Advance Care Planning: Mission and Opportunity

Chaplains’ skills are suited to the advance directive conversation – by David Lichter.........................2
Advance care planning takes hold across a system and a region – by Gundersen Health System.............3
Chaplain in outpatient office gets reimbursement for ‘the conversation’ – by James L. Robinson............5
Ethical and Religious Directives can help form care plan – by Michael McCarthy.................................7
POLST might help more patients get the care they want – by Daniel Waters........................................9
Chaplains should know advance directive laws in their state – by Danielle Sapega..............................11
How one advance care meeting led to three directives – by Tim Crowley.............................................13
Psychiatric advance directive might help patients with mental illness – by Daniel Waters......................15
The Five Wishes serve as helpful planning tool – by Maggie Finley......................................................16

Seeking, Finding

The Communion of Saints: A fresh look at a traditional belief – by Charles W. Sidoti.............................18

Book Review

Spiritual Care in Common Terms.............................................................................................................20
Chaplains’ skills are suited to the advance directive conversation

By David Lichter
Executive Director

This issue on advance directives is an important one. Many of our NACC members engage daily in the delicate discussion about preparing now for end-of-life decision-making. How critical our members’ intervention is! We are grateful to all who have a role in this process for patients, residents, and their families. We are grateful to all those who contributed substantive articles to this Vision issue. The theme was chosen to correspond with the 2018 National Health Care Decision Day (www.nhdd.org/about), which is April 16, as NHDD exists “to inspire, educate and empower the public and providers about the importance of advance care planning.”

The November-December Health Progress issue on end of life included an article on advance care planning by two physicians who shared some well-known dramatic data on how few Americans have an advance directive (www.chausa.org/publications/health-progress/article/november-december-2017/advance-care-planning-leads-to-wished-for-care). However, an even more significant statement was:

Unfortunately (but not surprisingly), advance directives “have had relatively little impact on end-of-life decision-making” and have been disappointingly ineffective. This is because of barriers that are conceptual (general reluctance to explore death and dying), structural (inadequate clinician training, etc.) and procedural (restrictions on who can serve as a health care agent or proxy), notwithstanding the passage of the Patient Self-Determination Act of 1990 and multiple initiatives to promote their use.

Facilitating an advance directive, they observe, has moved from a legal process of completing a document to a comprehensive communication process with patients and families to ensure the treatment plan aligns with the patient’s and family’s values, beliefs, and wishes.

They further make the point, which chaplains already know, that “conducting effective advance care planning conversations is a skill. Clinician training will need to begin in graduate school and continue during residency and post-graduate training. For more senior clinicians, instruction in advance care planning can be provided through recertification or continuing medical education.”

I suspect that such a curriculum for clinical training would be similar to much that is covered in the first unit of CPE — training that helps one tend to the other and listen deeply for the unarticulated. But listeners must also face their own finitude and end-of-life issues, whether their own or a loved one’s. These are the skills of all of you, who have been professionally prepared to be with the other in his or her vulnerability.

I wonder how many of our members have educated and trained other clinicians in how to conduct advance care planning? It would be interesting to hear from you. I wonder whether it would be worthwhile to convene via conference call those of you who do so, and whether we could offer the clinical community some leading practices in developing the skill?

Another important question: Have we all, whether alone or with family, tended to this most important task of completing our own advance directive, not as a legal document but as an opportunity for communication? Is yours up to date?

I have updated mine a couple of times, most recently when I had my right hip replaced last May. It was good again to sit down with my wife, Jackie, and together to discuss our end-of-life scenarios and complete our review of our advance directive, along with our power of attorney. Please treat yourself to the process, and be kind and thoughtful to your loved ones in doing so.
Advance care planning takes hold across a system and a region

By Gundersen Health System

At Gundersen Health System in La Crosse, WI, advance care planning is the process of communication aimed at helping people understand and articulate their thoughts and preferences for future medical decisions (www.gundersenhealth.org/patients-visitors/advance-care-planning). The process is crucial to help patients receive the best care according to what matters most to them, if a time comes when they cannot make their own decisions.

“Unexpected things happen when we least expect them,” says Danielle Rathke, DNP, RN, Gundersen’s advance care planning director. “The best time to begin to plan and prepare your loved ones is while you feel well — before a health crisis.”

Over the last few decades, the culture in La Crosse has shifted so patients have become open to planning for future healthcare. Now, the typical patient understands the importance and value in having these not easy but important conversations.

In 1995-1996, and again in 2007-2008, data was collected and published to study the percentage of deceased patients in the La Crosse region who had written plans accessible in the medical record and who had evidence that treatment decisions were honored. Gundersen had a high prevalence of planning (85 percent and 90 percent), the documents were accessible (95 percent and 99 percent), and treatment preferences were honored (98 percent and 99 percent).

