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

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A LETTER FROM REV. ERIC J. HALL



Rev. Eric J. Hall
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Most of us know by now that nothing comes handed to us on a silver platter. We have to work hard to get results. And when we step out into new territory, we have to power up even more. A challenge, yes. But the endgame can be career changing, even life changing.

I say all of the above as a motivational message because there's an opportunity before us now that can significantly change the perception of and payment for spiritual care services.

As background: One of the fundamental changes in today's health care system has been the shift from the basic health care payment model (aka "fee for service") to value-based purchasing. Rather than pay a health care provider a set fee for the delivery of a test, treatment, or other service, the new system bases payment on the extent that the service is deemed high quality and cost saving. Thus, "high quality," and its definition and measurement, and "cost savings" are what count most.

The Medicare Access and Children's Health Insurance Program (CHIP) Reauthorization Act (MACRA) passed by Congress with overwhelming bipartisan support in 2015 establishes, in part, new ways for the federal government to reimburse hospitals, doctors' groups, or other providers for care to Medicare beneficiaries. MACRA includes two alternative strategies for raising quality and lowering cost: the Merit-Based Incentive Payment System (MIPS), in which a provider chooses among many quality measures to report on; and the Alternative Payment Model (APM), in which the provider assumes accountability for providing a certain set of patient-centered services at a certain cost.

Here's the opportunity: While providers get paid for delivering quality care and/or an outcome that saves money, there is flexibility on how the outcome is attained. For the most part, providers can provide the service any way they choose.

So, for example, if a chaplain can provide a particular service more effectively and efficiently (i.e., at less cost), then the provider can hire a chaplain to provide the service. Under MIPS, chaplaincy care can easily influence many of the reporting quality measures, such as patient satisfaction and having advance directives. And, with APM, if the inclusion of chaplaincy adds to quality and cost savings, it can be among the services for which the plan is accountable.

Here's the challenge: For spiritual care to be included, we must clearly demonstrate that chaplaincy contributes to the buzzwords, high quality and cost savings. To do so, we have to garner a trifecta of achievements. We must have data to substantiate every claim we make. We must agree on the outcomes we can be and want to be accountable for. And we must clarify what services we will be accountable for and put a price tag on what we do.

For the first time in the health care arena, we have a viable opening to further integrate spiritual care into health care—and, moreover, to link the word "reimbursement" to chaplaincy. Getting there will take education, discussion and advocacy—proving and raising awareness of our worth. Are you up for it? I daresay that it will be up to all of us to give it our all.

Thank you for caring for the human spirit,

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



Enacting Family-Centered Care When Social Separation Occurs

By Darlene Barkman, Rachel Biblow, MSW, Colleen G. Coyne, MHA, and Julia Shaklee Sammons, M.D., MSCE

Children's Hospital of Philadelphia (CHOP) prides itself on family-centered care and strives to ensure that all families are included in the plan of care for their children. This includes enabling a parent or guardian to sleep at his or her child's bedside during an inpatient stay. But what happens when a potential infectious outbreak occurs and it is no longer safe to have a family member at the bedside? How can an organization maintain its commitment to family-centered care during extreme patient care scenarios?

These are some of the questions CHOP faced in late 2014 when the deadly Ebola outbreak reached the U.S. The crisis triggered teams to think creatively for extreme scenarios when concerns about safety and potential additional cases of the virus required separation between patients and their loved ones. It challenged CHOP to develop a response protocol—one that continues to be in place for other scenarios when a time of social separation may occur.

As a designated treatment center

for Ebola, CHOP worked closely with government agencies to design and deliver care. This included tight coordination of logistics ranging from defining specific locations within the hospital for care delivery and protocols for safe transport, to supporting the loved ones of patients suspected of having Ebola. All of these components required a team of experts and careful consideration of the necessary steps to keep patients, family members, and providers safe during this event.

At CHOP, it also meant finding ways to support patients and their families during a very frightening experience. In addition, it required the hospital's skilled and compassionate teams to find creative solutions for connecting families with their loved ones even when physical contact was not possible.

CHOP, which is the nation's first freestanding hospital devoted exclusively to the care of children, is known for innovation. Its core philosophy embraces family-centered care.

However, this situation was new for all those involved and incredibly

difficult. How could CHOP possibly separate a family from a child in such a potentially dire circumstance? The focus was on the child and making sure that clinically all the bases were covered. But due to safety concerns stemming from the contagious nature of the disease, CHOP's routine model for partnering with caregivers at the bedside was quickly challenged.

The hospital designated a task force that immediately began to find ways to meet these unprecedented circumstances. It successfully accomplished its goals by enlisting the help of patients and their families in addition to health care professionals and support personnel. The task force included clinicians, senior leaders, social workers, child life specialists, chaplains, interpreters, information systems specialists, ethicists, transport team members, and family consultants.

CHOP's family consultants are parents who are paid as staff specifically to share their experiences and guide the organization on key decisions that impact patients and their families. The family consultants

were part of the task force from the onset and worked side by side with the rest of the work team to think through the plans.

The execution of these creative plans needed teamwork, compassion, and skilled execution since the risks were high. The collaborative efforts of the multidisciplinary team assembled had to prevail. It was truly an all hands on deck time, calling in resources from other departments. The process design of managing the situation could not just include the clinical interactions.

The team started with the various scenarios of what might happen and began to chart out plans to address these situations as well as opportunities to support the patient, family, and care team during extreme events.

The design included planning for how a family might arrive at the hospital, such as via the emergency department, and be escorted to a designated area with the least amount of stress on the family as well as those around them; how a family would interact with their child as tests were being conducted; necessary safety protocols for patients and their families; and creating important talking points for other families who may have already been in the hospital and begin to worry about “specialized” care areas or how CHOP would keep their children safe while addressing Ebola.

As part of the overall process, the CHOP team conducted table top exercises and simulations of potential clinical and patient/family interactions. It gathered for drills around protective personal equipment, safe transport, and care delivery, as well as how to utilize technology to provide support to the patient by facilitating communication between the patient and his or her family.

For each step of the potential scenarios and processes, the team relied on the expertise and guidance of the family consultants for helpful language for the clinical staff to utilize with the family going through the difficult situation. Through the collaborative process, the CHOP team



redefined the ways clinical support services, such as social work, child life, and chaplaincy, would be able to interact with the patient and families since traditional methods would not be possible.

To facilitate communication, the team created job aids and educational materials for staff and families to help guide everyone through the challenging circumstances. By having tablets available, the family would be able to verbally connect from outside the room and potentially do face-to-face video chatting. This would be useful not just for a conversation and checking in, but it also would allow the family to read the child a book, play music, or engage in interactive games. In a time of difficulty, allowing these small comforts for the family would help tremendously.

CHOP's spiritual care team also prepared to be a continuous presence at the point of care and across the hospital to provide support for patients, families and staff. It was clear that the unprecedented set of circumstances could cause extreme emotions and challenges.

Ultimately, the hospital felt prepared, yet hopeful that the plans would not need to be enacted. The lessons learned during the Ebola crisis translate to other potentially life-threatening infectious diseases. By developing the response protocol for patient/family interactions, the clinical

teams and support services will be able to be more prepared in the future to address the clinical and emotional needs of patients and their families.

The ability for CHOP to overcome challenges is part of its DNA. CHOP reinforced its unwavering commitment to partnering with patients and families, even during the most challenging of circumstances. With fears of Ebola and outbreaks in 2014, the CHOP team did just that—and now is prepared to do so again should, unfortunately, similar circumstances arise in the future.

Darlene Barkman, Rachel Biblow, MSW, Colleen G. Coyne, MHA, and Julia Shaklee Sammons, M.D., MSCE, are all employees of Children's Hospital of Philadelphia (CHOP), Philadelphia, Pa. Barkman, the mother of two daughters, is a family consultant. Biblow is the senior director of patient and family services, where her responsibilities include overseeing operational activities for family-centered care programming, family relations, and spiritual care. Coyne is a senior advisor for patient and family experience. Sammons is medical director and hospital epidemiologist.

An Update From Down Under: *Spiritual Care Is on the Move*

By Cheryl Holmes



"You have to move, you cannot stand rooted in the grave."

Thus writes Australian poet Peter Steele in his book *"Marching on Paradise,"* and it is true of spiritual care in Australia. The field is taking hold of and creating opportunities for reform. Spiritual care is on the move.

Some major developments have occurred in the past two years, and others are in progress. As a result, spiritual care in health care in this country is becoming more defined and professional.

One of the most significant developments came in August 2016 with the introduction of the National Guidelines for Spiritual Care in Aged Care. It was made possible through a partnership between Meaningful Ageing Australia and Spiritual Health Victoria (SHV), and was funded by a federal government grant.

Since 2009, SHV had sought to develop best practice guidelines for spiritual care in a number of sectors at a state level. However, since funding for aged care is managed at a national level, it was not until the birth of a national organization for spiritual care in aged care in 2012 that a federal grant became possible.

The guidelines advocate spiritual care as the responsibility of all aged care staff, pastoral care practitioners and chaplains, and faith representatives, and recognize the place of spiritual care practitioners as the spiritual care experts. They place spiritual care firmly within a number of key principles, including the need for an organization-wide approach to spiritual care and the centrality of human relationships to any understanding of spirituality.

Spiritual care is increasingly being acknowledged in other ways. For more than a decade, practitioners in Australia have been encouraged by the national organization (initially the Australian Health and Welfare Chaplains Association and more recently Spiritual Care Australia) to use the ICD-10AM/ACHI/ACS Ninth Edition pastoral intervention codes for reporting. The National Centre for Classification is currently reviewing these codes to ensure they continue to align with health practices.

On July 1, 2017, the Australian Consortium for Classification Development will implement ICD-10-AM/ACHI/ACS Tenth Edition, changing the language from "pastoral interventions" to "spiritual interventions." This reflects the language commonly used in government documents and the movement away from language that holds specific religious connotations.

Earlier, for example, in 2015, the Australian Commission on Safety and Quality in Health Care released the National Consensus Statement: essential elements for safe and high-quality end-of-life care, which identified care for a patient's psychosocial, cultural and spiritual needs as a guiding principle.

