient and community-based palliative care.

These are initiatives that move outwards from hospital-based systems or upstream from hospices striving to create the continuum from their end. In every system and community, palliative care and hospice each have a role, and work together to keep the focus on addressing the needs of the patient and family and ensuring the best care possible, regardless of setting.

What particularly makes palliative care appealing to many patients, and sadly complicates the referral process for some physicians, is that palliative care goes hand-in-hand with curative treatment. The myth that **a referral to palliative care means giving up active treatment** or, its familiar partner in the eyes of family, giving up hope, needs to be debunked by physicians, nurses and health care providers everywhere.

Research^[1] consistently indicates that palliative care when it accompanies curative treatment enhances its effectiveness. Patients live longer and, as a bonus, are demonstrably more satisfied with the care that they receive^[2].

Because relief of pain is such a focus for every patient and provider, and palliative care has been successful in this arena, many feel that **palliative care is only about pain and physical symptoms**. Once again, this is not the case. If there is “magic” in palliative care, it is made possible by the use of an interdisciplinary team that focuses on both the patient and their family, and not just physical pain but on emotional, psycho-social and spiritual “pains” as well.

One of my favorite palliative care examples is of a physician who at wits’ end called for a consult on a woman with intractable pain from advanced breast cancer. The team,

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“Practical applications - I have already used some of the homework in my setting - very helpful!”

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including a Spanish-speaking social worker, talked to the woman and learned that she was concerned about what would happen to her children after she died. She wanted her children raised by her mother in Mexico not their father in the U.S. Once this was negotiated with the family, her pain was manageable with minimal use of medication.

This is just one story but it is one that happens every day. Simply by addressing the patient's emotional needs, along with her physical needs, the need for pain medication was reduced and her quality of life improved. The family is supported and the patient's satisfaction with her physician's care improves.

There is one large elephant in the room that remains to be addressed. Some physicians believe that **asking for a palliative care consult means giving up caring for the patient**. Hence, my comment above about the co-delivery of palliative care with curative treatment, complicating referrals for some physicians.

With palliative care workforce shortages, increasing demand and limited reimbursement for their services, palliative care teams must of necessity focus on "consulting". While those who work in palliative care tend to be passionate about the needs of patients and families, and like all human beings their skill at being a consultant versus taking charge may vary, their goal is NOT to take a patient away from their primary provider or even their specialist.

Their goal is to ADVISE AND ASSIST health care providers to provide the best care possible. On-going responsibility for care, and the reimbursements associated with on-going care, rightfully remain with the referring provider... unless or until that provider indicates the desire for it to be otherwise.

When I am talking with consumers, I am often asked "**Isn't palliative care just good medical care?**" My answer is always "Yes, but..." The concept of attending to a patient's quality of life is not new. In fact, before the last century, this was largely what medicine was defined to be for those who developed a serious or chronic illness.

Clearly, every physician should always be seeking to ensure optimal quality of life for their patients. The "but" is because sometimes this statement has been made to the consumer by someone who sees no need to refer to palliative care. This diminishes the role of what is decidedly a specialty area. If we are going to care for the growing number of Americans who have these serious illnesses, then every physician will need to know about palliative care at a generalist level.

Every physician will need to know how to have advance care planning discussions, how to discuss palliative care with patients and other basics, as well as where and how to refer as with any other specialist consultation.

But, palliative care is more than just good medical care. It is about focusing on the care

needs of both the patient and the family, and addressing all the various forms of suffering... physical, emotional, psychological, social and spiritual that impede both quality of life, as that patient defines it, and achieving the best possible outcomes for the patient and family.

At its very best, palliative care challenges every provider to take their ego off the table, be present to what that patient and their family feels are the optimal goals of care, and then bring the best skills and resources available to achieve those goals. In that, it is more than “just good medical care”, it is the best medical care.

[1] Temel JS et al. Early palliative care for patients with metastatic non small cell lung cancer. NEJM 2010;363:733-42.

[2] Gade G, Venohr I, Conner D, McGrady K, Beane J, Richardson R, Williams MP, Liberson M, Blum M, Della Penna R, : Impact of an Inpatient Palliative Care Team: A Randomized Controlled Trial; J Palliat Med, 2008; 11; 180-190

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A Standard System for Charting Spiritual Care in Electronic Medical Records

George Handzo, BCC, CSSBB, Director, Health Services, Research and Quality at HealthCare Chaplaincy Network

In the next several years, all health care systems in the U.S. will adopt some kind of integrated electronic medical record or suffer severe financial repercussions. These records will also have to be integrated across the whole system to provide the efficiency that new reimbursement formulas will demand.

Hopefully, in this process, spiritual and religious care will be included in the system and chaplains will be asked to take part in deciding how this care will be documented. The chaplain's contribution will be included at least in part to the extent that it is "evidence based" or "evidence informed." That is, what is the established practice in the field for this kind of documentation?

Unfortunately, up to this point, there has been little evidence-based practice for the documentation of spiritual care. Those many chaplains who have already been a part of this kind of process in their health care institutions have generally needed to contribute what made sense to them and/or what they gleaned from colleagues. There has been no discussion across the profession of health care chaplaincy about what the elements of this documentation might look like. Failing this discussion, decisions are going to be, and are already being made, on this topic without chaplaincy input.

Two Aims

I have two aims for this article. First, by proposing what might be the beginnings of a documentation system, I hope to set in motion a wider discussion on this topic. That is, I am not proposing that this system should be the one. I am hoping to "smoke out" those who have already done work in this area to share it with the rest of us and begin a wider discussion. Second, I do want to point out that in several recent publications, professional chaplaincy does have at least the beginnings of an evidence-based system for documentation.

For the purposes of this article, I am assuming the definitions of "spiritual care" and "chaplaincy care" as proposed in the glossary of the APC Standard of Practice so that "spiritual care" is, at least in part, the task of all members of the health care team.