Gundersen recommends that people review their advance directive every five to 10 years or with a change in health. The system suggests a review using the “five Ds” — each decade, new diagnosis, decline in health, divorce, or death of a loved one. Gundersen has a specific space in the electronic medical record where all ACP-related information is stored and easy to access. Advance care planning is reviewed with annual visits, hospital admissions and other clinical encounters as appropriate. Patients can access ACP information through Gundersen’s patient portal called MyCare as well.

Meaningful conversation about what matters most is the best way to begin planning for future healthcare decisions. For many people, this is not an easy topic to broach. Gundersen Health System provides trained facilitators who ease the process by guiding people and their families through a conversation. Advance care planning facilitators help people reflect on what matters most in their lives and discuss acceptable and unacceptable outcomes should they experience a health crisis.

Chaplains are typically excellent candidates for providing facilitation services. Pastors or parish nurses in the community can also make good facilitators. Gundersen holds both internal and community First Steps facilitation courses. Pre-course requirements take four to five hours before the full eight-hour instructor-led course. Participants leave the course with basic skills
for the conversations; ongoing practice leads to mastery. The organization provides mentoring through observation and co-facilitation activities for our facilitators.

“Advance care planning is not just talking about end of life but is about discussing how a person wants to live,” says Elizabeth Cogbill, MD, Gundersen’s advance care planning medical director. “We all have our own definition of quality of life, and we can’t assume that those around us automatically know it. We have to talk about it.”

In addition to assisting with the conversation, facilitators arm people with information, dispel myths, and answer questions. Typically these conversations result in a written plan called an advance directive. Gundersen recommends an advance directive that includes power of attorney for healthcare. Through this document, an individual legally designates a person(s) to speak on her behalf if she becomes unable to communicate her decision and includes instructions for future care.

In Wisconsin the legally designated decision-maker is known as a healthcare agent. A healthcare agent makes decisions based upon the person’s goals, values, and preferences as conferred in conversation and as set forth in an advance directive. The healthcare agent speaks on behalf of a person only when the person cannot speak for himself. An advance directive gives the healthcare agent authority for healthcare decisions but not for financial decisions. (Note the difference from a power of attorney, which allows a designee to execute certain property or financial matters on someone’s behalf — but not make medical decisions.)

“The best way you can prepare the people closest to you to speak on your behalf and to protect them from additional stress during a difficult time is to have the conversation. It’s a gift to your family,” says Rathke. “The conversation has so much value. Without it, there can be confusion, conflict, and guilt in a situation that’s already overwhelming.”

Advance care planning is an ongoing process that must be revisited over time. It’s important to begin when someone is healthy so that if he or she is faced with an illness, this type of planning is not a new concept.

“We provide assistance with planning over the course of a person’s lifetime,” Rathke says. “We begin when people are healthy, and our conversations become more specific when a person develops a serious illness and when a person is nearing the end of life. It is never too early to prepare yourself and loved ones for decisions that may be needed in the future.”

Learn much more about advance care planning at www.gundersenhealth.org/patients-visitors/advance-care-planning/#FAQs.
Chaplain in outpatient office gets reimbursement for ‘the conversation’

By James L. Robinson

In January 2016, the Centers for Medicare and Medicaid Services began to reimburse physicians for advance care planning conversations. That opportunity started CHRISTUS Santa Rosa of San Antonio on a journey to create a robust ACP program. The issue quickly became: where to house this initiative and would reimbursement work within the hospital setting?

Not so well, it turned out. Our hospitals are reimbursed by Medicare through a complex “bundled” payment method for services provided, which was not the method of reimbursement for ACP that CMS had in mind (although even that has changed recently). Incentives were written into the regulations that rewarded the physician for holding the conversations in the physician’s office during regular office visits, and most observers were consistent in the opinion that the preferred location for a conversation about end-of-life issues was the physician’s office.

However, those observers also noted that physicians often feel that they are not prepared to hold those patient conversations, nor do they generally have the time. Physicians, though perhaps aware of the opportunity, were not lining up to take on this additional task.

After many conversations within our Mission Integration department, the clear direction emerged for placing a chaplain in the associated CHRISTUS physician setting, on the physician’s payroll, as an advance care planning coordinator. In September 2017, the position was created within CHRISTUS Physician Group to serve two family medicine practices. The coordinator, a chaplain with five units of CPE, is a First Steps Certified instructor and is certified by the California State University program in palliative care for chaplains.

Patient visits in the physician’s office are generally scheduled in 15-minute and 30-minute slots, which, with multiple physicians, creates a fast-paced routine. After the physician visit, the opportunity to have a brief advance care planning conversation is presented to the patient. The conversation is then typically held in the exam room or in the coordinator’s office. For Medicare patients having their annual wellness visit, who comprise most of the coordinator’s patient load, the visit is free. For others, the normal Medicare co-pays apply.