Spiritual Care Australia and state-based spiritual care organizations continue to encourage practitioners to use these codes in patient records since health information coders collect and publish the data. While currently there is no funding tied to spiritual care interventions, this data collection offers evidence of the provision of spiritual care services and the increasing integration of these services

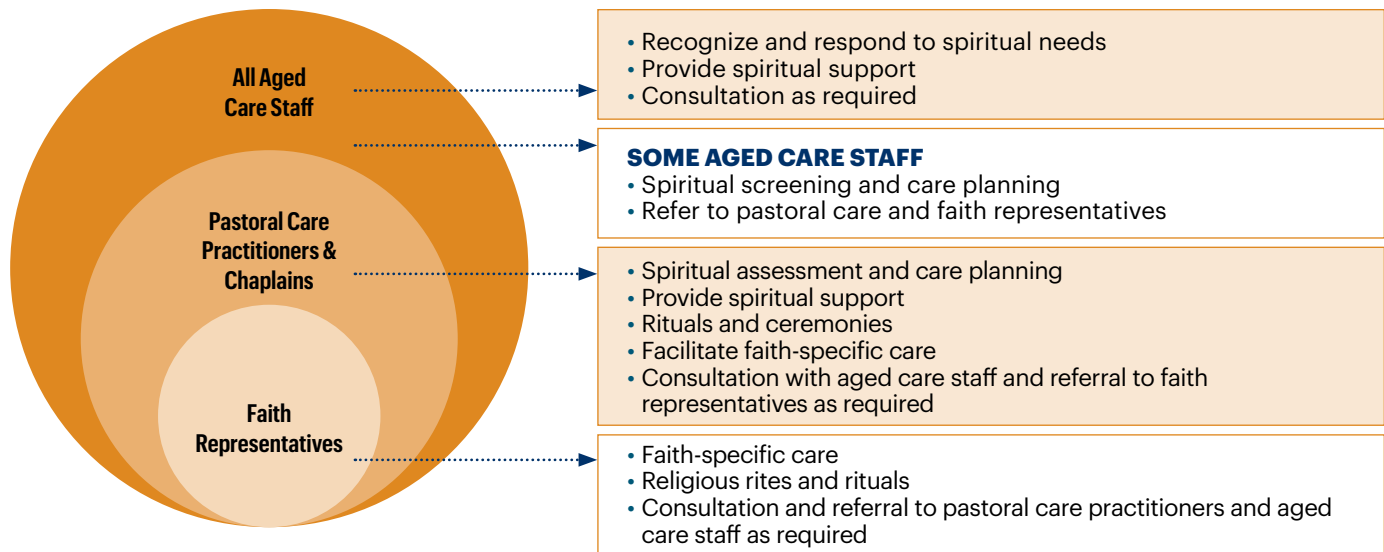
in Australian hospitals.

Moreover, the interventions also provide a national precedence for recognizing spiritual care as belonging with allied health. (Along with the four main spiritual care intervention codes, there is a general "allied health intervention: spiritual care" code. For other allied health professions there are similar codes—e.g., "allied health intervention: occupational therapy.")

Throughout the six states and two territories that make up Australia, there are a number of state- and territory-based chaplaincy/spiritual care organizations that liaise with their respective state governments and local faith communities to coordinate approaches to spiritual care. This results in a range of models for education, delivery, funding, and even the naming of spiritual care—i.e., chaplaincy, pastoral care, or spiritual care.

In Victoria, a state in southeast Australia, the Victorian Department of Health and Human Services recognized spiritual care as an allied health profession in 2016. The implications of this status will take some time to emerge. This recognition directly resulted from SHV's release of several significant new framework publications, which were intended to firmly set spiritual care within a professional context in health services and have since increased the profile of spiritual care in this sector.

Victoria continues to move toward a professional model that ensures that spiritual care is available in response to identified needs. This includes accessibility for all patients whether or not they identify with a faith tradition. It is essential given both an increasing multi-faith population and more people



with no religious affiliation in Australia.

However, this is not the same situation elsewhere in this country. While there has been a national Australia-wide award (detailing employment terms and conditions) since 2010 recognizing “pastoral care” as one of the common health professions, Australia’s states continue to apply state-based awards for employment, and there is huge disparity in employment conditions and arrangements for spiritual care practitioners. In some states, there is continued advocacy for a model that keeps employment and accountability tied directly to the churches.

Further integration of spiritual care in health care may be achieved through Australia’s first National Consensus Conference, which will be held June 1-2, 2017. The upcoming conference is the result of several developments.

First, the Community of Practice (Health), a group under the auspices of Spiritual Care Australia, began to meet annually in 2010 to identify common issues and explore possibilities for collaboration. While the issues were easily identified every year (e.g., lack of recognized education pathways; no consistent models of delivery and funding; lack of national standards; and multi-faith challenges), it was more difficult to pinpoint a way forward.

In 2014, Spiritual Care Australia’s release of the first National Standards of Practice marked a significant

advance. Then, in 2015, inspired by U.S. and international consensus conference experiences, the Community of Practice agreed to hold a consensus conference to work toward a consistent approach to the delivery of spiritual care in Australian hospitals.

Two years in the making, the National Consensus Conference seeks to bring together key health influencers, researchers, administrators and practitioners to guide national agreement on enhancing quality and safety in the health sector.

In preparation for the conference, Spiritual Care Australia and SHV undertook a survey in November 2016 to explore attitudes of people in the health sector about the role of spiritual care in health.

The survey included statements based on the Quality Indicators document for spiritual care developed in 2016 by an international panel convened by HealthCare Chaplaincy Network. It also had a number of open-ended questions—e.g., What are the barriers to the inclusion of spiritual care in health?—and it collected some basic demographic information.

The results from the survey, which was closed in February with 499 responses, will provide some rich data to the conference. Early analysis of the results show strong support for the Quality Indicators. Some of the barriers to the inclusion

of spiritual care were reported as lack of understanding about terminology and roles, and lack of resources and funding.

While there has been some significant shift toward a recognized professional model of spiritual care in Australia, there is still some way to go before spiritual care is fully integrated into the country’s health care system. Currently, a variety of people with a wide range of capabilities and competencies provide spiritual care. If spiritual care is an essential component of safe and quality care, there needs to be a consistent approach to education and training, delivery and funding of spiritual care across the health system.

With the latest developments and those on the drawing board, the hope is that Australia is moving toward that reality.

CHERYL HOLMES, of Melbourne, Australia, is the chief executive officer of Spiritual Health Victoria in Victoria, Australia. Holmes is also convenor, Working Group for the National Consensus Conference. She is the recipient of an Order of Australia Medal for her spiritual care roles in the health sector. Holmes sat on the international panel that developed the Quality Indicators document.

It's Time to Build on Various Endeavors to Advance Spiritual Care

By Rev. Eric J. Hall

If we want to continually strive to do the best for our patients and their families, the field of spiritual care cannot sit still. We must keep moving forward, generating new knowledge, new policies, and new best practices.

Along these lines, HealthCare Chaplaincy Network (HCCN) has prided itself on holding an annual educational and research conference that participants have referred to as transformative. This year's 4th Annual Caring for the Human Spirit® Conference, held in Chicago on March 13-15, was no different: it included the release of major initiatives to advance spiritual care.

Building the Knowledge of Interdisciplinary Team Members

Further incorporating spiritual care into health settings means promulgating that all members of interdisciplinary teams should provide spiritual care, to varying extents. To reinforce this, on the first morning of the conference, HCCN and its affiliate, the Spiritual Care Association (SCA), announced publication of the first evidence-based white paper on the integration of spiritual care in nursing practice, entitled "Spiritual Care and Nursing: A Nurse's Contribution and Practice."

The white paper highlights that nursing has long been associated with spirituality and meaning making—as exemplified by such well-known nurses as Florence Nightingale and Dame Cicely Saunders. Both despite this history and in light of it, it is time to reinforce nurses' valuable contribution to spiritual care and build on it, especially given today's increasing recognition that whole-person care and patient-engaged care rely on multiple disciplines.

The document's release couldn't have been timelier. HCCN designed the 2017 conference to mirror this interdisciplinary viewpoint, expanding the agenda beyond professional chaplains to offer workshops of specific interest to nurses and social workers. Attendees reflected multiple disciplines, including nurses.

With contributions by SCA's nursing advisory board and chaplaincy leaders, the new white paper is meant

training and education around providing spiritual care to their patients, and often have even less comfort attempting to do so."

At the same time, while most patients and families do not anticipate in-depth spiritual support from their nurses, a high percentage of patients have expressed a desire for providers, including nurses, to ask about and potentially address spiritual and religious concerns.



READ THE WHITE PAPER

"Spiritual Care and Nursing:
A Nurse's Contribution and Practice,"

www.healthcarechaplaincy.org/spiritualcare/nursing

to help guide the field—to empower nurses to better integrate basic levels of spiritual care into their practice, raise their comfort levels in addressing spiritual issues, and understand when to refer to professional chaplains to provide in-depth support.

According to academic studies cited in the report, many nurses recognize their role in caring for their "patients in their entirety . . ." Yet, "most nurses have had minimal

Among the questions explored in the white paper are: What can a nurse do to address the spiritual needs of a patient or family member? How is spirituality the same or different from religion? When should a nurse refer a patient or family to a professional chaplain? Is it ever ok to pray with a patient, or to share the nurse's own faith and religious resources?

I repeat here what one of the paper's contributors said about the



value of this document for her nursing colleagues. "This paper is a tool to help nurses more effectively contribute to providing better integrated spiritual care," said Cristy DeGregory, Ph.D., RN, a gerontologist and clinical assistant professor at the College of Nursing, University of South Carolina, who presented a nursing-related workshop at the conference.

"We often think spiritual care is only necessary at the end of life or reduce it to the screening assessment done upon admission," DeGregory continued. "But it is important to find ways of extending spiritual care and recognizing the potential importance for all patients."

Building a Collective Voice for Advocacy

In any field, it often takes a loud, collective voice to trigger legislative change. With that in mind, at the conference, HCCN introduced a petition spearheaded by HCCN and SCA that calls on Congress "to recognize spiritual care as a key aspect of whole-person health care; and to support and facilitate expanded access to optimal spiritual care and resources across health care settings."

Making our case, the petition notes that a significant body of evidence supports the efficacy of spiritual care as a value-added service in health care; authoritative bodies, including the American Medical Association's House of Delegates, emphasize the inclusion of spiritual care in health care; and patients and family members speak to the merits of spiritual support.

The initiative builds on my meetings earlier in the year with staffers of key bipartisan legislators, intended largely to raise awareness of spiritual care. That was a first step. Now, especially in today's unpredictable health care environment, it is time for this unprecedented call to action for consumers and health care professionals to send a strong message to Congress that "spiritual care matters."

The petition has struck a chord.

Soon after we posted it on Change.org, a popular mobilization website, signatures began rolling in, and backers began adding powerful messages of support.

One chaplain wrote: "I'm signing because I believe that as a chaplain working in health care we can no longer ignore the role we play and the impact we have regarding patient outcomes and satisfaction."



SIGN THE PETITION

www.SpiritualCarePetition.org

Other comments alluded to possible upshots resulting from our rallying cry. Here are two examples:

- "Do not cut money for chaplains. We need whole-person care when people are sick and most in need of care and support."
- "Chaplain services ought to be reimbursed just as other medical services are reimbursed through medical insurance companies."