For definitions and how the health care team is involved in Screening, History and Assessment, I would cite Fitchett & Canada, 2010; and Puchalski & Ferrell, 2010. In this system, screening is a short set of questions done on admission and/or at critical points in the process to find those with clear spiritual distress.

A Spiritual History should be part of the overall history taken by the primary care giver

(e.g. physician or nurse) and could follow the FICA system originally proposed by Dr. Christina Puchalski and recently validated. Assessment, by the cited definition, cannot have a formula or tool but should emerge from an ongoing discussion between the patient and the professional chaplain. That said, there needs to be a significant discussion with the chaplaincy profession about the elements that should be routinely included.

For questions on registration and future programs, contact:

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Keeping Your Deployed Military Loved One In Your Heart

Juliana Lesher, BCC, is Chief of Chaplain Service at the Fargo, North Dakota VA Health Care System.

Missing her husband thousands of miles away in Iraq, Beth (not her actual name) thought, "It is true... everything goes wrong when your spouse is deployed." It was October 2005, and her husband was deployed to Iraq. Beth was nine months pregnant, her mother was hospitalized, her little girl missed her daddy, and she was making the difficult decision of putting her husband's beloved dog to sleep.

Over five years later, with her husband having two extended deployments to Iraq during this time, Beth ponders, "It's been tough, yet my husband and I have been committed to our inter-related missions: my husband's mission as a U.S. Army Staff Sergeant, and my mission to serve our returning warriors as a VA Social Worker."

Beth's father was a Vietnam Veteran, and she grew up with a unique understanding of what it is like to love someone who never allowed his loved ones to enter a life-changing period in his life. Beth's desire to know more of her father's combat experience led her to study in Vietnam while working on her graduate degree in social work. While in Vietnam, she focused on social policy and Veterans of the Vietnam War. Beth commented, "Being on the grounds of the infamous Hanoi Hilton made me silent like my dad. With a hushed reverence, I pondered the locked secrets of my father's heart.

While feeling overwhelmed by the circumstances at home when her husband was deployed, Beth gave herself a pep talk and said, "We can do this for each other." When their son was born on Veteran's Day 2005, Beth marveled at the precious gift of life given to them on a day which honors the lives of people like her father and her husband. Looking at the tender eyes of her newborn son, she vowed to keep the face of her loving husband in the eyes of her children every day.

So Beth purchased a "Flat Daddy" for her children. The idea of a "Flat Daddy" originated in Bismarck, North Dakota, in 2003, when a military wife enlarged a picture of her husband for their young daughter while he was serving in Iraq. A "Flat Daddy" or a "Flat Mommy" is a life-sized, cardboard cut-out of a loved one who is deployed.

The "Flat Daddy" which Beth has of her husband stands 5'10", portrays her husband in army fatigues, and has an enlarged photo of her husband's face so that when she looks into the eyes of this "Flat Daddy"... she sees the man she loves. (More information about "Flat Daddies" can be found at www.flatdaddies.com)

Beth's husband's life-size "Flat Daddy" became an important part of the lives of Beth and her children. While performing gymnastic routines, Beth's daughter would look at

the audience of parents and always want to see the image of her daddy. Beth has even brought the “Flat Daddy” of her husband to the Fargo VA for special events.

As a Social Worker, Beth has led a meaningful Family Support Group for the past two years. Out of her own experience, struggles, and learning, Beth engages with other family members on topics which include: building strong relational bonds, coping with post-combat stress, communication barriers, dealing with anger, and establishing a “new normal.” As the daughter of a Veteran and aware of her own children’s questions, Beth has also led Children’s Support Groups for children who have a deployed family member.

On April 1, 2011, Beth’s husband will retire from the U.S. Army after twenty years of service. With her husband having spent the last five years away from the family at Fort Stewart, GA, or deployed in Iraq, Beth keenly recognizes that there will be challenging readjustments for all of them as a family. With a steadfast commitment to faith and family, Beth eagerly anticipates this new chapter in their family life. Her children look forward to having their daddy really present, instead of a “Flat Daddy” to remind them of their daddy’s love.

Above all, Beth prays to keep the love for one another continually kindled in the hearts of her husband, children, and herself. As Beth stated, “Repeated deployments are hard on relationships.” It’s easy for meaningful communication to disappear, and loved ones to become distant strangers. Yet we are committed to keeping our loved one in our heart.

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Are we Eating Our Way to Dementia?

By: **Caroline Boaz MSN, RN, ACNS-BC, ACHPN**
Community Educator CSU Institute for Palliative Care

Have you read about “Type 3 Diabetes” and found yourself scratching your head? It’s been proposed as the new label for Alzheimer’s disease. November is National Diabetes Awareness Month, National Alzheimer’s disease Awareness Month, and National Hospice and [Palliative Care](#) month, so it seems timely to explore how these two devastating diseases overlap and impact hospice and palliative care.

A study at the University of Pennsylvania published in 2012 demonstrated that people with type 2 diabetes have between a 50% and 65% increased risk of getting Alzheimer’s disease due to factors related to insulin resistance.

Another study that was funded by the National Institute of Health (NIH) and published in the [New England Journal of Medicine \(August 8, 2013\)](#) explored if higher glucose levels increased risk of dementia in non-diabetics. The researchers found that those without diabetes but with higher than average glucose levels were at increased risk of developing dementia, just as the participants with known diabetes were.

Finally, [another study at Brown University](#) showed that low levels of insulin in the brain lead to neuronal deterioration that mirrored Alzheimer’s.

We Must Treat and Teach

There’s considerable research being done to develop a diabetic drug that will combat the effects of the disease on the brain. So while we wait for mice in a lab to get smarter and eventually the years of clinical trials to come to pass, there’s something every nurse can do. It’s something very simple; we must teach our patients to eat differently.