After the visit with the patient, which is typically 20 to 30 minutes, the coordinator charts the visit in the physician electronic medical record as a “general procedure” with the CMS billing code attached to the documentation. The documentation notes who was present during the conversation, what was discussed, time of the conversation, and whether advance directives were completed. (CMS does not require advance directive documents to be completed in order for the physician to seek reimbursement.) That documentation and billing code become part of the normal office billing procedures. To date the two family medical practices that share the coordinator have billed for more than 250 advance care planning visits, which easily supports the costs of the coordinator.

What have we learned? First, “the conversation” in the physician’s office is quite different from “the conversation” in the hospital. Most patients are receptive to talking about advance directives. The physicians report that there has been 100 percent positive response. Occasionally, however, time is the commodity that is lacking in the outpatient setting. Patient appointments typically run late in the physician’s office, and adding an extra 20 to 30 minutes to the patient’s experience can be an unexpected burden. Charting in the electronic medical record is quick, using a standard template that covers most of the required information.
Texas requires two witnesses to the advance directives, but one of those witnesses cannot be an employee of the patient’s physician. Therefore, we are generally unable to complete the advance directives in the office, but we stress the importance of sending the completed documents back as quickly as possible. We discuss the details of filling out the documents, who should have copies, and where copies should be kept. We also discuss travelling with documents and, for those interested, making a digital copy and storing on their phone.

The conversation in the physician’s office is more document-focused. It is a conversation about “the conversation,” and it is often the first time that a patient has encountered advance directives. For those patients who have completed advance directives, the outpatient setting is a good place to review them and to talk about who should have copies of the documents, including their physician.

The Jan. 16, 2018, issue of the Journal of the American Medical Association Internal Medicine carried a brief research letter by Aoife C. Lee, DMin, BCC, who described a similar initiative in Chicago with similar results (https://jamanetwork.com/journals/jamainternalmedicine/article-abstract/2668630). Her conclusion: “It is feasible and acceptable for a qualified chaplain to conduct ACP conversations in a medical office. ... The physician’s introduction of the chaplain was vital to the initiation of an ACP conversation of a time limited office visit. ... A crucial step has been taken by initiating the discussion of patients’ (end-of-life) preferences.”

James L. Robinson, BCC, CHECK is advance care planning coordinator for CHRISTUS Physician Group in San Antonio, TX.
Ethical and Religious Directives can help form care plan

By Michael McCarthy

Matthew’s Gospel offers several narratives that center on Jesus’s healing ministry. While the miracle narratives center typically on the wonder of the miracle, for those in healthcare ministries, they also create an opportunity to reflect on the finitude of life, the challenges presented by illness, and the wisdom within the Catholic tradition for discerning the patient’s choices when treating a serious illness or near the end of life. The Ethical and Religious Directives (ERDs) serve as a helpful resource that emphasizes the importance of advance care planning, articulates how the Catholic tradition envisages decision-making, and provides a rationale for not offering treatments that go against Catholic teaching.

There are essentially three forms of advance care planning: a living will, healthcare power of attorney form, and a physician order for life-sustaining treatment. POLST could be the least well-known and has received some critique in Catholic commentaries.

One critique centers on the seeming permanence of an order made before knowing the specific context. Thus, does a patient prematurely refuse treatments without knowing the ramifications of that decision? Secondly, there is concern that the physician might not have enough information about the patient and is following an abstracted process. Tom Narin, the former senior ethicist at Catholic Health Association, acknowledges that the form is not perfect, but the goal of the POLST is to initiate further conversation on advance care planning. It brings the patient’s physician into care planning, and it seems most appropriate around a serious diagnosis. The form need not replace conversations with family that could then be written down in a living will.

The second form of advance directive is the living will, which proves helpful if a patient loses the capacity to make decisions. Capacity is determined by physicians based on the ability to communicate a choice; understand the information and appreciate its significance or consequences; and reason about treatment options. If a patient does not have capacity, the living will offers a clear statement of the patient’s wishes regarding what life-sustaining treatments he or she would find appropriate.

