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Caring Connections Volume 11 Number 2

Home

Editorial

**Advance Directives:
Relieving End of Life
Anxiety for Individuals and
Their Families**
Kris Maser

**"Physician Orders for Life-
Sustaining
Treatment" (POLST)**
Dave McCurdy

**Advance Directives: An
Important Part of Pastoral
Care and Counseling**
Kevin Voss

**FIVE WISHES - The
Advance Directive "With
Heart"**
John Schumacher

**Advance Care Planning:
Caring for Patients and
Families**
Pat Tadel

A Sandy Story
Melody Meeter

**The Chaplain as Educator
Regarding Advance
Directives**
Russell Belisle

**A Note From The
Trenches: Ten Things I
Wish Everyone Knew
About Advance Directives**
Heather Bumstead

About Caring Connections

EDITORIAL

Chuck Weinrich

Twenty-three years ago, in June, 1991, while I was a chaplain at Overlook Hospital in Summit, NJ, I was one of three guests on a Christian talk radio program in New York City. The topic was "Advance Directives and the Living Will." The host, Andy Anderson, welcomed me, along with Dan O'Connell, former chair of the New Jersey Bioethics Commission and lawyer for the parents of Karen Ann Quinlan. The third guest was Dorothea 'Doe' Dunn, RN, and chair of the Bioethics Subcommittee on Advanced Directives at Overlook Hospital.

Some of my more vivid memories of that hour are of the fear and anxiety I heard in the voices of those who called in, worried that we might be violating God's will by filling out a Living Will form, or angry that this was another way for government to control our lives. A particular personal highlight occurred when a caller asked if I was a born-again Christian who had accepted Jesus Christ as my personal Lord and Savior, and I could calmly answer, "Yes, I am"—although I'm sure my basis for saying so was likely different from his criteria.



At any rate, here we are, 23 years later, with significant progress made in the use of living wills, and even more with Advance Directives. Yet we are still struggling with various aspects of these documents ... while also continuing to develop greater refinements on them.

For example, the New York Times blog, "NewOldAge" (newoldage.blogs.nytimes.com/2014/06/24/) recently focused on "When Advance Directives Are Ignored," stressing the need to make sure the directives are available to all necessary personnel (including one's pastor), and encouraging wider use of POLST (see the articles by Kris Maser and Dave McCurdy in this issue for details on this most recent development).

This issue of *Caring Connections*, therefore, seeks to add to the discourse about Advance Directives through the various articles included in it.

- [Kris Maser](#) gives us a thorough overview of the various documents/tools available for people to use in determining how their wishes about the end of their lives might be made available to others. She has attached a helpful appendix detailing each state's provisions regarding Advance Directives.
- [Dave McCurdy](#) has developed a more detailed discussion of Physician Orders for Life Sustaining Treatment, or POLST, and the advantages of this specific Advance Directive over other options [a quote from a reader: "This (article) reflects Dave's incredible knowledge and experience in biomedical ethics at the intersections of pastoral/spiritual care"].
- [Kevin Voss](#) writes from his perspective as the Director of the Concordia Center for Bioethics located at Concordia University, Mequon, WI, lifting up Christian concerns and attitudes about Advance Directives.
- Have you heard of "5 Wishes"? [John Schumacher](#) writes about this unique format for gathering information about a person's desires at the end of his or her life.
- Gundersen Lutheran Hospital in LaCrosse, WI, has been the site of some creative and effective involvement with its surrounding communities in getting people to complete Advance Directives. [Pat Tadel](#) shares some of the history and rationale behind this heartwarming success.
- [Melody Meeter](#) relates a poignant story about a patient who had survived Hurricane Sandy in New York and whose wishes were honored at the end of his life.
- [Russell Belisle](#) informs us about the valuable role chaplains can play in helping members of church communities complete their Advance Directives.
- What are the things a chaplain wishes everyone knew about Advance Directives? [Heather Bumstead](#) offers her list of 10 important facts.

We hope you will be informed and/or encouraged by these presentations. Do you have a different take on these issues? We refer you, in particular, to an article by [Gilbert Meilaender in the 2010, #3 issue of First Things](#), titled "I Want to Burden My Loved Ones." On the other hand, [Crain's Health Pulse](#) for June 2, 2014 (subscription required) included an article that explores suggestions for *paying* people to fill out their Advance Directives. There certainly are a variety of responses to this ongoing and critical concern! What's your opinion about this all? Please write to either Chuck or Don, and we'll see about including your comments in the next issue of *Caring Connections*.