The root of the problem is the standard American diet (also known as SAD). This includes the over-consumption of foods that interfere with the many roles insulin has in our bodies. Sugars certainly play a part and we’ve all read and given recommendations on what constitutes a healthy diet. Following that, we’ve told our patients to eat fresh fruits, vegetables, whole grains, lean meats and low-fat milk and cheese. Recent studies however are turning the page on that advice.

Neurologist, Dr. David Perlmutter’s new book [Grain Brain](#) provides a solid argument that the fruit bowl, dairy products, sugars and particularly bread and grains are a probable source of the increasing numbers of degenerative brain disorders. He recommends that carbohydrates be kept between 60-80 gm/day and that we increase our fat intake as fuel for the brain. His research turns the food pyramid we’ve all known to be the standard on its head.

Why You Should Care

Today there are 5.4 million Alzheimer's patients in the United States. The number of diagnosed patients is expected to increase 100% in the next fifteen years. The cost of care is in the hundreds of billions each year. Keeping pace is type 2 diabetes, which has tripled since 1970. Tripled! A new drug alone won't correct this trajectory Americans are on. It's become evident that the pattern of disease at the end-of-life is changing and more people are living with these serious and chronic diseases longer.

With this shift, more people will need help with their final decade, through the end-of-life. Taken within the social impact of changing family structure and wider migration, employment and aging of potential caregivers there will be a dramatic increase in the need for integrated supportive and palliative care.

Coordination of care has historically been the shortfall of quality care. It will become increasingly critical for a team approach to managing the types of patients discussed here. Coordinated care allows more people to die at home, if they wish, and specialist palliative care is associated with a range of better outcomes for patients and their families. This area has been relatively neglected in health policy and nursing and medical education.

Development of practice standards for palliative care in pain and symptom management, communication and teaching skills and coordination of care are clearly necessary now more than ever. Bravo to those health care organizations that see the need and value in generalist palliative care training for all of their staff and demonstrate it by expanding education and training opportunities to their nurses, social workers and chaplains.

Chaplains, nurses and social workers are well poised to shift this path through seeking to deepen their own knowledge of palliative care practices. It is only through your own interest in continuing education that your patients and their caregivers will reap the benefits of great chronic care.

So, learn all you can about this link between diet, diabetes and dementia and help your patients strategize a way to maintain good health. Continue to seek out opportunities to increase your expertise caring for this changing paradigm that our aging population is heralding. Be an advocate for the compassionate and common sense health care that [palliative medicine](#) brings.

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Take Your Seat at the Table: Leadership Advice for Health Care Chaplains

Susan Jurevics, CEO Pottermore, and Board Member of HealthCare Chaplaincy Network

What all professional chaplains need to recognize is that your leadership has two sides – as the chaplain engaged in patient discussion and as the chaplain as part of the health care team. The latter may be putting you in a space that may be a little bit new or make you feel a little bit uncomfortable. Or maybe you're really excited about role. Nonetheless, interacting with a lot of people across different specialties – that may be quite different from how you interact with a patient or family member or a stressed-out nurse.

There's been a significant shift in what professional chaplains do. Chaplains are not just in the business of chaplaincy. Chaplains are in the core business of improving health care. You deserve and should have a very equal and balanced seat at the table in the health care dialogue, in the decisions that are being made for chronic illness, for end of life care, for spiritual guidance and care, for healing.

I work for the Sony Corporation. Just as Sony has moved from being an electronics manufacturer to a networked services provider, the professional chaplain role changes when the hospital announces a new palliative care initiative. As a senior marketing officer for Sony, I had to develop a mid-range plan and fiscal year roadmap for these changes. In a similar way, the chaplain leader needs to identify the percentage of palliative care patients seen by chaplains; then find ways to increase that percentage.

As chaplains, you are the experts in letting the patient take the lead, helping the patient discover and use his or her own spiritual and/or religious resources in the service of healing. You do really well in that patient/chaplain dialogue. You don't have an agenda you are imposing on that discussion or individual. You tend to tease out some of the things the person may or may not want to talk about. And you conduct a spiritual assessment.

Now we need to start applying leadership in that other part of a team environment; with the doctors, with the nurses, with the social workers, with everyone else who matters within the hospital communities. As a member of the interdisciplinary health care team you have to take the lead in insuring that spiritual care is provided and integrated into the treatment plan.

You have tremendous patience, and interpersonal skills, which is the emotional side. On the rational side, the analytical side, you may be dealing with someone in management who doesn't understand why they have to pay for a chaplaincy, along with physicians who are rational and analytical, and may wish to do everything in terms of medical procedures for the patient. What we're talking about is marrying those two, the emotional and the rational, which is something you do every day with your patients.

Understand Priorities:

The first principle of leadership is understanding priorities. You are serving in the institution where you work. How big is the gap from the current state of where you stand against the future state of ideally where you'd want to be? (In business school this is called gap analysis.) Let's say you've got three priorities to close that gap. The trick is going to be how you get measurement and performance against those three priorities and move your current state closer to your future state.

Look at what's urgent versus important. This is something we at Sony do every day. The worst place to be is to leave the important things unaddressed at the expense of the urgent things. The trick is to actually separate those and say, "What's important? What's important to be driving towards in my relationship in this team environment and how do I make it work?" A chaplain leader identifies a plan for how you and your colleagues can achieve those priorities.

Create an Environment of Collaboration: Developing the team is a top goal. The principles of leadership have to be applied in a team environment where sometimes you lead; sometimes you follow, but at all times you're participating. The trick is when to know how to do both: when to use different styles in different situations; when to hang back and tease it out, just as you do when caring for a patient.