Finally, the healthcare power of attorney form indicates patient preferences based off a standard checklist and identifies an individual to serve as the legal decision-maker if the patient loses capacity or would prefer that someone else make healthcare decisions. It ensures that there is a person whom the patient has talked to about preferences for treatment options. The role of the POA is to act according to the patient’s wishes, not the POA’s wishes. Absent of the patient’s known wishes for a particular decision, the POA might make decisions according to “substitute judgment” or “best interest.” While the best interest standard weighs the benefits and burdens of a particular treatment, substitute judgment makes the decision as if the POA was the patient. This decision requires thinking through values that the patient held or conversations that the POA and patient might have had in order to make the decision as if the patient were deciding. Chaplains can play an important role in listening and talking to patients, POAs, and family members about the patient’s values and wishes.
The ERDs both encourage advance care planning and offer a moral framework for what constitutes reasonable healthcare decisions at the end of life in the Catholic tradition. Directives 24 and 25 encourage advance planning that is mindful of patient’s preferences and values, while being informed by the Catholic tradition. The Catholic tradition emphasizes ethical decision-making that is informed by the medical facts, respects the dignity of the patient, and balances the benefits and burdens of treatment options. Patients are not required to pursue treatments that do not offer “a reasonable hope of benefit” or that “entail an excessive burden, or impose excessive expense on the family or the community” (ERD, 57). While a patient rarely requests a treatment that goes against the ERDs, it can happen. These requests may become more common in states in which physician-assisted death is legal.

In a Catholic institution, it can be difficult to inform a patient or family that such a choice is not available because it is against Church teaching. But it is important to be aware of patient preferences and listen to the patient’s or POA’s perspective, reflecting back the values you hear guiding the medical decisions. Often patients will cite concerns about losing independence, being a burden, or fear of pain and suffering. While these are reasonable fears, chaplains may be able to reflect on these concerns with the patient and help her consider hospice or palliative care as an alternative. Engaging family members or a patient’s pastor or religious leader could also be helpful. Discuss the ERDs and the guidelines that prohibit participation in physician-aided death. Finally, it is important to discuss the patient’s wishes with the healthcare team and/or a member of the ethics consultation service, in case a transfer of care is necessary.

While physician-aided death is not available in a Catholic institution, chaplains may find themselves working with patients in a secular context where it is. In this instance, a chaplain should listen to the patient and accompany them as far as their conscience allows, but ought not to facilitate making it more easily accessible. If a patient asks what a chaplain thinks about physician-aided death, try to offer the guidance of the ERDs regarding life as a gift, the dignity of all human beings, and the difference between extraordinary and ordinary means of care. These options allow Catholic chaplains to draw from the tradition, distilled into the ERDs. Even outside the walls of Catholic institutions, the ERDs serve as a concise representation of moral tradition that can inform the conscience of both Catholic chaplains and patients.

As in Matthew’s Gospel, many patients and families hope for a miracle without recognizing important decisions that need to be made. While no one wants to take that hope away, the Catholic tradition recognizes the finitude of life, and advance directives can ensure decisions that reflect the patient’s wishes and values. Patients arrive daily at the hospital without having talked about the end of life, which can result in treatment options that they would not have wanted. The ERDs serve as a resource for families and patients as they begin to plan for life’s inevitable end.

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POLST might help more patients get the care they want

By Daniel Waters

An article published in the *New England Journal of Medicine* in November was picked up by many mainstream news services. The elderly man lived in a nursing home but was found unconscious on the street with alcohol in his system. Upon arrival, he was found to have “Do not resuscitate” tattooed across his chest with his name signed and the word “not” underlined. He had no identification, and there were no family and friends present. When his condition worsened, the questions intensified. What if the tattoo was there because he lost a bet in a poker game? What if the tattoo was the result of another night of drinking and that was never his true intention?

Communicating one’s end-of-life wishes clearly and effectively can be more complicated than one might realize. Part of this is the number of invasive life-sustaining measures now in use. Some form of AND (allow natural death) or DNR (do not resuscitate) orders are in common use. Now the POLST (physician’s order for life-sustaining treatment) or MOLST (medical order for life-sustaining treatment) are being used in more than 20 states and are being considered in others.

A core aspect of POLST is that it is portable. A DNR is a doctor’s order put in place when a patient is admitted to a hospital, but when the patient is discharged, the order, like other orders, is discontinued. But POLST follows the patient and does not need to be reinstated at each admission.

The goal is for a conversation to take place between the primary healthcare professional and patient regarding the feasible options of treatment. The primary healthcare professional answers questions and advises the patient. The POLST that can take the shape of electronic and paper notification. Chaplains can relate stories of the bright bold color of their state’s form and how it very visibly accompanies a patient arriving at an emergency room or a direct admit.

In general, a POLST form will include options: full treatment; limited or select treatment with thorough detail; or comfort measures only. Medically administered nutrition and hydration are addressed in the document. The form will include the signature of the healthcare professional and of the patient or surrogate. A form codified by a state is honored in court, and a healthcare professional can have more confidence after these provisions.