Separately, we are encouraging the public to contact their U.S. senators to influence legislation related to the inclusion of chaplains on interdisciplinary health care teams—a topic I also raised in my recent congressional meetings.

Specifically, in the last session of Congress, bipartisan leaders of the Senate Finance Committee introduced S. 3504, the Creating High-Quality Results and Outcomes Necessary to Improve Chronic (CHRONIC) Care Act of 2016; on April 6, 2017, the legislation was reintroduced (S.870), largely unchanged, in the current Congress. Of interest is section 502, which requires the Government Accountability Office (GAO) to conduct a study on the formulation of a comprehensive plan of longitudinal care for Medicare beneficiaries with serious or life-threatening illnesses, which includes an examination of interdisciplinary care teams that,

as defined by the legislation, "may include a chaplain, minister, or other clergy ..."

Given the importance of spiritual care to individuals facing chronic conditions and assessing end-of-life options, we urge the senate sponsors to further refine the CHRONIC Care Act by changing the word "may" to "shall." This would ensure that spiritual health will be considered as part of

the GAO's study. Moreover, it would mark another step toward inclusion of spiritual care and enhanced overall health care.

Pounding policy makers with our message can pave the way for change. Let's keep it up!

Building on the Chaplaincy Taxonomy

An important milestone in the field of chaplaincy occurred on the evening of March 14: the Chaplaincy Taxonomy Review Council held its inaugural meeting to craft its mission, goals, and next steps. Now formally established, the Chaplaincy Taxonomy Review Council is an inter-organizational, international body promoting the use of standardized language for chaplaincy interventions and outcomes.

The council will build on and improve the Chaplaincy Taxonomy, which was developed during the HCCN–The John Templeton Foundation Chaplaincy Research Program, "Staking a Claim: Setting the Strategic Research Agenda for Chaplaincy" (2011-2014). It was presented at HCCN's 1st Caring for the Human Spirit Conference in New York in 2014. The study generated 100 taxonomy items, which chaplains around the world have since been using in various ways to describe their interventions and outcomes.

For me, as HCCN's president and CEO, I was pleased to lend support to

the council by hosting the inaugural meeting during HCCN's conference this year. Led by Advocate Health Care, headquartered in Downers Grove, Ill., the taxonomy project holds great promise in enhancing the field. Researchers have gathered a significant amount of data on chaplaincy activities, and the council can take these findings to the next level, especially given the caliber and commitment of its participants.

In addition to myself, council attendees at the inaugural meeting included the developers and early adopters and supporters of the Chaplaincy Taxonomy: Rev. Kevin Massey, Rev. Marilyn Barnes, Rev. Stacey Jutila, and Rev. Myron Erickson of Advocate Health Care; The Rev. George Handzo of HCCN; Deborah Marin, M.D., and Vanshdeep Sharma, M.D., of Mount Sinai Health System; George Fitchett, Ph.D., of Rush University; and Rev. Paul Nash of Birmingham Children's Hospital, U.K.

At the meeting, participants shared updates on continuing research and use of the Chaplaincy Taxonomy, and they discussed the vision of a standardized language of chaplaincy interventions and outcomes. This normative language is



VIEW THE CHAPLAINCY TAXONOMY

<https://tinyurl.com/jw2dpg9>

urgently needed: when chaplains use inconsistent language, they dilute the impact of what they do and confuse interdisciplinary colleagues.

Conversely, when chaplains use common language for their interventions and outcomes, colleagues can better understand and request chaplaincy care. Common language is also a prerequisite to improving research on chaplaincy by bolstering definitions of exactly what is being researched.

"For too long in our field, we have thought we need to wait until someone makes a perfect tool for normative language before we start using normative language," said Massey, one of the developers of the Chaplaincy Taxonomy. "The time is actually now to use one language to describe our work, while we continue the work of improving and expanding upon that language."

The council's immediate goals will be to meet virtually and regularly

review the literature on chaplaincy interventions and outcomes to provide the field with an ever-improving common language to use for clinical documentation and research. The group will soon be publishing a website where visitors can access the current inventory of interventions and outcomes as well as other tools and resources associated with the taxonomy.

Additional council members, who were unable to attend the first meeting, include Rev. Angelika Zollfrank of Yale-New Haven Hospital; and representing spiritual care organizations, Rev. Dr. Lex Tartaglia of the Association of Clinical Pastoral Education, Inc.; Rev. Dr. Jeffrey Garland of the Association of Professional Chaplains; Christopher De Bono, Ph.D., of the Canadian Association for Spiritual Care; and Rabbi Dr. H. Rafael Goldstein of Neshama: Association of Jewish Chaplains.

Look for more to come on this topic in the months ahead!

Rev. Eric J. Hall is president and chief executive officer of HealthCare Chaplaincy Network and the Spiritual Care Association, based in New York.

SAVE THE DATE

2018

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Conference

Integrating Spiritual Care in Health Care

Presented by

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April 23-25, 2018

Sheraton New Orleans Hotel
New Orleans, LA



Happy Anniversary! The Spiritual Care Association (SCA), an international membership organization that is an affiliate of HealthCare Chaplaincy Network, celebrated its one-year anniversary on April 11, 2017. With it, SCA is going strong: 1,300 members and a presence in 12 countries.

The future of evidence-based spiritual care has begun to emerge.

WELCOMING as members all individuals and organizations committed to the delivery of optimal spiritual care as a vital component of whole-person care and the overall patient experience

EDUCATING chaplains, nurses, social workers, other health care professionals, and clergy via a robust Learning Center

ENGAGING all interdisciplinary team members, recognizing that the delivery of spiritual care requires both generalists and specialists

OFFERING new pathways for chaplain credentialing and board certification to ensure demonstration of clinical competencies

ADVOCATING to advance the integration of spiritual care in health care around the world

From a chaplain:

“**Boldly taking the leadership in areas of direct interest to me and our profession ... The upgrade of standards for a ‘new age’ is very welcome.**”

www.SpiritualCareAssociation.org
info@SpiritualCareAssociation.org
212-644-1111

65 Broadway, 12th floor
New York, NY 10006
3415 South Sepulveda Blvd, Suite 1100
Los Angeles, CA 90034

The SCA Difference: An Open Letter to Health Care Executives

Dear Health Care Executive,

As the Spiritual Care Association (SCA) marked our one-year anniversary, on April 11, 2017, we're excited to share with you our progress to advance professional chaplaincy and the spiritual care field. These developments provide unprecedented opportunities for the current and future chaplains on your staff to secure board certification based on evidence-based knowledge and observable clinical skill. We hope you'll agree that this bodes well for health care professionals, health care settings, and those you serve. After all, isn't optimal care what we all desire?

Our innovative approach features the first objective, comprehensive evidence-based model that defines and tests for the provision of high-quality spiritual care. **How do we know our chaplains will deliver competent, value-added care? We know because our process is based on evidence-based quality indicators for spiritual care and an internationally vetted scope of practice.**

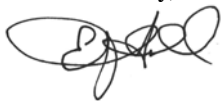
Today, evidence-based chaplaincy is coming into its own. Chaplains are taking our standardized clinical knowledge test and standardized patient exam—objective tests that ensure demonstration of clinical competencies and put the profession on par with other disciplines. Using this model, we've begun certifying chaplains—both chaplains who meet SCA's requirements and those currently certified by other organizations. The applications for SCA's board certification have been steadily increasing.

So, why encourage chaplains on your staff to pursue SCA's BCC, and, when hiring, look for and accept chaplains with these credentials? Simply, a chaplain with SCA's certification brings value to your organization because:

- Our certifying process is grounded in evidence-based knowledge and practice.
- Certification features the only standardized clinical knowledge test in health care chaplaincy and a standardized patient exam, which assesses communication and other skills as well as "human touch." Both are objectively scored.
- The evidence-based knowledge, which is tied to quality indicators and competencies, establishes what chaplains should be doing to provide evidence-based quality care and impact outcomes.
- Our online training and test prep course are available to bring chaplains up to the level of competence that you would hope for in this demanding health care environment.

You can learn more about our approach at www.spiritualcareassociation.org. In the months ahead, we look forward to more and more chaplains becoming certified by SCA, demonstrating that they have the knowledge and clinical competencies we require—and that we know will bring value to your organization. Fully committed to this process, we believe the care of our patients and their families depends on this. As we have from our start, SCA welcomes insights and suggestions from the field. With this, we—and our profession—will continue to evolve.

Sincerely,



Rev. Eric J. Hall
President and Chief Executive Officer

P.S. In addition to chaplains, who are the spiritual care specialists on the interdisciplinary team, we believe that other health care professionals, including physicians, nurses, and social workers, should be trained to provide basic spiritual care. For an overview, please read our recently released white paper entitled "Spiritual Care: What It Means, Why It Matters in Health Care" at www.healthcarechaplaincy.org/spiritualcare

The SCA Difference: Education

By The Rev. Sue Wintz, MDiv, BCC

The value of any health care service is increasingly determined and reimbursed by the quality of that service rather than the volume of services that are produced. Determining quality of care rests on having an agreed set of quality indicators, the metrics that indicate the degree of quality present, and tools that reliably measure those metrics.

Education for professional chaplains is essential to produce better and more effective spiritual care that meets the needs of patients, families and staff. Current chaplaincy education processes include some of the same elements: group process, verbatim, discussion of patient interactions, and didactic. However, what is taught—particularly in the didactic knowledge area—varies widely depending upon the setting and the clinical pastoral education supervisor who designs the training.

Other than the Spiritual Care Association (SCA), no organization has engaged in the development of standardized education or worked to provide a basis for standardized chaplaincy care. The SCA Learning Center is unprecedented in that it is the first and only chaplaincy organization to develop standardized education based on Quality Indicators and Scope of Practice documents. The courses are developed from a core knowledge document identified from international guidelines, and research and tools that are evidence-based, providing learning and skills that are in-depth and consistent.

As a result, for the first time within the profession, SCA's education ensures that chaplains are trained in a set of competencies that are reliable and grounded in research to provide value-added care. This education prepares chaplains for the first and only evidence-based knowledge test in health care chaplaincy as a required part of their certification process through SCA.

As part of its uniqueness, the SCA Learning Center also offers courses for professionals in other disciplines, including social workers, nurses, physicians, therapists, and patient

Needs to Know About Spiritual Care."

In addition to offering the courses directly, SCA also makes the curriculum available to other chaplaincy organizations and clinical

Quality Indicators: www.SpiritualCareQualityIndicators.org

Scope of Practice: www.SpiritualCareScopeofPractice.org

advocates, who desire to integrate spirituality and an understanding of the expertise of chaplains into their scope of practice as spiritual care generalists.