Call for Articles

Caring Connections seeks to provide Lutheran Pastoral Care Providers the opportunity to share expertise and insight with the wider community. We want to invite anyone interested in writing an article to please contact the editors, Rev. Chuck Weinrich (cweinrich@cfl.rr.com) and/or Rev. Don Stiger (dstiger@lmcsmc.com).

Specifically, we invite articles for upcoming issues on the following themes.

- 2014, # 3, "Ministry in the Second Half of Life"
- 2014, # 4, "Christus in Mundo – A History of the Award for Lutherans in Specialized Ministries"

Have you dealt with any of these issues? Please consider writing an article for us. We sincerely want to hear from you!

As always, if you haven't already done so, we hope you will subscribe online to *Caring Connections*. Remember, subscription is free! By subscribing, you assure that you will receive prompt notification when each issue of the journal appears on the *Caring Connections* website. This also helps the editors and the editorial board to get a sense of how much interest is being generated by each issue. We are delighted that the numbers of those who check in is increasing with each new issue. Please visit www.caringconnectionsonline.org and click on "Click here for free subscription" to receive automatic notification of new issues..

Finally, you may recall that when the ILCC disbanded, the money from the "Give Something Back" Scholarship Fund was divided between the ELCA and the LCMS. This endowment makes a limited number of financial awards available to individuals seeking ecclesiastical endorsement and certification/credentialing in ministries of chaplaincy, pastoral counseling, and clinical education. Applicants must:

- Have completed one [1] unit of CPE.
- Be rostered or eligible for active roster status in the ELCA or the LCMS.
- Not already be receiving funds from either the ELCA or LCMS national offices.
- Submit an application, along with a financial data form, for committee review.

Applicants must complete the Scholarship Application forms that are available from Judy Simonson [ELCA] or John Fale [LCMS]. Consideration is given to scholarship requests after each application deadline, August 15 and February 15. Email forms to Judith Simonson at jsimonson@pennswoods.net and to John Fale at John.Fale@lcms.org.



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Caring Connections Volume 11 Number 2

[Home](#)

[Editorial](#)

[Advance Directives:
Relieving End of Life
Anxiety for Individuals and
Their Families](#)
Kris Maser

["Physician Orders for Life-
Sustaining
Treatment" \(POLST\)](#)
Dave McCurdy

[Advance Directives: An
Important Part of Pastoral
Care and Counseling](#)
Kevin Voss

[FIVE WISHES - The
Advance Directive "With
Heart"](#)
John Schumacher

[Advance Care Planning:
Caring for Patients and
Families](#)
Pat Tadel

[A Sandy Story](#)
Melody Meeter

[The Chaplain as Educator
Regarding Advance
Directives](#)
Russell Belisle

[A Note From The
Trenches: Ten Things I
Wish Everyone Knew
About Advance Directives](#)
Heather Bumstead

[About Caring Connections](#)

Advance Directives: Relieving End of Life Anxiety for Individuals and Their Families

By Kris L. Maser, Esq. with contributions from Paul Hallgren

Even for members of the ministry and people of faith, the end of life can be a truly daunting time.

Watching a family member leaving one life for the next, or experiencing it personally, is weighty enough alone to occupy the mind, but when the process also involves seemingly unrelenting medical treatments or conflict among family members, the situation can quickly become overwhelming. Thankfully, there are ways to make this trying period easier for everyone involved. One such way is by preparing an Advance Directive.

Advance Directives are legal documents that provide instructions for one's medical treatment in the event of incapacity, and the goal of these documents is to ensure that doctors and medical personnel adhere to a person's wishes and directives for care. Some examples of Advance Directives are Health Care Powers of Attorney, Living Wills, Do Not Resuscitate/Do Not Intubate statements, Health Care Directives, and Physician Orders for Life-Sustaining Treatment forms. This article provides an overview of these specific types of Advance Directives, and encourages individuals without one in place to begin the important process of planning ahead for end of life care. Taking this step goes a long way toward alleviating the stress that individuals and their families face during medical hardship. Be advised that the laws regarding Advance Directives and the definitions of their key medical terms vary from state to state, so it is beneficial to consult with an Elder Law attorney to ensure that your Advance Directive is drafted and executed properly.