In a similar way no single style of supervision or parenting is right for every situation. The successful leader and the successful chaplain each have a variety of styles they put to use depending on the situation. I see this at home where my seven-year old daughter responds to a very quiet, one to one, nurturing and rational discussion.

On the other hand, my four-year old son, a crazy loud man, needs very firm parenting and strict behavioral limits. My daughter would never respond to that.

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“Practical applications - I have already used some of the homework in my setting - very helpful!”

“Having such a variety of very well-known and experienced professionals providing materials for each segment. Excellent readings!”

An effective leader creates an environment of collaboration, where people trust the team, and feel open, where they can exchange and suggest new ideas, and frankly share knowledge. Find meaningful ways to express gratitude and deliver tough messages. We have these discussions a lot in my group at Sony. Balance a tough message against the positive, delivered with sincerity and authenticity. Remember there is always enough thanks to go around.

One of the quickest ways to get some positive morale is just to celebrate something really small. In my group we get together every six weeks and it's just crazy because we've got people from everywhere. Everybody phones in but if you're in the room we always have cupcakes. Cupcakes are just easy, and they make people smile, and it doesn't cost a lot of money and is just a good mood up lifter.

Take a Seat at the Table:

I sense there's a hesitancy to speak up in individual chaplains and that's true too for the profession as a whole. There's an almost apologetic nature, saying I'm the sympathetic one, the empathetic one, and I'm softer, I'm here to help. That undermines what you do. I don't think you ever have to apologize for the role that you play. The mental state you need to get yourselves into is that you deserve a seat at the table.

In my own career I have had to do this for myself. So I'm proposing something I know requires initiative and tenacity. I know it's not easy. I know too that if you do not do it, your role as a chaplain may very well decline. Sure, it may be hard to execute that steel edge. But what I see about the state of the American health care system, the answer is clear. You're all professionals. You need to demand the seat. You have to own that seat.



Palliative Care Education - Critical for Chaplains

By: Caroline Boaz MSN, RN, ACNS-BC, ACHPN

Community Educator at [California State University Institute for Palliative Care](#)

The silver tsunami is here. What does it mean for chaplains? How will the focus of your responsibilities shift? Are you prepared? As our patients are living longer with serious and chronic illnesses, they are at increased risk of having their pain and complex symptoms undertreated. Our elders are facing long and expensive inpatient stays, treatments and surgeries that are likely futile and suffering through a prolonged dying process. This isn't what patients and families want. Additionally, it's this sort of care that can lead chaplains and other health professionals to burnout and suffer with moral distress.

The solution lies in focusing on a plan of care that matches the patient's preference and reflects the highest possible quality of life as defined by the patient and family. In order to provide evidence-based care in alignment with patient values and goals, we need well-trained professionals who can provide both generalist and specialist-level palliative care and function effectively as a part of an interdisciplinary team.

In September, the Institute of Medicine released a report titled *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*. The report states, "Many patients also do not receive adequate explanation of their treatment goals, and when a phase of treatment concludes, they frequently do not know what they have received or the consequences on their future health.

In addition, many patients do not receive palliative care to manage their systems and side effects from treatment. Most often this occurs because the clinician lacks knowledge of how to provide this care (or how to make referrals to palliative care consultants) or does not identify palliative care management as an important component of high-quality cancer care."

The only way to bridge the gap from where we are now to being effective as part of (or leaders of) competently trained teams of professionals who are equipped to respond to the complex needs of a population with multiple, long-term illness, is through palliative care training. Whether your goal is to develop a sub-specialty in palliative care or to meet the basic requirements for generalist knowledge there are many educational seminars and programs available.

Recent research by the national polling firm *Public Opinion Strategies* has shown that, once informed about palliative care, 92% of the American public are highly likely to consider palliative care for themselves or their families when they have serious illness. When this demand reaches a tipping point, which it is likely to in the next 5 to 10 years,

will there be enough people trained in palliative care to handle the spiritual needs of the growing number of cases that need attention?

Investing time and money in continuing education can be challenging, but the benefits far outweigh the challenges of finding the time and the income to become certified in the specialty area of [Palliative Care](#). There are cost-effective, online programs now being offered for chaplains that are flexible enough for the working professional to tackle. And if the concept of online learning intimidates, you can feel confident that many of the programs today are very user friendly and include unprecedented 1:1 support of the instructors.

There are many resources to be found at The Health Care Chaplaincy Network to help you choreograph your next move towards specializing in an area of healthcare that is growing by leaps and bounds. Job security is almost guaranteed in an area of care that provides comfort care across all medical needs.

The seriously ill patients you interface with already want and expect the type of services that palliative care provides. Be ready to ride the wave and get the training you need to competently help patients and families live well throughout the course of their illness. It's important to your career and it's even more important to the people you serve.

*Palliative in Practice - Palliative Care: A New Paradigm for Managing Serious and Chronic Illness (via American Cancer Society Cancer Action Network) <http://palliativeinpractice.org/2013/09/16/>.

**Institute of Medicine - Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis www.iom.edu/reports/2013/delivering-high-quality-cancer-care-charting-a-new-course-for-a-system-in-crisis.aspx

***Public Opinion Strategies research poll <http://www.capc.org/tools-for-palliative-care-programs/marketing/public-opinion-research/2011-public-opinion-research-on-palliative-care.pdf>

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Palliative Care in its Infancy Yet, Need Exploding

By Gary Gardia, M.Ed., MSW, LCSW, CT. Curriculum development for CSU Institute for Palliative Care

Palliative Care as a healthcare specialty is, in the grand scheme of things, still in its infancy. That means that we are still learning and growing and in many ways fine tuning who we are and what we do. Change (not unlike all of healthcare) is just standard operating procedure.