To meet the needs of participants regardless of their geographic location, SCA education is web-based, offering both self-directed and, most recently, several instructor-led courses. Each course is written by a recognized subject matter expert from a variety of health care disciplines, including chaplaincy, medicine, social work, nursing and psychology. Students receive reading materials, videos, study guides, and additional resources for each course. Every course contains requirements that students must meet to successfully complete the course to receive credit.

To meet the fast-changing demands of health care, the SCA Learning Center is constantly developing new courses and updating existing courses in response to new evidence and requirements in order to provide the best knowledge base for quality care to patients, families and staff. In response to student requests, four of the self-guided courses are now available as instructor-facilitated cohorts in which students participate in a collaborative learning environment: "Care for All: Cultural Competence, Inclusion, and Vulnerable Populations"; "What We Hear and Say: Spiritual Assessment and Documentation"; "Value, Obligations and Rights: Health Care Ethics"; and "What Every Health Professional

training programs that desire to standardize their training according to the Quality Indicators and Scope of Practice documents.

According to evaluation feedback, students have praised the courses' foundation in evidence and thoroughness in covering the topics. They have also welcomed the ancillary materials for the courses.

One chaplain, for example, who was enrolled in "When Care Is Tough: Supporting the Interdisciplinary Team," said: "While I greatly appreciated the skills and knowledge I learned to provide more effective support to staff, I really liked the opportunity to read the various articles and material. I found the material intellectually stimulating and inspirational for my profession."

The Rev. Sue Wintz, MDiv, BCC, is director of education at the Spiritual Care Association; director, professional and community education at HealthCare Chaplaincy Network (HCCN); and the managing editor of HCCN's online journal, *PlainViews*®. She has more than 30 years of experience as a professional chaplain, consultant, educator, writer, and community leader. She is a past president at the Association of Professional Chaplains and the recipient in 2013 of its highest honor, the Anton Boisen Professional Service Award.

The SCA Difference: **Certification**

By **The Rev. George Handzo, BCC, CSSBB**

The SCA certification process breaks new ground in health care chaplaincy certification. It shifts the basic paradigm of certification from who one trained with, for how long, and in what particular subjects to whether the chaplain has the knowledge and skills necessary to deliver quality, value-added spiritual care.

The process features the first and only evidence-based knowledge test in health care chaplaincy. The test was developed after a lengthy process, including two international panels of interdisciplinary experts who used current research to develop the first set of evidence-based Quality Indicators for spiritual care and the first evidence-based Scope of Practice for health care chaplaincy. These documents then guided the writing of a core knowledge document that, in turn, generated the questions on the test. Thus, every question on the test maps to at least one evidence-based quality indicator.

The second major innovation is the clinical test that, for the first time, uses Zoom remote video conferencing to enable candidates to interview a simulated patient and have that interview scored according to a set of objective

criteria. This standardized patient exam replaces the use of a chaplain's written self-report of a patient interview as the mechanism for determining clinical competence. It enables evaluation of the non-verbal as well as the verbal components of the visit. Finally, since the testing is done completely online, it is fully available to candidates for whom attending a live committee interview would be a significant barrier.

Other than SCA, current chaplaincy certification processes are based on a long-accepted set of training requirements and a highly subjective evaluation process. However, there is currently no evidence that any particular set of training requirements for health care chaplaincy reliably produces chaplains who add value to patient care. For instance, we do not know how much clinical training is optimal. More than likely, it will vary from individual to individual but that theory is untested. Thus, any claims that any set of requirements is a gold standard or best practice based on a set of training requirements is unsupportable.

However, what we can do as a profession is establish what constitutes

competence and then test for that competence. This is the goal that the SCA certification has set for itself. SCA engaged in an extensive process resulting in the first Quality Indicators, Scope of Practice, core knowledge document, and evidence-based testing that will increase the focus on competence. As a process that is highly objective, the extent to which this procedure produces competent chaplains will be measurable, and the tests are quickly adaptable to new evidence and to the fast-changing requirements of the health care context.

The Rev. George Handzo, BCC, CSSBB, is the director of credentialing and certification at the Spiritual Care Association; and director of health services research and quality at HealthCare Chaplaincy Network. He has authored or co-authored more than 50 chapters and articles on the practice of spiritual care and chaplaincy care. He is a past president of the Association of Professional Chaplains, which in 2011 awarded him the Anton Boisen Professional Service Award.

What Makes CPE.org Click?

By **Rabbi Maurice Appelbaum, BCC, ACPE**

Clinical Pastoral Education (CPE) has been a fundamental element of pastoral training for seminarians, clergy and chaplains for nearly a century. CPE teaches students of a diversity of faiths to offer spiritual care to a multi-faith population in a manner that is authentic to their own beliefs while respecting and being present to their patients' faiths.

For nearly its entire history, CPE was taught exclusively at physical sites for both its academic and clinical components. But, it had become increasingly clear that some prospective students needed a different approach to achieve their educational and professional aspirations.

Many don't live near local CPE centers and would have to uproot

their families in order to enroll in CPE. Others already work as chaplains in some capacity and desire CPE for board certification, but cannot afford to leave their jobs and volunteer at a CPE center.

To address this, HealthCare Chaplaincy Network (HCCN) introduced CPE.org in May 2016 in line with the newly created distance learning standards of the Association for Clinical Pastoral Education, Inc. (ACPE), www.acpe.edu. HCCN is accredited to offer Level I/Level II CPE by ACPE.

What makes CPE.org different? Its distance, online academic study is built around convenience and accessibility, and, moreover, incorporates a standardized, evidence-based curriculum.

With CPE.org, students video conference for the majority of the educational hours, including group process and supervision, and also take self-guided online courses. They then perform clinical hours at local facilities.

So far, more than 100 students from across the U.S. have participated in CPE.org. These include aspiring chaplains like Sheila. After Sheila left her church ministry in Mississippi, she felt a calling to become a chaplain. The closest CPE center was a four-hour drive. She had scouted out apartments where she would live during the week, away from her husband and two sons. Days before she signed the lease, she found CPE.org.

Rabbi Maurice Appelbaum, BCC, ACPE, is director of CPE.org, and coordinator of chaplaincy and education at HealthCare Chaplaincy Network.

All you have to do is look around—in supermarkets, houses of worship, and the waiting areas and treatment rooms of health care settings. The people you see reflect what experts have been underscoring for years: the population both in the U.S. and globally is rapidly growing older.

What does this demographic shift mean for older adults, family caregivers, and health care professionals? How do we best address spiritual care, end of life, cognitive decline, and other aspects of aging?

As these questions point out, this sector demands attention from multiple angles. We address some of them in this special section on aging.

PERSPECTIVES

Why Should We Care About Spiritual Care For the Aging?

By **Joseph F. Prevratil, J.D.**



There is a crisis of aging services in the U.S. Every day some 10,000 persons turn 65 years old. In 2014, the latest year for which government data is available, there were 46.2 million persons 65 years or older, or 14.5 percent of the U.S. population. By 2060, there will be about 98 million older persons, more than twice their number in 2014. Those who are in decent health, active, and have a secure income and appropriate insurance are among the fortunate persons entering the aging arena.

In actuality, however, many older adults suffer from six or more chronic conditions, live in poverty, and are hungry, socially isolated, lonely, and often in despair. They face medical and long-term care systems that require seniors to impoverish themselves to pay for nursing homes, and that often humiliate and overmedicate older adults instead of respecting, understanding and honoring them.

In a world that celebrates youth, government at all levels is saturated with bureaucrats who would rather keep themselves comfortably numb than fight for true culture change and the lives of older adults. Far too many legislators, health providers, and political donors view the aging population as liabilities rather than opportunities, as costing money instead of building wealth. When mined for their experience and wisdom, older adults offer immense cultural and political capital.

Clearly what we need is an independent, fearless and dedicated voice for aging at the local, county, state and federal levels. It's time for these leaders to reverse decades of institutional apathy and act boldly without any strings attached to donors or fears about a secure retirement.

Despite the many injustices older adults have endured for so long, it is amazing how aging Americans of all

racess, cultures, and economic levels have coped with these multiple issues.

One of the key elements in this coping is a strong spiritual character. Spirituality is relevant today more than ever in our diverse culture and society—among both old and young.

The consensus definition of spirituality from the 2009 National Consensus Conference, hosted by the City of Hope National Medical Center, Duarte, Calif., and the George Washington Institute for Spirituality & Health (GWish), Washington, D.C., states, "Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred."

A number of people still confuse religion and spirituality, and controversy over definition continues. While the young online generation are

not much interested in ritual and dogma, spirituality has a tremendous appeal to them because it directly addresses life's biggest questions: "What on earth am I here for?" "What is my purpose?" These questions resonate with them.

Most older adults have already dealt with the many challenges of daily life and these two big questions. They're rethinking what really matters to them.

Spirituality goes beyond readily defined social roles and relationships, and focuses on one's relationship with an interior world (the soul) and a limitless external world. Finding meaning and purpose in life is the key to a strong spiritual life. "Remembering, Reassuring, Reconciling and Reuniting"—what Joanne Lynn, M.D., co-author of "A Handbook for Mortals," calls the 4 R's of the spirit—are the drivers for finding that meaning and purpose, and thereby finding peace of mind.

Why should we be interested in spiritual care for the aging? Simply put, because it provides a better quality of life for older people. It can help them cope with the difficult and inadequate medical and long-term care systems, along with the other holes in the social safety net (e.g., poverty, isolation, hunger).

It is time to improve both the perception and reality of aging. Aging should not be labeled as a problem and expense, but rather as an accomplishment. Public and private sectors should do everything possible to make longevity a healthy, purposeful and compassionate experience. Assuring access to quality care, including spiritual support, should be a vital part of that.

Joseph F. Prevratil, J.D., is president and CEO of the Archstone Foundation, a 30-year-old private grant-making organization in Long Beach, Calif., whose mission is to contribute toward the preparation of society in meeting the needs of an aging population.



WATCH INTERVIEW

with Joseph Prevratil
www.healthcarechaplains.org/magazine

Elder Wisdom: What Older People Can Teach Us About Death

By Karl A. Pillemer, Ph.D.



As little as we like to admit it, all of us are personally involved (or will be) with death. For those whose professions involve working with people in life-threatening

situations, dealing with death and the dying process is a daily occurrence. As a gerontologist who has done research on palliative care, I have long been interested in the question of how people cope with the idea of their own mortality.

Like most people, the idea bothers me personally—that one thing you just can't get out of. Of course, I'm not alone: There's now a whole school of psychological research based on the concept of "terror management." This theory (not one of the more cheerful ones in social science) posits that the awareness of our own inevitable death creates the potential for debilitating terror, against which we then find ways to psychologically defend ourselves.