Health Care Power of Attorney (HCPOA)

When someone is appointed as an HCPOA, this person becomes the medical decision-maker who manages health care during another person's period of incapacity. The HCPOA, often called a "health care proxy" or "health care agent," interacts with medical providers and steers them toward treatments that best serve the interests of the patient. The purpose of assigning a health care proxy is to ensure that people over the age of eighteen (as children are still under the care of their parents or legal guardians) have someone to advocate for them in the event of sudden and unforeseen medical circumstances. For example, if someone slips into a coma after a car accident, his or her agent has access to medical records, consents to medications and surgical procedures, and is entitled to make the other medical decisions that a doctor would have asked the patient directly.

Serving as a Health Care Power of Attorney involves many crucial decisions. It is important to select the HCPOA carefully and to talk with him or her about what it means to be responsible for someone else's health care management. It may at first be a challenging or uncomfortable conversation for the future patient and the potential health care proxy, but taking the opportunity to express one's wishes ahead of time goes a long way in preventing inter-family conflict and ensuring that the person has a strong advocate who will make decisions according to instructions that are provided both verbally and in written form. It is a good idea to appoint one or two backup proxies, too, just in case the primary health care proxy is unable to act on the patient's behalf for any reason. Bear in mind that national law prohibits medical personnel from one's hospital or living facility from serving as the health care agent.

One important matter to note about an HCPOA is that the document does not address one's wishes when it comes to end of life medical issues, organ or tissue donor preferences, and burial or cremation desires. As you will see shortly, there must be other Advance Directives in place in order to address these issues.

Living Wills

Unlike HCPOAs, which cover patients who are incapacitated but not dying, Living Wills specifically address the period of time between a patient's terminal diagnosis and his or her death. In addition to providing post-death requests regarding burial versus cremation and donor status, Living Wills describe a patient's preferences for end of life care. These preferences are called Do Not Resuscitate/Do Not Intubate (DNR/DNI) orders, a type of Advance Directive that identifies for medical personnel which actions are appropriate for prolonging the life of a terminal patient who later becomes incapacitated. Many people write in their Living Will that if a treatment or procedure will only diminish their

quality of life or cause more pain, they prefer to die peacefully. For example, if a patient were to go into cardiac arrest, a DNR order directs medical personnel to abstain from administering CPR or electric shock to restart the heart. Similarly, a DNI order stops doctors from inserting a machine-powered breathing apparatus to maintain the flow of oxygen to the lungs. Remember, it is possible to make specifications when it comes to DNR and DNI orders; patients can order DNR but not DNI and vice versa, and they can also select certain revival methods that they consider less invasive or physically debilitating.

Health Care Directive

In Minnesota and many other states throughout the country, people may execute a Health Care Directive instead of an HCPOA and/or a Living Will. Having this option is beneficial because Health Care Directives combine HCPOAs and Living Wills into a single legal document. Instead of drafting and maintaining two separate documents – the HCPOA for the non-terminal period and the Living Will for afterward – a Health Care Directive simultaneously appoints a health care proxy and delivers one's wishes for end of life medical treatment. Virtually everything, from providing DNR/DNI orders to selecting burial or cremation preferences, as well as donating organs and giving anatomical gifts, can be incorporated into a Health Care Directive. States that embrace the use of Health Care Directives allow their citizens to address the same issues covered by an HCPOA and a Living Will within their Health Care Directive. For general information about the Advance Directives available in each state, refer to the Appendix.

The best ways to learn specific information about the Advance Directive laws in your state are to contact your state's Bar Association or consult with an Elder Law attorney. State-specific forms that can be used to quickly execute a uniform Advance Directive are available online, at your doctor's office, at the hospital, and in places like senior living facilities. However, for Advance Directives with greater richness and detail, it is best to draft original documents with the assistance of an Elder Law attorney or a health care professional. It may be helpful for frequent travelers to familiarize themselves with the Advance Directive laws of their regular destinations to verify whether the rules are similar to those of their home state. Additionally, travelers should make sure that their executed Advance Directive becomes an essential item on their packing list.

Physician Orders for Life-Sustaining Treatment (POLST)

Here is a question that Elder Law attorneys hear often in one form or another: What is the difference between my Advance Directive and a POLST form? This inquiry arises because Advance Directives and POLST forms include similar topics, even though there are some important differences. POLST forms are written and signed by a physician. After checking into the hospital with critical illnesses, doctors have the patient answer questions about who should be the proxy in the event of incapacity and what the patient's preferences are regarding DNR/DNI orders, and the physician takes notes from the conversation on the POLST form. The problem is that the matters of appointing a health care proxy and providing DNR/DNI statements are already addressed in a person's Advance Directive, which was drafted at a time when the patient is healthy and able to arrive at more objective conclusions. The POLST form is useful if the end of life treatment decisions have not been addressed in an Advance Directive, but it should not be used as a substitute unless an Advance Directive was never completed.