Unfortunately, some Catholic individuals and groups operate out of the fear that POLST will compromise a patient’s care or even lead to physician-assisted suicide or euthanasia. Instead, a POLST helps to ensure a patient’s desired quality of life and consultation with their healthcare professional. In November, Pope Francis addressed European members of the World Medical Association. The Holy Father directly addressed the complexity of current treatment options. He referenced the Catechism’s desire that decisions should be made by a patient who is
competent and able to discuss treatment with their physician. He cautions against abandoning the sick, particularly the most vulnerable. He states that these sensitive issues should be addressed calmly, seriously, and thoughtfully.

In the case of the patient with the DNR tattoo, the hospital ethics team was consulted. Minimal treatment was initiated that would not be irreversible in the face of uncertainty. The confirming DNR paperwork was eventually secured, and the patient died the next morning. A fluorescent-colored POLST form might not have traveled with this patient anyway, but a pocket card might have. The details provided would have benefited the patient and the medical team.

The conversation regarding care is not easy. Operating out of fear of details of care overlooks the challenge of the conversation. When we listen intently to the heart of another, the difficult conversation becomes an act of God’s love.

Daniel Waters, BCC, is spiritual care coordinator at Mercy Health in Oregon, OH.
Chaplains should know advance directive laws in their state

By Danielle Sapega

Advance care planning is an interesting blend of clinical, ethical, moral, and legal issues. Some complex scenarios require the input of a multi-disciplinary team consulting on conflicting opinions of a large family. Other situations might simply involve a quiet conversation between a staff member and the patient’s spouse. Laws provide guidance and can help resolve conflict, but the letter of the law does not always settle outstanding problems and arguments around healthcare decision-making.

While advance care planning is still a relatively new concept (the associated laws and legal documents did not appear until the second half of the 20th century), its underpinnings are rooted in the ethical principle of autonomy, which can be traced to ancient Greek philosophy. Autonomy is the principle of self-governance or self-determination, that every human being has the right to dictate how to live his or her own life and make choices. In the context of healthcare, autonomy translates to every human having the right to control every aspect of his or her medical care. Healthcare autonomy has made the legal spotlight multiple times in the past few decades in the form of “right-to-die” cases, including the U.S. Supreme Court cases involving Karen Quinlan, Terri Schiavo, and Nancy Cruzan. These cases arguably represent the worst-case scenarios that can arise, but each case could have been potentially avoided if the patients had prepared advance care planning documents.

In 1991, the federal government enacted the Patient Self Determination Act, which requires healthcare providers to (1) inform patients of their rights to make decisions concerning their medical care under state law; (2) document in the patient’s chart whether or not the patient has executed an advance directive; (3) not discriminate against patients who have executed an advance directive; (4) ensure that advance directives and documented medical care wishes are respected and implemented to the extent permitted by law; and (5) provide education for staff, patients, and the community on ethical issues concerning medical choices and advance directives. The act recognizes a patient’s right to refuse medical treatment, including life-sustaining interventions, and the importance of advance care planning.

The Patient Self Determination Act was not the only legislative development resulting from these controversial cases. Many states responded by passing legislation — or amending already-existing legislation — governing living wills and powers of attorney to help avoid legal uncertainty and confusion. States continue to update their advance care planning laws, and while the laws must comply with the federal law, each state’s laws might be slightly different. This can be crucial when assessing validity of a power of attorney or living will, the extent of the healthcare agent’s powers, and many other issues that could potentially arise during the course of a patient’s treatment.

For example, Pennsylvania law requires that a healthcare power of attorney document must be signed by the patient and witnessed and signed by two adult individuals. However, in New Jersey, such a document is valid if signed by the principal and two witnesses, or if signed in the
presence of a notary and the document is notarized. Whether the New Jersey healthcare power of attorney is valid in another state would depend on whether the other state has permitted legal reciprocity to New Jersey’s laws, or whether that state would hold the document to the standard of its own laws.

However, while a healthcare power of attorney document might not be “valid,” it does not necessarily mean the document will be set aside entirely. To provide another example, if a patient arrives in a Pennsylvania hospital with a document considered invalid for one reason or another, Pennsylvania law provides that the patient’s writing still directs the staff to look to the individual named as the agent to serve as the healthcare representative. In some states, an individual named in a healthcare power of attorney document is considered a “healthcare agent,” while an individual otherwise designated by the patient or by the state laws as the decision-maker is a “healthcare representative.” Other terms include “surrogate decision maker” or “representative.” In many states, a healthcare representative/surrogate decision maker has almost the same extent of decision-making authority as a healthcare agent. So chances are good that the legally invalid document would not mean any disruption in care or a hectic search for available next of kin.

While it might not always be readily apparent, laws are intended to create structure and help society function, and laws governing advance care planning are intended to preserve a patient’s autonomy and help guide healthcare providers and family on decision making. Healthcare providers and patients alike are encouraged to, above all, create advance care planning documents, but they should also familiarize themselves with their respective states’ laws.