Perhaps that's why we are now inundated with books about death—and in particular about how great it is. We have doctors and neuroscientists and children claiming to have visited heaven. And unsurprisingly, it's just what we thought it would be, with angels, hymns and bliss. I do get a bit

suspicious when visions of heaven are exactly what we humans expect (my favorite quote from monk and spiritual writer Thomas Merton: "One thing's sure about heaven — there won't be much of you there").

The idea occurred to me: Why rely on young people for advice about how to handle our own mortality? If we want to know how to prepare for inevitable death, why not ask the people who are almost there? That's right: older people.

"The elders told me that the fear of dying is very much a young person's game."

Over the past decade, I've conducted surveys of the oldest Americans, asking them about their lessons for living—that is, their practical advice for having a happier, healthier, and more fulfilling life. They provided excellent guidance for a host of issues, from choosing a career, to having a happy marriage, to raising healthy children. The Cornell Legacy Project has gathered these lessons and made them available to the public.

In the Legacy Project interviews, one topic I really wanted to explore is how people so close to life's finish line think about death. So I decided to bite the bullet, to look 80-, 90- and 100-year-olds in the eye and ask: "When people reach your age, they begin to realize that there are more years behind them than in front of them. What are your feelings about the end of life?" In our hundreds of interviews, we discussed what the elders thought about dying and whether it concerned them and occupied their daily thoughts. And I was in for a surprise.

In fact, one question repeatedly entered my mind while listening to the interviews: Where's the terror? Because what the elders told me is that the intense, overpowering fear of dying is very much a young person's game. I did not detect denial from these elders, but rather a matter-of-fact approach to dying and a willingness to discuss it and what it means.

The vast majority of the elders described themselves as not thinking about death much, and much less so than when they were younger. I knew that research exists showing that overall death anxiety decreases with advancing age.



Nevertheless, I wasn't prepared for the comfort level most of the elders expressed about their own deaths.

Edwina Elbert embodied what I learned is a common attitude of the elders toward the end of life: a mix of interest, curiosity and acceptance. She is a warm, witty, and very open 94-year-old. Her brushes with a serious accident and an illness have led her to reflect on the end of life and what it means.

It has made me realize that there's always that question of why nobody knows where we go. Well, there must be a reason for that. We'll never know because that's a mystery. I know about as much about it as the most learned men in the world, I would imagine. Because nobody really knows what happens to you.

But about dying, I'm not one bit afraid. Well, if you stop to think about it, it's a natural thing. Everything dies. Whether we come back or not or what happens there, I don't know. But it's like my husband used to say whenever we did discuss it: "If you go to heaven, how wonderful. But if you go to sleep, what's wrong with that?"

As you might expect, deeply religious elders found their beliefs to be comforting as they contemplated the end of life. Rosemary Brewster, 90, is a regular churchgoer and has been all her life. When asked, "Do you believe in life after death?" she replied: "I often wonder about that. I think and I wonder if there really is. And I'm going to find out. I wouldn't bother worrying about it too much, because I'm going to find out."

She pointed out that her feelings had changed greatly in later life.

But, you know, when you're younger you go to bed and you think about death, and "Oh my God!" Or you're sick: "What if I don't wake up?" I don't think that anymore. Now that I'm old, I'm at peace when I go to bed. I figure if I don't wake up, well, maybe I'll be someplace nicer. It's just a funny thing. I used to be scared to go sleep when I wasn't feeling good, but not anymore. I'm not ready to die or anything like that, but I'm just not afraid to die. I think there's something on the other side, and I've got some sisters over there who will be waiting for me. I'm not worried at all. And that's something I didn't think I'd ever come to terms with.

I would like to dispel the notion, however, that it's just religious people who shed an intense fear of dying as they grow older. I found the same kind of matter-of-fact comfortableness with life's end among elders who were vehement nonbelievers.

Take Trudy Schaffer, whom I interviewed in her art-filled and book-lined apartment in New York City. She told me: "I believe nature is God. My mother and her mother came from a religious family. But my father did not believe in religion and so we did not grow up with religion."

However, she, like Brewster, told me about the change in her fear of death as she aged. She explained that the panic over death is "a younger person's game."

I mean, life is death and death is life. If I die, I die. Dying is what I was thinking about when I was younger. I remember thinking, "How can I die? How can I not be alive?" That panicky feeling. But now I haven't thought about it in years. I know it can't be much longer—I'm 87. But I just don't worry about it. That's why



I want to go out every night, as long as I can afford it. I want to do everything I can do. But I'm not worried about dying—don't even think about it, really.

Although they seem unconcerned about the fact of dying, the elders do have one end-of-life recommendation for people of all ages: plan for it. Indeed, when asked about their views of death and dying, the worry they mentioned most frequently was not being organized and leaving a load of work behind for their families. I learned that planning "for the journey," as some experts referred to it, was seen as responsible behavior as well as providing a significant source of comfort.

One particularly delightful interview I conducted was with Ted and Lucy Rowan. I interviewed this couple, married for 57 years (as Ted

put it, "to the girl of my dreams") in their cozy apartment in a retirement community.

Their approach of the end of life is to plan. Lucy told me:

Well, I think about death easily because our proxy and our will are all set. But our concern right now is more about the stuff we have. Do you see all of these things we've accumulated? Look at the albums I have, and I'm sure my children are not going to want them. What am I going to do with them? And Ted has boxes of lectures stored in a garage. I am really an organizing person, I really enjoy that.

These sentiments were echoed by most of the Legacy Project elders. The experience of "tidying up" one's possessions emerged as

a metaphor for tidying up the loose ends of life, bringing things together in a meaningful whole rather than a disorganized set of unrelated parts. My frank and open conversations with the oldest Americans about the end of life did not reveal an underlying terror but rather a sense of curiosity, acceptance, and a desire to "prepare for the journey" ahead. In fact, the awareness of death and the short time horizon remaining produced a desire to savor life in the moment and to take every advantage of the time that is left.

So perhaps more than listening to young people's trips to heaven, we can benefit from talking to people who are close to making the real and final trip to—well, whatever's next. I have to admit, it helped me. If they're not so worried, why should we be?

Karl A. Pillemer, Ph.D., of Ithaca, N.Y., is a professor of human development at Cornell University in Ithaca, and professor of gerontology in medicine at the Weill Cornell Medical College in New York. An internationally renowned gerontologist, he has authored five books and more than 100 scientific publications, and speaks throughout the world on aging-related issues. He is the founder of The Legacy Project, which began in 2004 when he started collecting practical advice for living from America's elders. This project led to the book *"30 Lessons for Living: Tried and True Advice from the Wisest Americans"* (Penguin/Hudson Street Press, 2011).

A SPIRITUAL WELL-BEING GUIDELINE REVITALIZES ASSISTED LIVING RESIDENTS

A Million Stories to Tell—and Interventions to Explore

By Hutch Walch, ORDM, Phyllis Gaspar, Ph.D., RN, and Katie Westberg, BS

A former grade school teacher residing in an assisted living community missed being around children. She played piano for most of her life as well, and regretted not being able to bring the piano to her current living situation. As a result, she lost her purpose and reason for living. For this longtime resident, sharing these two important aspects of her past has guided an ongoing intervention—and now her spirit is soaring again.

The woman's new lease on life is a result of a spiritual well-being guideline developed and implemented by The Goodman Group, a senior living corporation that manages the community where she resides.

The guideline addresses spiritual well-being through a one-on-one comprehensive assessment of spirituality, intervention with an individualized care plan, and follow up. The process has resulted in meaningful outcomes, providing opportunities to assist residents in resolution of past issues and, thus, bring closure and increase well-being.

The organization embarked on this new model of spiritual care as part of its continuous quality improvement (QI) efforts, and based on its perspective that spiritual well-being is influenced by mind and body and in turn influences the mind and body.

The effort initially focused on assisted living residents, all older than 65 who were experiencing a transition in their living environment and were requiring assistance related to decreased physical and cognitive function. Team members recognized informally that these residents were experiencing spiritual distress, and that this distress was not being

adequately dealt with.

The Evidence-Based Practice Improvement Model that integrates evidence into the Plan-Do-Study-Act QI method guided the project. An inter-professional guideline for implementation in the organization's assisted living facilities was developed based on a review of the evidence, and the feasibility and sustainability potential.

The guideline incorporates the administration of the Functional Assessment of Chronic Illness Therapy – Spiritual (FACIT-Sp) measurement system, which was developed to describe spiritual well-being and is not limited to any religious or spiritual tradition.

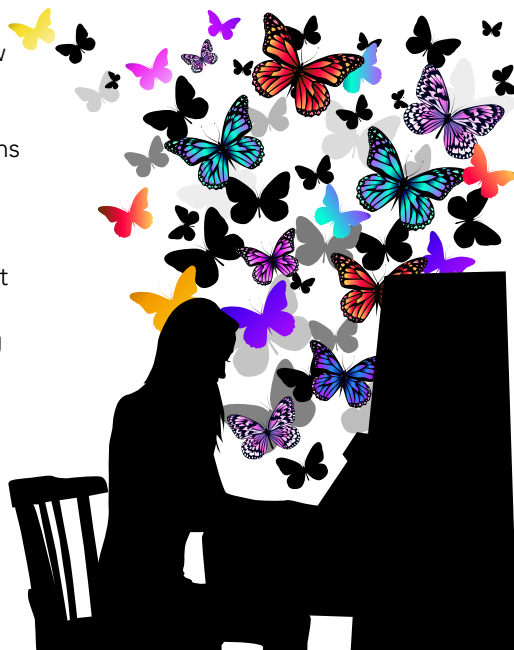
The community's spiritual director—a pastor, chaplain or counselor who the organization deems naturally gifted to provide the assessment and appropriate resident-focused care—administers the instrument as an interventional assessment. The one-on-one interview serves as an opportunity for the resident to reflect and share his or her strengths as well as issues and concerns related to spirituality.


The FACIT-Sp consists of 23 questions with response options on a 5-point Likert scale ranging from 0 (not at all) to 4 (very much). The questions address meaning and purpose, asking about reason for living, sense of purpose, forgiveness of others and forgiveness of self, compassion for others and what they are facing, and feeling loved and loving others. Total scores can range from 0 to 92, with the higher the score indicating a higher level of spiritual well-being. The sub-concepts of meaning and

peace can be computed from the questionnaire, each concept with a possible range of scores from 0 to 16.

Since the FACIT-Sp has two questions focused on the diagnosis of cancer, permission was obtained to omit these questions. All scoring was computed based on these missing questions to allow comparison with standard scores. A shorter form of the instrument consisting of 12 of the 23 questions (scores range from 0-48) is now commonly reported in the literature and can be easily computed. Scores for the shorter form were calculated for comparison purposes.