As chaplains, social workers and as leaders, we have work to do. It is critical that we continue to hold true to our core values: spiritual needs, service, social justice, dignity and worth of the person, importance of human relationships, integrity and competence, especially as we look at these numbers provided by the Administration on Aging (AoA): http://www.aoa.gov/Aging_Statistics/Profile/2012/2.aspx

- The older population (65+) numbered 41.4 million in 2011, an increase of 6.3 million or 18% since 2000
- Older women outnumber older men at 23.4 million older women to 17.9 million older men
- In 2011, 21.0% of persons 65+ were members of racial or ethnic minority populations
- About 28% (11.8 million) of non-institutionalized older persons live alone (8.4 million women, 3.5 million men)
- Almost half of older women (46%) age 75+ live alone

The statistics go on and on and we know that members of our older population will be requiring care of all kinds in ever increasing numbers. Enter...the critical role of the chaplain. But, I hate to ask, is the role of the chaplain really critical? Let's take a look: Palliative care is defined in part by the following:

- Holistic care, utilizing the biopsychosocial/spiritual model
- Addresses the needs of the patient and her/his family system
- Assists people to design and achieve their best possible experience
- Guides, supports and empowers people through the process of understanding what is important to them in their lives
- Utilizes highly skilled and well-coordinated interdisciplinary teams
- Assures teams are guided by the patient/family centered plan with the goals they have given to us, and...
- Aggressively addresses both pain AND suffering (suffering physically, emotionally, and spiritually)

Eric Cassell describes suffering as distress brought about by the actual or perceived impending threat to the integrity or continued existence of the whole person. He states that suffering can include physical pain but is by no means limited to it.¹

But it is not just “pain and suffering” on people’s minds as they live in the light of serious illness. In addition, people struggle with thoughts of letting go of life and as they look for ways to find meaning in their experience. Hospice and [palliative care](#) can never have a predominant focus on pain and symptom management with the rest of the team serving in a “by-the-way” capacity. That is not who we are and it is not what we promise. All members of the team are necessary for a person to have a true palliative care experience – and all need to be working in concert around a person-centered plan.

It is now critical for chaplains to step up as leaders in palliative care, whether it is raising the bar for more efficient teamwork or at the mezzo level, influencing care nationally and internationally. The goal is to help assure a more consistent approach to care that includes our clinical skill development and best practice approaches.

With this in mind it is exciting to discover that educational opportunities for palliative care and hospice social workers abound. Everything from live intensives to all online programs are available to accommodate diverse learning preferences. [Online programs](#) offer chaplains the flexibility to obtain certificates without ever leaving home and completing modules/assignments while working part or full-time.

So here is my challenge for chaplains:

- **Service** – work on raising the bar for true inter/transdisciplinary practice
- **Social justice** – make a special effort to identify the underserved individuals and populations in your community and reach out
- **Dignity and worth of the person** – never forget that “the person” not “the patient” is who we seek to serve
- **Importance of human relationships** – “problem focused care plans” are not who we are...nor is our approach “diagnose and treat”. This about assisting people to have THEIR best possible experience which includes “opportunities” they might not have identified on their own
- **Integrity** – Our job is to do the best job we can, in every situation, with every person
- **Competence** – it is our responsibility to never stop looking for better ways to serve – to never stop seeking ways to improve/complement our skills
- **Spiritual healing** – help patients to find peace with any situation while truly honoring their traditions, values and beliefs

In the book “Phantom”, author Ted Bell describes a conversation between a young naval cadet and his boxing instructor. The instructor said:

“The ideal fighter has heart, skill, movement, intelligence, but also creativity. You can have everything, but if you can’t make it up while you are in the ring, you can’t be great. A lot of chaps have the mechanics and no heart; lots of guys have heart and no mechanics; the thing that puts it all together, it’s mysterious, it’s like making a work of art, you bring everything to it and you make it up while you are doing it.”²

Learn more on palliative care [courses for chaplains](#).

¹Cassell, Eric J. 2004. The Nature of Suffering, Oxford University Press, New York, N.Y.

²Bell, Ted (2012). Phantom. Harper Collins, New York, N.Y.

For questions on registration and future programs, contact:

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The Death Attitudes Profile Revised as a Tool for Spiritual Care in Hospice

Keith Rasey is a hospice chaplain in Medina, Ohio.

The hospice nurse, Ann, told me, 34 years ago, on May 25, 1977, that Walter Knox, my parishioner, was the first person to die at home with hospice care in the United States. It was an amazing moment for me as I was accepted as a full member of the care team rather than just a sort of modern witch doctor.

Evidence-based care brings up the old dichotomy between science and faith. It is not a completely false distinction, but it is often overdrawn. It is helpful, and perhaps reconciling, to realize that the enlightenment, and the epistemology of science which it spawned, grew out of the careful nurturing of western traditions of religion. I take the long-term perspective. Evidence-based care is just the latest thing.

To paraphrase Mohammed Ali, it may be the latest but that doesn't mean it is the greatest. Still, because I have two degrees in science and only one in -divinity, I recognize the value of evidence-based care while simultaneously maintaining that the spiritual care traditions have equal validity.

My response has been to use the tools of science to refine my spiritual care and document its applicability and effectiveness. I use a psychological assessment tool, Death Attitudes Profile-Revised, to better understand what patients and their loved ones are going through at the end of life. The Death Attitudes Profile-Revised, from here on abbreviated as DAP-R, has been published in peer-reviewed journals¹. It has legitimacy as science in all the ways that science can measure.

It has high alpha coefficients of internal consistency meaning there is a kind of validated, central logic in the attitudes, images, beliefs and feelings about death that it assesses. It has a high content validity meaning that when the same people filled out the DAP-R after a lapse of time that the results were very highly similar. Its components were subjected to principal-components factor analysis in order to determine how much variability there is between each statement in the DAP-R.

This is a way of measuring how closely related or far apart each statement is to the others. The DAP-R was scrutinized for convergent-discriminate validity which is a way of making sure statements that are supposed to be related are and those that aren't related are not. It more than passed.