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How one advance care meeting led to three directives

By Tim Crowley

In 2015, as a CPE student at a local senior living community, I and hundreds of other healthcare professionals were trained to become certified advance care planning facilitators. Hospice of Cincinnati offered the project, using the Respecting Choices advance care planning program from Gundersen Medical Center of La Crosse, WI (www.gundersenhealth.org/respecting-choices).

During my CPE training, I was privileged to spend time discussing advance care directives with more than 40 residents and families across all levels of care: independent living, assisted living, memory care, skilled nursing, and rehabilitation. I quickly learned that a chaplain, or chaplaincy student, is uniquely qualified to assist residents and families through what can be time-consuming and complex conversations. Almost none of these conversations was done quickly, and many extended over weeks or months, as people need time to process and pray about their decisions.

Our goals were to have each resident consider how they wanted the final chapter of their life to be written and to help them write that chapter. Additionally, we wanted their families to agree with the resident’s wishes. On occasion, the resident was no longer able to make these decisions, and helping the family through the process became the goal. Commonly, we would end up with a living will, durable healthcare power of attorney, a DNR form (if appropriate), and a medical order for life-sustaining treatment form (if appropriate). Other legal documents and arrangements, such as a will, a financial power of attorney, funeral arrangements, and burial site, were often discussed but were not the focus of this effort.

One resident we’ll call Mary said she had her advance care planning documents complete but wanted to review them. I volunteered to meet with her. Mary was approaching her 90th birthday. She had never married and had no children. A nephew was her durable healthcare power of attorney, and on her living will, she had herself listed as a full code and wanted artificial nutrition and hydration. I wasn’t very familiar with her medical history but knew that she had been hospitalized a few months before. I made several attempts to meet with her, but she continued to delay. Her anxiety was palpable. Finally, one day she said she’d like to meet.

I pulled the living will and healthcare POA that she had on file and brought them to the meeting. When I arrived, her nephew, whom we’ll call Mike, was there, as were Mary’s older brother and his wife, whom we’ll call Bob and Carol. I framed the conversation as a chance to review Mary’s wishes about how she wanted things to progress, should her health begin to fail. I explained the meaning of each of the documents, and that they could be changed if they no longer clearly articulated Mary’s wishes. Our first surprise was that Mike was not aware that he was designated as his aunt’s healthcare POA. This led to a long conversation about that role, but he agreed to serve. We agreed that he needed a backup, and his wife was chosen.

Mary then disclosed that she was living with a serious health issue, which could prove fatal. When we got into a detailed conversation, she quickly acknowledged that she was not
interested in having CPR, and that brief trials of mechanical ventilation, artificial nutrition, and hydration were the most she wanted. We prepared a list of items that she would discuss with her physician on her next visit, as she wanted to have a DNR completed by her physician, and wanted to engage in a MOLST conversation with him. The detailed resources that Respecting Choices provides to assist in these conversations were invaluable.

Then the next surprise came. Bob and Carol looked at me and said, “We haven’t done any of this, and probably should. Can you help us?” Bob was in a wheelchair, on oxygen, and in apparently poor health. Carol was near tears. I realized that Mary had invited Carol and Bob, not to support her, but for their own education. I entered the room that day thinking that I would help one resident but ended up affecting three lives. I subsequently helped Bob and Carol through their own advance care planning.

Medicare now reimburses physicians for having end-of-life conversations with patients. I can assure you that a physician, during a 30-minute office visit, cannot go into the depths that a chaplain can. But Mary, at the end of our session that day, was prepared to spend 30 minutes with her physician to cover those items that only he could handle.

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Psychiatric advance directive might help patients with mental illness

By Daniel Waters

The patient faces yet another emotional crisis. He feels that he just cannot hold it together. The acting out intensifies once again, and once again, a psychotic breakdown is imminent. The patient arrives in the hospital emergency department in psychiatric rather than medical crisis, although the two are so often intertwined. This patient’s psychosis manifests with a severe paranoia, and the usual medication regime is now highly suspect, as are these strangers in the emergency department. This patient, who under “normal” circumstances is compliant with all medications, is spinning out of control while refusing to take even blood pressure medication.

For such a patient, the psychiatric advance directive is a relatively new legal document that allows an individual with mental health issues to document his or her wishes for future mental health treatment, and it allows for a proxy to make those decisions during a crisis. Normally in the above scenario, a court order might be required to administer medication by force. With the PAD, the decision to override the patient’s refusal is accomplished with the psychiatric healthcare profession in consultation with the proxy.

The document is drafted when the patient is well enough to execute it, as determined by their mental healthcare professional. A patient hospitalized due to a mental health crisis cannot execute the directive. This is not a document that a chaplain can take to an inpatient room to have a conversation.