It should also be noted that confusion arises from the very nature of the term, "Physician Orders for Life-Sustaining Treatment," because patients are unclear about what the form is intended to do. Contrary to what the name implies, patients are not choosing treatments that will sustain or continue life; they are choosing which treatments they do not want at life's end, when recovery is no longer a medical possibility.

Communication

As you may have gathered already, communication is a common thread among the Advance Directives explained here. You and your loved ones deserve to be as comfortable as possible in the midst of critical medical conditions. The best way to assure that this happens is by preparing an Advance Directive. The key to success during that process is having a conversation with the people who love you to ensure that they understand what you want. As a result, even if your appointed health care proxy does not personally agree with how you prefer your care to be managed, this person will comply with the wishes and directives that you have chosen. When you execute an Advance Directive, make copies, share your thoughts with those closest to you, and revisit your wishes from time to time to gauge how your preferences have evolved. Coping with end of life matters is rarely straightforward and easy, but thoughtful planning and a capable support system can relieve much of the fear and anxiety for everyone involved.

Review of Advance Health Care Directive Laws in the United States

*The Appendix chart ([click here](#)) is shared with the courtesy of Diana Anderson, Esq., and is taken from "Diana Anderson, Review of Advance Health Care Directive Laws in the United States, the Portability of Documents, and the Surrogate Decision Maker When No Document is Executed, 8.2 NAELA J. 183, 200 (2012)."

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planning for incapacity, guardianship and conservatorship issues, and related issues pertaining to wills, trusts, powers of attorney, and health care directives.

An aspiring lawyer, Paul Hallgren is a 2013 Augsburg College graduate with degrees in English and Philosophy and is a member of the administration team at the law firm of Maser, Amundson, Boggio & Hendricks, P.A. in Minneapolis, Minnesota.



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Caring Connections Volume 11 Number 2

Home

Editorial

**Advance Directives:
Relieving End of Life
Anxiety for Individuals and
Their Families**
Kris Maser

**“Physician Orders for Life-Sustaining
Treatment” (POLST)**
Dave McCurdy

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Important Part of Pastoral
Care and Counseling**
Kevin Voss

**FIVE WISHES - The
Advance Directive “With
Heart”**
John Schumacher

**Advance Care Planning:
Caring for Patients and
Families**
Pat Tadel

A Sandy Story
Melody Meeter

**The Chaplain as Educator
Regarding Advance
Directives**
Russell Belisle

**A Note From The
Trenches: Ten Things I
Wish Everyone Knew
About Advance Directives**
Heather Bumstead

About Caring Connections

“Physician Orders for Life-Sustaining Treatment” (POLST)

Dave McCurdy

Not Just Another Advance Directive (and Coming Soon to a State Near You!)

A Case

Ken Norstad (not a real person) is a part-time chaplain at Dignity Hospital. On duty one Sunday evening, he is paged by the nursing supervisor. She asks him to see Mr. Warren, a 66-year-old pre-surgical patient. The unit nurse explains that the patient has questions about “that new Advance Directive” and might wish to complete one. The nurse adds that the questions concern a “POLST” form, which only last month became a legally valid form in their state. Chaplain Norstad has heard about the POLST form but has not seen one. He wonders whether or even how he could be of help to the patient, who is facing surgery in the morning.



Introduction

The case above (which should be an extreme case) suggests some pitfalls that an unsuspecting chaplain encounters when confronted with POLST for the first time and without orientation. This article highlights several features of the POLST process and POLST forms, partly with a view to the conversation Chaplain Norstad might eventually have with Mr. Warren. In the process it flags some general areas of concern that merit chaplains' attention, and suggests ways that chaplains can play an important and positive role in the POLST process (Since space does not permit full exploration of the complexities of POLST implementation, readers are urged to consult the referenced sources and the [national POLST website](http://www.polst.org)). A concluding section will address opportunities and challenges the POLST paradigm presents to chaplains, with special attention to concerns about POLST that have arisen in certain religious and “pro-life” constituencies.