Baseline FACIT-Sp scores (total score, 12-question subscale, meaning subscale, and peace subscale) have been completed for 309 residents. The average scores of the 309 residents at baseline were: Total score – M = 64.42, SD = 11.70; 12 question score – M = 34.99, SD = 7.63; Peace subscale





score – $M = 10.95$, $SD = 3.28$; Meaning subscale score – $M = 11.89$; $SD = 2.93$. The scores for this population (total score, the 12-question score, peace and meaning subscales) reflect a generally lower spiritual well-being score compared to the level reported for older adults with various types of cancer and select chronic conditions, according to several research studies.

Responses to individual questions indicate that more than 60 percent of the respondents have trouble feeling peace of mind, and more than 20 percent lack a sense of purpose in life. A majority of the respondents find strength in their faith or spiritual beliefs, feel love, and feel love for others. As the residents reflected on their responses to the questions, they shared issues and concerns related to these themes: health, lack of purpose, grief, loss, faith concerns, lack of social engagement, and unresolved family conflicts.

Based primarily on a critical review of each resident's responses during the administration of the FACIT-Sp, the spiritual director then works with the resident to develop and implement an individualized approach focusing on the development of strengths and addressing each area of need.

The one-on-one visit by the spiritual director allows for immediate follow up on those questions that the resident responded to with low levels of spiritual well-being, was hesitant in the response, or displayed non-verbal behaviors demonstrating discomfort with the question(s). Providing the opportunity for the resident to reveal life-enduring feelings, issues and concerns is the first step toward resolution.

Interventions are almost always personalized in this model. While there are life enrichment programs to enhance purpose and meaning, oftentimes the deep hurts the residents carry with them need to be specifically addressed. For example, residents have shared personal stories of physical or mental abuse earlier in life, being hurt by the church, feeling unforgiven, and living lives with dreams unfulfilled. There are a million stories that need to be told and listened to, and just as many

interventions that must be explored.

For follow up, the professional administers the FACIT-Sp assessment as an outcome measure to determine changes in a resident's spiritual well-being. So far, follow-up assessments have been completed for 31 residents who received a focused intervention. The results show a significant increase in total spiritual well-being, and on the peace and meaning subscales scores.

For the longtime resident who missed being with children and playing piano, her trust in the community's spiritual director and her comfort with the assessment tool, enabled her to express for the first time why her reason for living and purpose was low.

Equipped with this knowledge, staff have implemented an intervention that includes inviting the woman to play on one of the four pianos in the community. While she initially did that privately, she now plays—and sings—weekly for the residents in the assisted living community's memory care unit. She also entertains visiting school children, and she leaves the residence weekly to mentor grade school Girl Scouts.

Subsequently, scores on her FACIT-Sp increased considerably over a three-month period—from 69 to 77. Contributing to the increase were her positive responses to the questions about having a reason for living and feeling connected to other people. She found purpose and meaning in her life.

Another resident of a long-term care unit, who is 105-years-old, and nearly blind, also had low scores for purpose and a reason for living. Since, the spiritual director has built on this resident's memory of teaching Sunday school, and has revived her lifelong love for reading the Bible and other religious material. As joy and the remembrance of what this material meant to her surfaced, she began to regain confidence and purpose. She even thanked the spiritual director for "caring for her spirit."

A few days later, she shared with the spiritual director that she knew why God had brought her to this facility: to host a women's Bible study. They established a plan in which the spiritual director reads the material to her and

the woman teaches it in the study group. Residents have already started signing up, providing the perfect opportunity for this centenarian to serve others while gaining meaning and purpose in her life.

In addition to the individual approach, the organization has been reviewing group data for each question of the scale with an eye on redefining activities that will add purpose to the lives of the residents.

In another related action, the team currently is piloting a simplified tool for measurement of spiritual well-being among residents in memory care assisted living communities to address this population's spiritual needs. Efforts continue on establishing an inter-professional guideline that will address each resident's spiritual well-being throughout the company's senior living communities.

This model of spiritual "Spirit" assessment opens doors previously not unlocked by traditional spiritual and religious visits and programs such as weekly church services and prayer groups. Many residents who were known to us for years revealed their true selves to us in the course of this spiritual model. This approach changed the direction of that resident's life and his or her family and personal relationships, has changed the culture of our senior care community—and has been setting our beloved residents' spirits free to soar again.



Hutch Walch, ORDM, Phyllis Gaspar, Ph.D., RN, and Katie Westberg, BS, all work at The Goodman Group, Chaska, Minn., which developed and manages 70 senior living and memory care communities, health care centers, residential communities, and commercial properties in 10 states. Walch is an ordained minister and the director for spirituality, senior living & health care; Gaspar is the national director for research and development; and Westberg is the national director for life enrichment.

Q&A *With Actress* **Kimberly Williams-Paisley**

Her Touching Memoir Reflects Hope, Faith, and Silver Linings Amid Her Mother's Dementia



Kimberly Williams-Paisley is an actress who first lit up the screen as the radiant young bride in the comedy feature film series “Father of the Bride” and “Father of the Bride Part II.” Williams-Paisley continues to garner praise for both her

dramatic and comedic roles in the feature film and television arenas, which have included “Alvin and the Chipmunks: The Road Chip,” “How to Eat Fried Worms,” and “Nashville.”

In addition to her acting work, Williams-Paisley is an accomplished writer who has had articles published in national magazines. As an outgrowth of a compelling essay she wrote for Redbook about her family’s experience with her mother’s dementia, she authored her debut novel, “Where the Light Gets In: Losing My Mother Only to Find Her Again” (Crown Archetype, March, 2016; paperback released April, 2017).

Williams-Paisley started noticing odd changes in her mother’s behavior when she got engaged to country superstar Brad Paisley in 2002. In 2005, her mother, Linda Williams, then 62, a former journalist and nonprofit fundraiser, was diagnosed with primary progressive aphasia (PPA), a progressive loss of language function that was caused by early-onset Alzheimer’s disease. Williams-Paisley’s father, journalist Gurney Williams, was her mother’s primary caregiver until she moved to a long-term care facility in 2012. Linda Williams passed away in November 2016.

We were prompted to interview Williams-Paisley by the actress’s touching and insightful memoir as well as the growing threat of Alzheimer’s disease to the aging population (see sidebar).

Photos courtesy of Kimberly Williams-Paisley

Q. What were the surprising blessings and silver linings that emerged from your mom’s illness?

A. Any challenge carries the potential for great spiritual growth, and my mother’s dementia provided me a multitude of opportunities. Mostly, I learned about forgiveness on a deeper level. I practiced accepting and loving the “new” changed mother in front of me, connecting and communicating with her in unique ways. I also worked to forgive myself for the days I didn’t feel that connection. I see it as a blessing that I am in a position now to help others from our experience. Dementia is a complex challenge that requires a lot of support from family, friends, and the community at large.

Q. What epiphanies enabled you to move from darkness to light?

A. Hearing from a friend of mine about her last conversation with her dad showed me what could still be possible with my mom. Late in her disease, I had written off any chance of having a relationship with my mother, but I realized I had been shortsighted. I wound up discovering new ways to communicate. We had a couple of brief conversations that were unexpected and illuminating, long after I thought those kinds of interactions were impossible. And we found new ways to express love, through physical touch, music and laughter.



Q. You refer to finding your mom in “small things and brief moments” as mysterious and miraculous. Can you explain further?

A. I saw some “God-winks,” or little divinely inspired signs that restored my faith and gave me encouragement. I found a gold paper clip on the floor of the pantry in my kitchen moments after I’d been writing about the gold paper clips my mom used to attach to mailings at The Michael J. Fox Foundation where she worked in fundraising. She used gold because she thought they were fancier than the boring silver, and wanted the recipient to feel special. It was more than just coincidence to me when the first one appeared, and others surprised me over the following months in the oddest of places.

Q. You understandably went through many emotional clashes during your experience, but, ultimately, how vital was it to both your mom and you to embrace the person as she was at that moment?

A. I don’t know that I will ever know how vital it was for the journey my mother was on, but for me, accepting the person she’d become was profoundly healing. When I stopped wishing for things to be different, a huge weight lifted from my shoulders.

Q. Family members whose loved ones have dementia, or other chronic illnesses, might find it very difficult to wrap their heads around finding a positive aspect to this; what’s the secret?

A. Reframing the goal. There is no easy way around or through dementia. It is a hard disease, often called a family disease because it affects everyone around the patient. It was helpful to shift the agenda from trying to do everything perfectly or wishing things were different, to focusing instead on spiritual growth and acceptance of what is. The only way through for me was learning to let go of guilt and regret, and forcing myself to keep my eye on the blessings.

Q. You recall that you saved a Post-it note scribbled with your therapist’s advice—“Turn anger into compassion, and fear into faith.” How did that mantra guide you through your mom’s illness and death?

A. Yes, it is a good mantra, and I still repeat it! It was useful for my evolving struggles with my mom, as well as in other areas of my life.



Q. During your mom’s illness, you periodically questioned your faith and your belief “that good things or divine revelations could come from any crisis,” and you noted as well that your dad “started to feel spiritually anemic.” Yet, you returned to your faith, your beliefs, your spirituality at times as well. How did this get you through?

A. For me, facing this disease as a spiritual journey was the only way through. There are so many unanswered questions, so many things we won’t ever know—about what this was like for my mother, or why she got sick. We do know now that her PPA was caused by Alzheimer’s disease, but we may never know why. Rather than banging my head against the wall in frustration, I choose to embrace what I believe: that there is a divinely inspired beautiful picture here if you look at it that way. It’s a spiritual challenge worth accepting: to find light in the darkest places. The more I practice, the easier it becomes, in all aspects of my life.

Q. Early on in the book, you declare, “My mother is not her disease”—a very powerful statement, especially when talking about people living with some form of dementia. How can that realization help family members cope and help health care professionals provide optimal care?

A. It’s tempting to blame the patient for their anger, confusion, aggression, sadness, forgetfulness. It’s helpful to remember that they can’t help it.

Q. How does a person’s desire for secrecy about a diagnosis—like what happened with your mom and often in other families—pose challenges for the ill person, families, and even health care providers?

A. One of the biggest mistakes we made was honoring my mom’s wish for secrecy. Because we didn’t reach out for

help and support sooner, we missed out on a lot of the resources that could have helped us. Perhaps if we had been more vocal and honest about what was happening to our family, we wouldn't have made some of the other mistakes we made. I know we wouldn't have felt as alone.

Q. Similar to the increasing emphasis today among health care professionals to encourage people to make their wishes known, you speak about the importance of having advance care conversations and, moreover, writing a personal message about wishes and/or thoughts. Why is that so critical?