The DAP-R measures five domains or landscapes of death:

- 1) Approach Acceptance--acceptance of the approach of death and the hope for a better after life
- 2) Escape Acceptance--the desire to leave this painful world behind
- 3) Neutral Acceptance--the belief that death is just a part of life
- 4) Death Avoidance—denial; and 5) Fear of Death

Usually there is a mix of landscapes in each person's journey so the manners in which each of these domains interacts becomes important in structuring individualized, sensitive and relevant spiritual care.

I use it informally, rather than formally, administering it to patients and or loved ones. If a patient shares they have a great fear of dying, for example, I will let a long period of silence unfold and then, if it feels right, I will offer another statement from the fear landscape such as: -It must feel pretty grim.

We know all the statements, or landmarks, in each landscape are related and likely present because of the high alpha coefficients of the DAP-R statements. Because of the high internal consistency of the DAP-R, I just use one statement from each landscape to informally assess where the patient/loved ones are in their journey. It helps me to orient myself to the terrain they are traveling through so they know I am present with them and can see the same landmarks they are experiencing.

For example, Edna was looking out the window when I came to see her in the hospital at the end of her life. After a period of silence in the conversation, she noted that the trees were losing all their leaves. The seasons are changing, was my response. She nodded. It was clear to me this conversation was not about the trees. I waited to see where she might be going with this. "Death is a natural aspect of life," I finally offered. She agreed saying that she had a long life and reminisced about all the people who had gone before her who she hoped were waiting for her on the other side.

You are looking forward to a reunion with your loved ones, was my response. "Yes," she said. "It has been a long time since I have seen some of them and it is getting near my time to go home. Your season of change has come?" She nodded and wistfully replied, "Just like the trees."

In this conversation I used statements from the landscape of Neutral Acceptance and Approach Acceptance to walk with her through the particular landmarks of her experience. The feeling between us was that we were walking together, arm in arm, through the same experience.²

The DAP-R helps me to individualize my spiritual care and document that. I will make a note in my visit record that the patient/family expressed ideations and/or feelings that indicated they were experiencing death as a particular kind of landscape or landscapes.

I will also note how I tailored my interactions in hymns, prayers, reading, conversations, etc., to be present with them as they travel through the landscapes. It provides a means for me to scientifically validate that, as death becomes salient, I am present with the patient and his or her loved ones rather than an outside observer. It may even offer an opportunity, after death, to find out if the family/loved ones experienced our care as being with the patient in a deep and quantifiable way.

Given that the Centers for Medicare and Medicaid (CMS) is requiring hospices to document quality care, this may provide spiritual care givers a way to document their effectiveness in a manner that the managerial, statistical process types can understand. I realize it is sometimes difficult for spiritual care personnel, usually humble non-assuming persons, to withstand the aggressive assaults of those who are driven by efficiency. Use the tools of science to document the efficacy of spiritual care. Humans usually cannot comfortably leave this world without it.

I wonder if other hospice chaplains have developed or discovered any quality measures that go beyond just noting that a conversation about the availability of spiritual care was held.

References: Paul T. P. Wong, Gary T. Reker and Gina Gesser, -Death Attitude Profile-Revised: A Multidimensional Measure of Attitudes Toward Death,|| Death Anxiety Handbook: Research Instrumentation and Application, ed. Robert A. Neimeyer (Washington D.C, Taylor and Francis, 1994) 121-146. (see also Omega: Journal of Death and Dying 18:2). -The Landscapes of Our Patients' Journeys by Keith A. Rasey. Available on e-publishing platforms, such as Kindle, or from Amazon or from Create Space.

[Palliative Care Chaplaincy Specialty Certificate](#)

The California State University Institute for Palliative Care and HealthCare Chaplaincy Network – two leaders in their fields – have created a new online-certificate course to support chaplains and other spiritual care providers with the delivery of palliative care to patients and their families in hospitals, hospices, long-term care facilities, and elsewhere. This is a very popular and successful course so new cohorts are being started frequently. Check our website for details. Here are some comments from chaplaincy participants

“Practical applications - I have already used some of the homework in my setting - very helpful!”

“Having such a variety of very well-known and experienced professionals providing materials for each segment. Excellent readings!”



Living Longer With Palliative Care

By Helen McNeal, Executive Director of the California State University Institute for Palliative Care at CSUSM

It is estimated that 1.5 to 1.6 million patients in the United States received hospice or palliative care services in 2012. Anecdotal accounts indicate that many more who would benefit by this care did not have access to it or had to wait so long that services were provided only during their final few days of life.

Considering that 90 percent of American adults live with a chronic illness before they die, this is an important issue. While some manage well on their own with minimal assistance from healthcare professionals and/or friends and family, others may need more hands-on care and supervision, particularly as their disease burden becomes heavier. We cannot forget that as the population ages, more people with multiple illnesses or conditions will require more supportive care.

Doctors, nurses, social workers, chaplains, and allied health professionals play a vital role in educating the public about palliative care and the fact that it is much more than just hospice. Sharing the same philosophy and patient and family-centric approach, palliative care is the broader umbrella of care for those with a serious or chronic illness and goes hand-in-hand with curative treatment.

Palliative Care is care that may be given while someone is receiving treatment that they hope will either cure them of their illness or prolong their life. Hospice on the other hand is the intensive end-of-life care offered to patients who are projected to have less than six months to live and who have elected to discontinue curative treatment.

The other role that health professionals, in particular physicians and nurses, play is in referring patients to palliative care. When we explore the reasons why health professionals are not referring their patients to palliative care, many reasons surface. Some of these reasons include the fact that services are not available in their area or that they are afraid of “losing” their patient. The first reason is valid; the second is not, as most palliative care is consultative. But the reason that is hardest to understand is when providers do not refer because they believe that a palliative care referral means giving up on life. In fact, the opposite is true.