**POLST may be characterized as a movement, a
“paradigm,” and—most visibly—a form.**

Comment on the Case and POLST Overview

In the case at hand, the chaplain is at a disadvantage and is—appropriately—perplexed about how to proceed. With 20-20 hindsight one could wish that Dignity Hospital and its spiritual care department had provided basic information to their part-time chaplaincy staff about POLST with this kind of situation in mind.

Before addressing some specific concerns, it is important to offer an overview of POLST itself. POLST may be characterized as a movement, a “paradigm,” and—most visibly—a form. As a movement, POLST is a nationwide initiative that aims to improve the quality of care for patients at the end of life (see www.polst.org). The POLST movement has developed a “tool” (the POLST paradigm) that ultimately crystallizes “patients’ goals of care into medical orders for a certain subset of patients—those with advanced progressive illness and/or frailty” (Nairn 2013a).

At present the POLST movement is active in 43 states (National POLST 2014a). Nearly half the states have statutes that recognize the POLST form as a valid medical order, and the number of these states continues to grow. The POLST paradigm—which begins with a significant conversation process between a doctor or other healthcare professional and a patient—and the POLST form incorporate a set of nationally recognized best-practice standards for end-of-life care and treatment.

The authorizing POLST legislation and accompanying forms vary somewhat from state to state. Even the acronym "POLST" is not standardized; states have adopted "MOST," "POST," and "MOLST," among others. States' forms differ in appearance and in content. My state, Illinois, essentially grafted POLST orders onto an existing "DNR Advance Directive" form. The disciplines eligible to sign the medical order also vary; in addition to physicians, some states permit nurse practitioners and/or physician assistants to sign POLST orders (In these states, the "P" in POLST may stand for "practitioner" rather than "physician").

It should be noted that completing the form and acting appropriately on written POLST orders present providers, including chaplains, with some challenges that require education and attentive practice. Used thoughtfully and alertly, POLST orders mark a positive step forward in respecting patients' preferences and providing optimal end-of-life care. If used unreflectively or without adequate understanding, they may achieve suboptimal results for patients despite others' good intentions (Nairn 2013a).

A newly published study of POLST outcomes in Oregon, which has a longstanding, well-regarded POLST program, suggests that POLST orders succeed in ensuring that patients' wishes for end of life care are indeed honored. "Of patients who requested that, if their conditions worsened, they be given only comfort measures and not be transferred to the hospital, only about 6%" eventually died in a hospital. Medical ethicist Mark Siegler, not known for overstatement, described this outcome as "absolutely breathtaking" (Brotman 2013).

Completing the form and acting appropriately on written POLST orders present providers, including chaplains, with some challenges that require education and attentive practice.

The POLST Form and Process

It is crucial to remember that the POLST form is the fruit of conversations that should be grounded in an advance care planning process (Nairn 2013b). Chaplains with appropriate training can play a helpful role in this process, as the National POLST Task Force recognizes (2014). Informed participation in such conversations does require familiarity with the POLST form and with some pressure points where issues and concerns may arise. What follows is a general discussion of POLST forms and the POLST process, with a focus on areas that may or should be of particular interest to chaplains.

Typically the POLST form begins by offering the option either to require or forgo CPR in the event of a cardiopulmonary arrest. An ensuing section offers a checklist of "level-of-care" options that can be used to summarize the patient's wishes about overall treatment, given the patient's current condition and goals for future care. One or more additional sections address more specific medical interventions. The aim here, as in the CPR section, is to allow patients to express their treatment preferences effectively, as components of an "actionable" medical "order set" (Goldstein 2013, p. 22).

Beyond the CPR options, the forms move to more comprehensive orders that implement the "level of care" a patient prefers in the event of a non-arrest, life-threatening emergency.

Resuscitation options and patient safety

It is common to assume that POLST orders always aim at limiting treatment. That assumption misplaces the emphasis. The POLST paradigm seeks first of all "to ensure that seriously ill or frail patients can choose the treatments they want or do not want" (National POLST 2014b). This could sometimes mean more treatment rather than less. For example, the form offers the option to elect rather than forgo CPR in the event of an arrest. Therefore a provider should always consult the form to see whether or not the physician has ordered that CPR be attempted. Especially in an era when patient safety has become a central concern in health care, taking the no-CPR option for granted should never be the provider's "default." Chaplains who work with POLST forms might take special note of which option is selected in this area. Similarly, if Chaplain Norstad were to discuss any particulars of the POLST form with Mr. Warren, he would not want to assume that the patient's interest in POLST automatically implies a desire to forgo CPR.