A. My mom didn't write down any of her wishes, and so we were left trying to guess what she would have wanted after she could no longer make decisions for herself. For example, how would she have felt about long-term care? She told my sister once that she didn't ever want my dad to take care of her, but what did that mean exactly? My dad waited so long to move her out of their home that we were afraid we would lose him before we lost her. The caretaking duties were overwhelming him. Had she written down even a general plan, we still may have made the same decisions, but maybe we wouldn't have felt so guilty about it. I encourage people to write down their wishes before they get sick. And don't say what I've heard some people flippantly joke, "If that ever happens to me, just shoot me!" because that is not helpful or practical.

Alzheimer's Disease By the Numbers

- An estimated **5.3 million** Americans aged 65 and older are living with Alzheimer's disease, the most common form of dementia.
- Approximately **200,000** individuals under age 65 have early-onset Alzheimer's disease.
- By 2050, more than **16 million** people are expected to have Alzheimer's disease.
- **One in three** seniors die with Alzheimer's disease or another form of dementia.
- More than **15 million** Americans are unpaid caregivers of people with dementia.

Source: Alzheimer's Association "2017 Alzheimer's Disease Facts and Figures"

Q. And speaking of hard conversations, at one point, you asked your mom if she was ready to die. Why was that a question you needed to ask--and perhaps others need to ask loved ones?

A. I thought maybe she was hanging on for our sake, and she just needed permission to let go. She was largely nonverbal, in a wheelchair, unable to recognize people, or do anything for herself anymore. She had lived a lot longer in long-term care than I thought she would. In the end, I don't think it made a difference for my mother that I gave her "permission." She was on her own journey.

Q. Throughout your mom's illness, is there anything you would have wanted one of her health care professionals to say/provide that would have better helped you and your family?

A. I think the best health care workers we had found real joy in taking care of my mom, but also supported the family beautifully, allowing us to evolve in our lives and to feel some contradictory emotions honestly, without imbuing guilt, judgment, or personal attachment.

Q. You relate in the book that you attended a caregiver conference with your dad and spoke with attendees whose loved ones had died. About one former caregiver, you candidly wrote, "I couldn't help envying her. She was already done with this hideous disease, and in a position to counsel others on how to survive." Now that your mom has passed away, what would you say to people who might look enviously at you?

A. I get it. I have closure now that I craved when my mother was alive. I determined then—even in the midst of finding the blessings in that challenging situation—that I would one day take hold of the reins of this story and not allow the disease to have the final word. I planned to model what my mom did when she was well, and to raise awareness and funds. Now that is what I am doing ... So I'd say to the people in the position I was once in, hang in there. There is a huge community of support and love out there available to you now, and one day, should you want to get more involved, we would love your voice and experience.

Carol Steinberg, editor-in-chief of *Caring for the Human Spirit Magazine*, and executive vice president of HealthCare Chaplaincy Network, conducted this interview.

Understanding Cultural and Spiritual Aspects of Aging

By Steven Z. Pantilat, M.D.



There are unique challenges when talking about palliative care with older patients. For example, accepting caregiving can be stressful to older people—it's a frightening admission that they aren't well and may even be in decline, and that they now need assistance.

Caregiving that requires a complete change of lifestyle can be particularly disruptive. This situation is sometimes compounded when a

patient has the onset of dementia, making caregiving additionally challenging to family members who worry about "losing" the person they love, and to family and professional caregivers who must deal with common issues such as wandering, safety, and behavioral changes.

This is why understanding the patient's cultural norms and spiritual beliefs can make a huge difference in providing care. Equipped with

this information, caregivers can tailor treatments and environments to add comfort and familiarity as well as address unique issues in a way that aligns with the individual's beliefs.

The excerpt below discusses how to include culture, religion and tradition when treating patients, particularly older ones, and offers suggestions that medical providers can convey to patients and their families to ensure that patients' desires are being met.

Serious illness doesn't discriminate; it strikes patients of all ethnic and cultural backgrounds. Members of particular groups frequently have traditions that govern how they deal with serious illness, dying and death.

In today's Western cultures, the wishes of seriously ill people are paramount. Our laws and institutions are geared to see that their directives are carried out. In other cultures, decisions are based on what's best for the family, and the individual's interests are less important. The patient's family, not the patient, is expected to make the important decisions, including treatment and end-of-life decisions.

If you want your family to make those decisions, make your wishes clear. Put them in writing. Make sure that they're in your medical record. Tell your family, friends, and medical providers that you authorize your family to make all the necessary decisions regarding your treatment and end of life.

When it comes to cultural differences, my major concern is that assumptions will be made that don't reflect patients' wishes.

I was treating Mae, a Chinese-American patient in the intensive care unit (ICU), when it became clear that she had only a matter of days left. I asked her nurse, who was also Chinese-American, if she knew whether anyone had asked about Mae's spiritual preferences.

Did she want to see a spiritual leader or have particular customs followed? "Oh, no," the nurse replied, "We Chinese aren't religious." Her answer surprised me. It was not what I had experienced. So I asked Mae's family, learned that they were Catholic, and was told that both Mae and her family wanted her to receive the Sacrament of the Sick, which we soon arranged.

You can't assume that you know about someone because you know that person's ethnicity, country of origin, religion, or primary language. You certainly don't know his or her preferences for something as personal as medical care and spiritual needs at the end of life.

Although cultural traditions play a role in making treatment decisions, that role is not absolute. For example, in some cultures the tradition is to withhold unfavorable information from patients. In those cultures, physicians don't discuss diagnosis and prognosis directly with the patient. And yet, cultures are not homogeneous. Opinions diverge even in the most traditional communities. They are never 100 percent one way or the other. Ultimately, treatment and end-of-life decisions are personal and vary with each case.

I tell my students to be curious—to ask respectful questions like, "What do I need to know about your culture or religion to make sure I take good care of you?"

Share these traditions and practices with your doctors and nurses. If the person who is ill in your family is potentially more traditional than you are, you can ask him or her the same question: "Grandma, what are the traditions in our family that are important when taking care of people who are sick?" This question about traditions is another opportunity for the person who is sick to find meaning, purpose, legacy and dignity by sharing family and cultural traditions.

On the other hand, I sometimes

find that people don't want straight talk. Some people prefer to be a bit in the dark, to live with some denial. That's OK, too. The point is that you can never know what someone will say. That goes for me as a doctor and for family members. The goal is not to assume what someone wants, but to ask.

At 84, Mr. Wong was admitted to the hospital with right-side abdominal pain. An ultrasound revealed a mass in his gall bladder that looked like cancer. His family told us not to tell him what we found because he wouldn't be able to take such bad news. They said that, in their tradition, the family would make all medical decisions for him.

One morning, when Mr. Wong was feeling better, I visited him. He was in bed, and a Mandarin interpreter was with his family in his room. I wanted to respect the family's wish but I also wanted to respect Mr. Wong. So, I said, "Mr. Wong, I have information about what's going on. Some people want me to tell them everything while others prefer that I only speak to their families. How do you feel?"

Mr. Wong thought for a moment and then spoke in Mandarin, which the interpreter translated. "You know, Doctor, everyone has to die someday." I was stunned. I hadn't said anything about dying. I regrouped and said that yes, he was right, but what I wanted to know was how he wanted me to handle new information about his condition and whether he wanted me to tell him or his family. "Oh, Doctor," he replied, "you will tell me everything. And by the way, it's OK if you also want to tell my family."

Mr. Wong went on to tell us that he felt better and wanted to go home. He declined a biopsy that his family had been ready to consent to. Mr. Wong's family thought they were protecting him, but they complicated the situation and made it more difficult. They nearly exposed him to a biopsy that he didn't want.



The federal government, along with every state in the U.S., has laws that mandate that health care providers make interpreters available for any person who doesn't speak English. These laws are so important because they support better patient-doctor and patient-nurse communication, which is the backbone of good medical care.

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Healing the INTENSIVE CARE UNIT

By Samuel M. Brown, M.D., MS

I received an unexpected email a couple of years ago from Spence, a young man whose wife I had recently treated. He told me,

Beyond using your medical skills to treat her physical problems, you went out of your way to make sure my questions and concerns were taken care of. You spent extra time talking with me and giving me honest assessments and advice. When she returned to consciousness you again took the time to talk with us about her experience, helped us understand what to expect and what recovery would be like. In other words, you treated us, and especially her, like an individual. She wasn't another body in a bed and I wasn't another shadow in the corner.¹

Call me maudlin, but I felt the rush of warmth in my face that heralds tears when I read that paragraph. I took care of Kristi after I had already spent a year developing the Center for Humanizing Critical Care, and she and her husband, Spence, were one of the first couples to experience our integrated efforts at personalized, humane care in the intensive care unit (ICU).

A few days after the birth of her third child, Kristi developed a pneumonia gone wild. The inflammation of an immune system out of control caused her lungs to fill with fluid, her blood pressure to plummet, and her kidneys to fail. She had a classic case of multiple organ dysfunction syndrome (MODS). Hers came as a result of a serious Strep infection.

When we had to transition Kristi to life support on her first day in the ICU, I told Spence to hope for a positive outcome but acknowledged there was a chance that Kristi would not survive. Before I intubated Kristi, I encouraged Spence to tell her how much he loved her and how much he was cheering for her recovery.

Kristi's outcome was the best we could have hoped for: full recovery of body and mind, and no obvious psychological harm inflicted by the systems of care. Unfortunately, while medical successes like Kristi's are increasingly common, most people carry deep scars from an ICU experience. Many of those scars could have been prevented. No one will ever be able to remove entirely the pain of life-threatening illness, but medical professionals are morally responsible for eliminating the needless suffering

of patients and their families.

Efforts to improve the ICU experience and replace advance directives should provide a cultural context in which life-threatening illness and death can be meaningfully interpreted, honor and acknowledge people in their diversity, create useful maps between people's individual values and priorities and specific patterns of decision making, and employ multiple, complementary approaches to improving conditions in both medicine and society.

What I'm advocating is the development of systems that allow human beings to flourish even in the face of serious illness in ways that are attentive to what people actually want and aspire to. I describe several ideas here; many more are possible.

Let Families In

Humanizing the ICU requires that medical professionals acknowledge that they can heal or harm people beyond their individual patient. Historically, the medical system has focused exclusively on the individual patient lying in the ICU bed. But when life is threatened, people rely heavily on and are represented by networks of people who love them. The exclusive spotlight on the patient has caused



collateral damage, and a humane ICU will support an expanded vision of “patient,” one that includes families.²

This does not mean risking harm to the patient or keeping the patient in the dark to satisfy inappropriate requests from a family member. Rather, it means understanding families and guiding them through the experience of an ICU admission. I don’t mean to gloss over the fact that some families are dysfunctional or that some individuals lack families entirely. In those circumstances, clinicians and the medical system will have extra responsibilities. The key point is that clinicians should not disrupt people’s networks of trust and strength.