This type of directive can include not only a name of proxy, but depending on the state, many or all of the following: a yes or no list of medications; yes or no to electro-convulsive treatment; yes or no to inpatient admission to a facility and for how long; an area to spell out a wellness recovery plan; a yes or no list of physicians; names of facilities to be or not be admitted to; a list of family/friends who can or cannot visit; a place to name someone to care for pets or home.

There are 25 states with psychiatric advance directive, although specifics can vary. The legal definition of capacity is not the same in each state, hence in some a designated physician can make the decision while others still require a judge to decide capacity. The document should be shared with a case manager, the proxy, primary physician, specialists, and family members.

A chaplain in any setting dealing with patients with mental health issues should be aware of these directives for their state. As an integrated member of a care team, it would be important to know whether an individual patient has a PAD. The focus of the PAD is to treat an individual with the dignity that they request when they are well. A chaplain can help to keep the focus on the dignity and value of everyone, especially when it is hard to care about patients who does not seem to care about themselves. Directive 23 in the Ethical and Religious Directives for Catholic Healthcare Services states that the inherent dignity of the human person must be respected regardless of health problem or social status. A PAD helps to extend the healing ministry of Jesus in a challenging area of healthcare.

Daniel Waters, BCC, is Spiritual Care Coordinator at Mercy Health in Oregon, OH.
The Five Wishes serve as helpful planning tool

By Maggie Finley

One of the better tools available for beginning a discussion around advanced directives may well be The Five Wishes (www.agingwithdignity.org/five-wishes). Used by some hospitals and hospices, the Five Wishes function as something of a manual, capturing what needs to be considered about aging with dignity and putting an end-of-life plan in place without solely relying on legalese.

The opening pages define terms and state how the wishes help and who could benefit the most from implementing them. It contains a listing of the 42 states and the District of Columbia where the Five Wishes comply with state requirements by law. But even where it fails to meet state statutes, the Five Wishes is still a helpful workbook or guide in how to have what are difficult conversations, even in the best of circumstances. One section suggests that some people may even choose to revoke a living will and durable power of attorney in favor of the Five Wishes.

The document spells out each wish in clear, accessible language and proposes considerations as well as action steps around each:

1. **The Person I Want to Make Healthcare Decisions for Me When I Can’t Make Them for Myself:**
   The initial section includes what to consider when picking a healthcare agent, along with a list of their duties and expectations. Space is provided for personal notes and a subset titled “If I Change My Mind About Having a Healthcare Agent.”

2. **My Wish for the Kind of Medical Treatment I Want or Don’t Want:**
   Wish two begins with a belief statement about the preciousness of life and human dignity. It defines and expands what it means to have a patient’s wishes respected and followed, plus the patient’s understanding of what constitutes life support.

   On paper, the discussion now opens up to accommodate what to do in particular patient scenarios: in case of an emergency; close to death; in a coma and not expected to recover; permanent and severe brain damage; or “another condition under which I do not wish to be kept alive.”

3. **My Wish for How Comfortable I Want to Be:**
   The next three pages focus on personal, spiritual, and emotional preferences. There are nine statements to be reviewed, and any with which the person disagrees are to be crossed out.

4. **My Wish for How I Want People to Treat Me:**
   This brief section covers a couple of wishes that unfold like spiritual care assessment: Does the person want pastoral presence from a minister or a praying community? Does the patient wish to be touched and talked to even if it appears they can’t respond? Does the patient wish to die at home, and does the patient wish to have others present when death seems imminent?

5. **My Wish for What I Want My Loved Ones to Know:**
   Again, this seems to be within the scope of spiritual care as the patient is asked to reflect on family dynamics, issues of forgiveness and reconciliation, disposition of the body, and funeral
arrangements. There is room to articulate more on the patient’s autonomy and personal belief system.

The booklet concludes with what steps to take once the Five Wishes are completed. Particular steps are articulated, which make the document legal, binding, and a matter of public record. The wishes conclude with special attention to institutional residents, particularly in those states where witnessing requirements are in effect.

_Maggie Finley, BCC, is a retired chaplain from Providence Hospice of Seattle._
The Communion of Saints: A fresh look at a traditional belief

By Charles W. Sidoti

Life can be lonely at times. It is also true, however, that we are never really alone. In many religions, certain men’s and women’s lives of faith stand out in such a way that they serve as examples for others. Some religions call them saints, while others do not. But most have their great men and women whose lives inspire those who read or hear about them.