As noted above, palliative care goes hand-in-hand with curative treatment. Most importantly, as an article, published in *The New England Journal of Medicine* (NEJM) in August 2010 highlighted, researchers have found what many had suspected for some time, that receiving palliative care actually helps patients to live longer.

The researchers evaluated the utility of early palliative care for patients with metastatic non-small-cell lung cancer. Newly diagnosed patients were randomly assigned to either

early palliative care in addition to standard cancer care or cancer care alone. The results showed that not only did the patients who received palliative care have a better quality of life; they also lived longer, with a median survival of 11.6 months compared with 8.9 months in the group that did not receive palliative care. Since this article was published, other smaller scale studies have duplicated these findings.

There are many benefits to the health care system of palliative care because it reduces readmissions, results in few admissions for futile care, and in general, reduces costs associated with serious illness and end of life care. But, as important as reducing costs is, it pales besides the human imperative to enhance the quality of life of those we care about. And, no one would disagree that enabling those we love and care for to live as long as possible with the highest quality of life possible is a higher order goal.

Palliative care is an approach that requires close teamwork from healthcare professionals, from nurses and physicians to social workers, pharmacists, dietitians, chaplains, counselors and many more.

Thanks to this teamwork, the needs of the patient and family can be assessed, understood and addressed. And, thanks to this teamwork, palliative care professionals are helping patients with serious and chronic illnesses live longer and enjoy their lives more. Isn't it time that all of us who are health care professionals set aside our preconceptions and control issues, make the necessary referrals, acts as teams and focus on the best for patients and their families?

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Making a Difference: Speaking the Language of Recovery

Elizabeth Jones, M.Div., CADC, serves part-time as Chaplain at Swedish Covenant Hospital in Chicago.

I work part-time at a hospital on the north side of Chicago. I can work either overnight shifts or day shifts as needed by my pastoral care department. My fellow chaplains are aware that I also have a certification in Alcohol and Drug Counseling. Recently, I was scheduled for a day shift. I finished all the duties assigned to me by mid-afternoon and I went to one of the full-time chaplains to ask whether I could perform any visits for her. She serves on the ethics committee at our hospital, and since she had an extended ethics consult earlier that day, she appreciated my offer of help.

Accordingly, I visited several patients on one of her regularly-assigned floors. I had a particularly meaningful interaction with one patient that afternoon.

A fair number of patients are admitted to our hospital each week for difficulties involving drugs and/or alcohol. This patient (whom I'll call "Pat") was causing some agitation among staff. I do not always stop by the nurse's station on each floor where I visit, but I did on this afternoon. I heard several staff members make comments. I mentioned that I was intending to visit "Pat." This relieved the staff. On the way to the private room, I checked the short reason for admission on my patient list. I noticed a description of an overdose. Interesting. I looked forward to the visit.

I need to insert a brief sidebar to let my colleagues know something about addicts and alcoholics. (Some are quite aware of this already.) This is a very challenging patient population. Often times they can be changeable, difficult, in denial, manipulative, even charming.

There are those with a dual diagnosis, with both mental and physical difficulties. Addiction is definitely a medical-psycho-social disease. I might add that I also consider addiction very much of a spiritual disease. All in all, I feel called to minister to drunks and druggies and to those in recovery, as well as their loved ones, those who qualify for Al-Anon.

Back to the designated patient, Pat. The door was closed all the way. (This is not usual for our hospital.) I knocked, paused a moment, opened the door, and said "Hello." When I entered the patient's darkened room, I noticed Pat sitting up leaning back against a raised bed. From the facial expression and general body language, Pat seemed to be defeated and depressed. I introduced myself as a chaplain, smiled, and said I wanted to pay a friendly visit. The patient looked at me cautiously, but with a spark of interest.

The story Pat told was not a happy one. There were difficulties with employment, with

extended family, and with continuing, chronic health issues. However, Pat also told me about some personal success. Pat was a poly-substance user, clean and sober from two substances for a number of years. I affirmed this sobriety, and mentioned to the patient that this was tremendous! However, the third substance was the really difficult one, and that was why Pat had come back into the hospital. An overdose of this particular substance—especially after a period of extended non-use—caused the patient to need hospital detoxification.

We spent the next half hour in deep conversation. I met Pat where that patient was. I did not sugar coat or use spiritual or clinical language. I think that was one reason I connected so well with Pat—I used the language of recovery. I wanted to continue to affirm the patient's continued sobriety. I also asked about a sponsor. Yes, Pat has had the same sponsor for years. That sponsor knew exactly where the patient was, and strongly encouraged this hospitalization. Pat mentioned to me—ruefully and lovingly — My sponsor kicks my butt, on a regular basis.

One major part of why this patient was so depressed and disillusioned with the hospital admission was the treatment Pat had received. According to Pat's report, the staff had been less than attentive. It is true that our hospital sees quite a number of alcoholics and addicts (especially in the Emergency Department). However, Pat was trying to get clean and sober, and being rigorously honest about the drug use.

Rigorous honesty is one of the hallmarks of recovery. While actively using, alcoholics and addicts are certainly not honest. They can habitually lie to employers, spouses, friends, and especially themselves. When someone initially comes into Alcoholics Anonymous or Narcotics Anonymous (for example), one of the first things they often learn about is the concept of rigorous honesty.

Even people with years of sobriety need to be regularly reminded about this bedrock concept. That was one reason I was so impressed with Pat. Pat was striving to be rigorously honest. That was why Pat freely reported the overdose to the ED doctor and nurse, as well as the resident on the floor. And Pat's sponsor was fully in support of this rigorous honesty.