Relatively immediate changes include establishing Patient-Family Advisory Councils (PFACs), opening up visiting hours, and making ICU diaries available for patients and families. In my view, a PFAC should be a standard component of any substantial ICU. The voices of actual patients and families should be heard.

Fortunately, an increasing number of ICUs has embraced open visitation; the time is long overdue to open every ICU for family visitation. Whenever the issue has been studied, open visiting hours have been either neutral or positive. ICUs should be open to visitors as dictated by the patient’s desires and occasional procedures. Anything less constitutes a moral failure.

With very rare exceptions for the safety of the patient, I personally allow families to stay, even during the procedures I perform, as long as they and the patient want them there (about half do in my experience).³ Having families by my side has changed my experience dramatically, for the better. I find that our communication is better, their stress is lower, and our sense of working together as a team is heightened. Hard conversations about death come naturally when we have always been working as a team.

The ICU diary, a day-by-day account of events, written in collaboration by clinicians and family members, is the most

successful intervention to decrease psychological distress among ICU survivors. Because false memories are common, patients need help reassembling what happened to them while they were unconscious. Such ICU diaries allow families to document the true memories so that they can share them with the patient later.

I’m convinced that even these three simple steps—creating PFACs, open visitation, and ICU diaries—will do more to humanize the ICU than any living will could.

“I’m advocating [for] the development of systems that allow human beings to flourish even in the face of serious illness ... “

Fixing Code Status

In my experience, physicians in training feel an urgency to settle the question of code status right at the time of admission. That urgency is usually misplaced.

Our team has spent the last three years working on this problem and discovered several things. Tricky discussions about the possibility of death need to come in context and need to be framed in terms that make sense to people. I rarely ask directly about “code status” or CPR anymore, waiting until our conversations or the patient’s physiology make such procedural questions necessary.

To give the relationship some time to mature, I now follow a “third visit” rule for conversations about the patient’s phase of life. I don’t guide conversations toward questions about whether to refuse some medical procedures until I’ve had two previous meetings with patients and their families. Those first visits are devoted to the medical problems at hand and to getting to know each other better. I watch closely during those initial visits to see how patients and their family members react to good news and bad. I listen for clues that they feel that life

is naturally near its end. I learn about their health before the crisis. I ask them how they like to communicate. And I demonstrate that I am fully committed to providing the best possible medical care, both technological and humane. It’s been my experience that by our third such encounter most people are willing and able to have an honest, illuminating conversation about whether to entertain limits to heroic medical treatments.

When a patient is perilously ill, we may have three visits in two hours. When a patient is less sick, it may take two days before we have the conversation.

Meaningful “code status” discussions must focus on the person whose life is at stake—not just the procedures to be refused—and acknowledge uncertainty in a way that leaves room for both hope and realism.

Wrapping Up

Preparing for the worst means, in part, attending to life completion. The completion tasks suited to life’s end can occur throughout an ICU stay.⁴ Normally used in hospice settings, Ira Byock’s “Four Things”—“I love you,” “Thank you,” “Please forgive me,” and “I forgive you”—represent an excellent script for making peace with death. Harvey Chochinov’s dignity therapy, another technique used in hospice, is about summarizing one’s life and taking leave. I combine Byock’s and Chochinov’s ideas in my own practice, telling people about the Four Things and encouraging them to take oral histories when they can.

There will be some people who face death alone, individuals departing life whose social connections are used up, for whatever reason. New rituals may be necessary to honor those solitary individuals, and medical and related professionals may have to step up to the plate when family is absent. These exceptions prove the rule that the dying process calls out for a community ready to carry the person forward.

In the ICU, life completion often must occur quickly. Just because it’s

challenging, though, does not mean it isn't worth the effort. Creating space for life completion will take time, careful attention, and extensive research.

Recognize the Crossroads

A system able to identify warning signs and communicate when a crossroads is near would be a great boon. Identifying such crux moments does not mean refusing medical treatment, although some people will certainly choose an earlier, natural death at a crossroads. It does mean making it possible for people to navigate crucial decisions well informed and able to understand not just the medical risks and benefits but also the personal implications of those decisions. Such guidance when it matters is far more important than a hypothetical list of theoretical treatments to refuse in the event of unconsciousness.

Today, though, we should be open, in a compassionate way, about the option of allowing a natural transition into life's final phases as part of informed consent discussions around procedures or surgeries at potential crossroads.⁵ To put it simply, we oughtn't be saying, "If you don't do this procedure you'll die," but perhaps something like, "Some people in this situation feel that their life is coming to its natural end and don't want medical procedures to interfere with that process. Others prefer even aggressive treatment in the hopes of getting more time. How do you feel?"

To date, very little research has investigated how to recognize crossroads, let alone how to tailor medical responses to the values and priorities of individual patients and their families at a given crossroads. But even without much new research, a modified advance directive could state simply, "If I'm ever in a situation where I could choose to undergo medical treatments or choose instead to allow a natural death for myself, please advise me and my family of this before we start the treatments."

As part of identifying and communicating clinical crossroads, we should be tying advance care

planning to what actually lies ahead for individual patients. To create relevant guidance requires knowing something about the expected course of a given illness, not the standard list of hypothetical events.

Create a Support Community

Patients and families will be better able to identify clinical crossroads if they have communities to support them in the effort. Two expansions of community make sense right away.

We've already seen that families need a place at the table in terms of PFACs and open visitation. New experts of several different kinds may also prove important in spanning the gap between clinicians and patients/families. Guidance will be a team effort that includes more than just traditional clinicians.

[For example], chaplains, where they exist, may be helpful—they receive excellent training and have a proven track record of caring for people of various faiths, including strict atheists.

Authentic Personalization

Treating the experience of life-threatening illness as if it were a problem for a contract to avoid medical care has contributed to the failures of advance directives. This framing has driven the questions asked and answered most often: "When can physicians override your family's desire to keep you alive?" or "Should we ever perform CPR?" To get personalization right will require asking different questions.

Our group at Intermountain prefers to think of advance care planning in terms of Personalized Care During Serious Illness. From this perspective, the better questions to ask include, "What phase of life are you living in now?" "How do you like information to be presented to you?" "Would it ever be okay with you if your family and/or your physicians decided that further medical technology wasn't of service to you?" "Are there any specific things that you worry about if you were to develop a serious illness?"

Good questions are a start, but

answers matter too. Without extensive education and experience, most people don't know how to map their own values and priorities onto specific medical decisions. This step will be crucial to solving the problems with advance directives.

I've described a vision for how the ICU can change in the near future. There is momentum within society and the medical community for real and substantial change. There's much to look forward to. A humane ICU, brimming with healing and meaning, is within our reach.

Notes: 1. While the email, in my possession, is reproduced verbatim here, the story that follows is lightly hybridized to maintain privacy. 2. Hilde Lindemann Nelson and James Lindemann Nelson, "The Patient in the Family: An Ethics of Medicine and Families" (New York: Routledge, 1995) provides a useful overview of consideration for families in medicine. 3. Very rarely, a family member is so emotionally overwhelmed that she or he is unable to be present in the room without creating a dangerous distraction from the medical tasks at hand. I'm mindful that such an exclusion could easily be overinterpreted to justify broadly exclusionary policies. In my experience, this is only true of perhaps one percent of family members. 4. Ira Byock, "The Four Things That Matter Most: A Book About Living" (New York: Free Press, 2004); Harvey Chochinov, "Dignity Therapy: Final Words for Final Days" (New York: Oxford University Press, 2012) 5. One of the elements of the ABIM [Foundation] Choosing Wisely campaign for critical care is offering people the option of a natural death whenever aggressive treatment is proposed.

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



“Youth is the gift of nature, but age is a work of art.” — POET STANISLAW JERZY LEC

THROUGH MY EYES

By Rev. Dr. Jade Angelica, MDiv, DMin

*Do you not see or understand?
Do you have a hardened heart?
Having eyes, do you not see?
And having ears, do you not hear?*

— Mark 8:17b-18a (NIV)

“It is only with the heart that one can see rightly.”

— Antoine de Saint Exupéry, *The Little Prince*, 1943

Too often individuals, communities, and whole societies make judgments about persons with Alzheimer's [disease] through “eyes that see but do not see,” and conclude that they are lost, gone, useless. In order to “rightly” see persons with cognitive diminishment, we need to look with the eyes of our hearts.

Through the great honor of being my mother's companion on the journey, I developed a clear and blessed vision of persons with Alzheimer's. And now I see that they still have the potential to inspire us, teach us, love us, heal us, amuse us, befriend us, calm us, touch us, energize us, enlighten us, empower us, forgive us, nurture us, open our hearts, bring out the best in us, and bring meaning into our lives. With an unending desire—and capacity—to give and receive love, persons with Alzheimer's can reveal to us the healing potential of relationships.

Peggy was my mom's neighbor in the nursing home. Her husband was

away for the winter, and although they had spoken on the phone, she hadn't seen him for six months. The first day he returned, he took her out for lunch. When they arrived back at the nursing home, he kissed her goodbye and left her at the nurses' station. With this dreamy, teenager-in-love gleam in her eye, she shouted to everyone, “I'm going to marry that man!” She didn't remember that he was already her husband, but something in her knew they belonged together.

Perhaps her Spirit recognized his Spirit. That's what I felt happening between Mom and me. One day, I came into her room and she stopped what she was doing. She looked at me—really looked at me. Then she said, “You. You. It's you.” It was a moment of pure recognition and belonging, even if she wasn't exactly clear about the relationship between us.

If we can look beyond the losses of memory, cognition, and motor skills, we will make a surprising discovery. Persons with Alzheimer's can still show us the true value of life: theirs and ours. This timeless, human-defining truth is so beautifully expressed in the words of St. Teresa of Avila: “The important thing is not to think much, but to love much.”

Holy Spirit, sustain us, please, as we care for our loved ones with Alzheimer's and dementia. Help us to soften our hearts, and to see them through the holy eyes of one who seeks God in every corner of life. Amen.



Rev. Dr. Jade Angelica, MDiv, DMin, of Dubuque, Iowa, is a Unitarian Universalist community minister. She is the founder and president of the board of directors of Healing Moments Alzheimer's Ministry, and the author of *Where Two Worlds Touch: A Spiritual Journey Through Alzheimer's Disease* (Skinner House, 2014). Her most important ministry, to date, she says, has been caring for her mother, who died from Alzheimer's disease in 2011. Her essay “Through My Eyes” is included in *Seasons of Caring: Meditations for Alzheimer's and Dementia Caregivers* (ClergyAgainstAlzheimer's Network, 2014). It is reprinted with permission.

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“Faith is the bird that feels the light when the dawn is still dark.”

—POET RABINDRANATH TAGORE

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