There are also people found in many faith traditions whose life stories, though less well-known than saints, nonetheless are an inspiration to the faithful. These could be authors, speakers, clergy, or laypeople. They might simply be caring, courageous people whose life stories serve to lead others on their own spiritual journey. There are people we have known personally, living and deceased, including family members, friends, coworkers, and acquaintances, who have helped and taught us in the way of faith. The point is that the lives of others, the famous and the well-known, as well as those in our everyday lives, touch and influence us in deep, meaningful ways.

One thing I find most beautiful about the Catholic faith is the Communion of Saints. In this theological reflection, I will share with you what the teaching means to me, and how I integrate this belief into my spiritual life. The beauty of the Communion of Saints is that it serves to remind us of our basic connectedness to one another as human beings. The Communion of Saints, however, goes a step further by saying that this connectedness is not bound or limited by the power of death. Our love and unconditional regard for one another transcend space, time, and even death.

One day I was sitting in the hospital chapel, praying about something that was worrying me. As I sat there, feeling kind of sorry for myself, I began thinking about the lives of such well-known biblical figures as Moses and Abraham. And it occurred to me that they, too, had to live their lives by faith, just like me.

We tend to see such biblical figures as larger than life and living with some mysterious advantage that we don’t have. But when we fail to see them as regular people, we limit how helpful their lives and stories can be to us. We sometimes see them as having an inside track to God, kind of like having the “God card” hidden in their back pocket to use when they need it. In Scripture, it can seem as if God broke through the clouds during their times of crisis to speak with them directly, giving them the advice they needed. We ignore the fact that God has ways of speaking with us, too, offering the same guidance in our lives. What set these biblical heroes apart is how receptive (open) they were to God’s message.

The value to us in the lives of those biblical figures is that they were human, that they had to walk in our shoes, really walk our path. I felt connected to them when I realized that living a life of faith was as challenging for them as for me. I found myself calling upon their faith to come into my being. I said these words in a prayer, “Faith of Abraham and Moses, come unto me.”
Faith of Mary and Joseph, come unto me.” I immediately felt a connection that was both consoling and comforting, and that has remained with me. It is a peace that transcends time and space and the separation of religions, a spiritual connection.

Many people, myself included, feel a connection with loved ones or special people who have gone on before us in death. We come to know that the love and guidance we enjoyed with these special people did not end with death. Because of physical death, however, the way we experience the relationship changes.

It is not uncommon to hear people say that their deceased loved one lives on in their heart. In our daily lives we help, console, comfort, and pray for one another all the time. The Communion of Saints acknowledges that the bonds of love, support and connectedness that we have with others in this life are not limited in any way. It brings to our conscious awareness that in a transcendent and meaningful way, we are all connected. We are already one.

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Spiritual care treatise goes beyond medical records


By Marilyn Williams

Gordon Hilsman’s “Spiritual Care in Common Terms” is essential reading for both beginning and seasoned healthcare chaplains. Although the subtitle implies that it is a how-to manual regarding medical record documentation, the book is much more than that. Hilsman has written a comprehensive, in-depth treatise for understanding and articulating a patient’s spiritual needs and spirituality from a humanistic perspective. As such, his book is not just for chaplains in this era of holistic, person-centered care, but for physicians and other clinicians.

“Capturing the soul,” or the person’s unique essence, is the goal of writing chart notes, Hilsman writes. However, first he argues for the importance of recording the “intangible,” the human spirit of the patient. Secondly, Hilsman explains a humanistic theory of four primary arenas of spirituality: personal, interpersonal, transcendent, and communal as the means of eliciting and hearing the patient’s story. He asserts that what happens in these arenas “constitutes spiritual needs, the content of spiritual care, and recording it in the medical record.”

Hilsman identifies the most common spiritual needs of patients that he has seen in more than 40 years as a CPE supervisor based on four axes: emotional support, major loss, religious/spiritual practice, and referral needs. After a consideration of these spiritual care needs, he describes fashioning specific goals of spiritual care to address them.

For the actual format of the chaplain’s clinical note, he begins with this quote from a medical resident: “This one chaplain guy writes the same thing every time! What’s the sense in that?” My guess is that many chaplains have experienced the same exasperation in reading another chaplain’s previous note. Hilsman advocates using sentences versus phrases to succinctly summarize the patient’s immediate life situation and the chaplain’s impressions of the current state of the person’s human spirit. The first sentence, he says, is vital for grabbing the reader’s attention. Examples are given of chart notes with suggested improvements.

The next chapter covers extracting the relevant in a patient encounter for providing holistic, person-centered care and thereby for writing a chart note that will be useful to the other members of the interdisciplinary team. Also, Hilsman discusses issues of confidentiality, ethics, and laws. He concludes with a discussion of outcomes and an epilogue for becoming and remaining a spiritual clinician.

*Spiritual Care in Common Terms* should be in every chaplain’s library. It is an invaluable tool for preparing and maintaining board certification because it addresses a number of competencies.

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