This patient asked me whether I would pray at the end of our extended visit. Of course I did! We had an excellent time of interactive prayer and we closed with the Lord's Prayer, just the way that those in recovery close their meetings. I know that I truly made a difference in this patient's time in the hospital because Pat emphatically told me so. When I left the room I felt energized and uplifted. Pat did, too.

Psycho-social support groups (such as Alcoholics Anonymous, Narcotics Anonymous and Cocaine Anonymous) can be effective in the long term. These groups are excellent sources of camaraderie and support for the abusing person, if they are willing to consider stopping substance use.

For additional information:

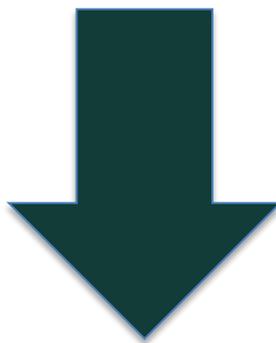
- 1) <http://www.drugabuse.gov> for further information regarding alcohol, drugs or specific illegal substances
- 2) www.aa.org for further information regarding alcoholism. There is a solution
- 3) www.na.org for further information regarding drug addiction. One day at a time.

Many articles in this eBook are courtesy of PlainViews®, the preeminent online professional journal for chaplains and other spiritual care providers. PlainViews® enriches your professional practice with stimulating content and dialogue that arrives in your in-box twice a month. [Learn more.](#)

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Get the specialized training that will strengthen the quality of your professional practice and the credentials that will increase your value to your organization.

[The California State University Institute for Palliative Care](#) and HealthCare Chaplaincy Network—two leaders in their fields – have created a new online certificate course to support chaplains and other spiritual care providers with the delivery of palliative care to patients and their families in hospitals, hospices, long-term care facilities, and elsewhere.

Created by a team of national experts, the nine-week curriculum strengthens the quality of palliative care by providing a foundation of knowledge and practice built on the 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.

[HealthCare Chaplaincy Network](#) is the leading national multi-faith organization for the integration of spiritual care within health care and palliative care through scientific research, professional education and clinical practice.

In this groundbreaking program participants will receive the training on:

- Educating their respective communities about palliative and end-of-life care in order to prepare them to overcome obstacles to considering palliative care and to make informed decisions about care for themselves, family members, and friends
- Becoming effective and articulate administrators of spiritual care programs in palliative care and hospice settings
- Creating and sustaining programs that meet both human and institutional needs
- Developing the skills needed to become leaders in the field of Palliative Care Chaplaincy through conceptual tools for analyzing and constructing innovative solutions to challenges facing the timely delivery and reception of the multiple dimension of palliative care, especially spiritual care

PROGRAM DESCRIPTION

The program of study is designed to benefit both Board Certified and non-board certified chaplains working or preparing to work as palliative care chaplains as well as other health care providers interested in the importance of spirituality as an essential domain of palliative care. For Board Certified Chaplains, the coursework is specifically designed to support learning towards developing the competencies required to apply for specialty certification by their professional association.

The curriculum builds essential knowledge base for professionals who deliver spiritual care, in a palliative care context, to improve the quality of care delivered to patients and families and meet accreditation requirements for expertise in the area.

The coursework is a fully online, text-based program, delivered in a continuously available and easily accessible format that allows chaplains greater flexibility in balancing work responsibilities with furthering their education.

The program comprised of the following nine individual modules developed by experts in the palliative care. The program will be taught by HealthCare Chaplaincy Network faculty.

- **Module One:** History and Philosophy of Palliative Care
- **Module Two:** Spiritual, Existential and Emotional Issues
- **Module Three:** Family Systems and Group Facilitation
- **Module Four:** Ethics and Common Palliative Care Issues
- **Module Five:** Social and Cultural Influences on Palliative Care
- **Module Six:** Chaplain Leadership as Mentorship
- **Module Seven:** Ethical/Critical Reasoning Using Cases
- **Module Eight:** Professional Wellness While Working in Palliative Care
- **Module Nine:** Palliative Care, Science and Religion Together

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Participants will be expected to complete one module each week, with the entire program taking a total of nine weeks. The program is asynchronous, which allows participants to complete the coursework on their own time with assignments due at the end of each week. Participants may expect to spend 8 to 10 hours a week on the reading and assignments for the course.

Course work includes activities designed to enhance learning through questions/answer sessions, interactive case studies, opportunities for students to apply knowledge in virtual palliative care contexts, and the ability to interact with fellow participants in an online community cohort.

All participants that proficiently complete the coursework will receive a certificate of completion from the California State University Institute for Palliative Care at Cal State San Marcos and HealthCare Chaplaincy.

Prerequisites

The program of study is designed to benefit both Board Certified and Non-Board Certified chaplains working as, or preparing to work as, palliative care chaplains, as well as other spiritual care and health care providers involved in or interested in spirituality in the field of palliative care. While there are no formal pre-requisites for taking this program, enrollees are encouraged to have prior experience with or exposure to spiritual care in a health care setting.

For nurses, social workers, chaplains, physicians and other health care professionals

The California State University Institute for Palliative Care at CSU San Marcos has an ongoing series of professional development programs designed to help health care professionals enhance their skills and integrate the latest evidence-based palliative care practices. These online and offline programs include a robust slate of specialist certificates, workshops, and fellowships.

Check our website for up-to-the-minute updates on program costs and logistics. Many of these programs provide Continuing Education Units (CEUs). Visit www.csupalliativecare.org for more information.

Palliative Care Chaplaincy Specialty Certificate

This is a very popular and successful course so new cohorts are being started frequently. Check our website for details.

“The most valuable part of the course was my group and all the interactions we had.

People responded to one another then responded to the responses. There was much learning that was involved in all this for me. I also liked all the readings!”

“Practical applications - I have already used some of the homework in my setting - very helpful!”

For questions on registration and future programs, contact:

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