Level-of-care medical interventions, feeding tubes, and more

As the acronym "POLST" suggests, the POLST form is indeed an actionable medical order set. Beyond the CPR options, the forms move to more comprehensive orders that implement the "level of care" a patient prefers in the event of a non-arrest, life-threatening emergency (Goldstein 2013, p. 24). Although the wording varies, level-of care orders typically encompass these options:

- Comfort measures only: optimal symptom management to relieve pain and suffering;
- Limited additional interventions: comfort measures plus basic medical treatments that may include hospitalization; and

- Full treatment/intubation and mechanical ventilation: interventions that may extend to life support measures in the ICU (with comfort measures as indicated).

In addition, the POLST framework normally includes an optional section offering choices about use or non-use of a feeding tube. In some states the form also provides an opportunity to address other medical options, such as the use of antibiotics.

The level of clinical complexity that is involved in the three level-of-care options, as well as the more specific options, suggests a need for the POLST discussion to include a clinically knowledgeable professional. In any event, Chaplain Norstad will hardly want to undertake a serious POLST discussion in the absence of orientation and some level of training. In-depth POLST conversations are in fact often carried out by trained facilitators, such as healthcare personnel (who may include chaplains) trained in a program called "Respecting Choices," that is offered through Gundersen Health Systems (Nairn 2013a). If the facilitator is not a practitioner authorized to sign the POLST order set, there is still a need for review and a signature by a doctor or another eligible professional (Nairn 2013a).

In practice, POLST discussions should normally be the "last phase" in a series of advance-care planning conversations that begin when a patient is healthy.

Patient selection

Another important concern in the POLST paradigm is close attention to the identification of POLST-appropriate patients. It is not clear from the case information whether Mr. Warren is actually an appropriate candidate for POLST orders. In a typical advance directive scenario, the issue might simply be whether he is "competent"—has decisional capacity—to express and record his wishes on an advance directive form, such as a living will or power of attorney for health care. POLST is different in this respect. At 66, Mr. Warren is not particularly elderly, and he could be in relatively good health. POLST is intended for patients with advanced, progressive illness and for the frail elderly. A test question that POLST practitioners are invited to ask themselves is, "Is this a patient about whom you would not be surprised if he were to die in the next 12 months?" If the answer is no, a POLST conversation is likely to be mistimed. The patient would not yet be in a clinical circumstance where POLST would be truly appropriate; inappropriate treatment decisions might be made based on a premature choice among the level-of-care interventions (Goldstein 2013).

Some sources do advise clinicians to consider POLST for other patients, particularly those with strong opinions about CPR and end-of-life treatment (POLST Illinois Task Force 2013) who want to insure their wishes are carried out. There is an ethical case to be made for providing these patients with POLST orders. However, any expansion of the POLST-eligible population raises concerns in some quarters, as described below. In general the key factor is "real-time" discussion of treatment options in the context of a medical condition that makes the options more palpable. In practice, POLST discussions should normally be the "last phase" in a series of advance-care planning conversations that begin when a patient is healthy (Goldstein 2013, p. 22). The POLST discussion can include family members if the patient agrees.

Translation of POLST into hospital orders

Since Mr. Warren is an inpatient, if he were to have POLST orders the question of how best to "translate" his POLST order set into specific hospital orders might arise. The correspondence between POLST's tersely stated level-of-care options and specific treatment options involving vasopressors and other medications, for instance, can be ambiguous. This is not normally a problem for the chaplain to address, but it is a dimension of POLST that chaplains should recognize. Some clinicians have recommended that POLST orders simply replace other in-house orders, but POLST's level of specificity can leave something to be desired. As Goldstein puts it, "one could argue that ... staff at the bedside would prefer to know exactly which [treatments] to use and which not to use, rather than take precious time to translate the level-of-care orders into orders for particular treatments" (2013, p. 24).

The overriding fear of some has been that POLST opens the door to hastened death and even "stealth euthanasia."

Advance Directives and surrogate decision-makers

The question often arises whether POLST orders replace or invalidate "other" Advance Directives, especially if there are discrepancies between them. The legal relationship of POLST orders and Advance Directives varies from state to state. In general POLST orders are not considered patients' Advance Directives (Nairn 2013a) because they are in fact physician orders.¹ Further, the patient's signature is not required on POLST orders in all states (although it is in most). In a handful of states, when there is a conflict POLST orders override advance directives, or the most recently executed document prevails (Nairn 2013a). In practice, such discrepancies have apparently not been a significant problem (Nairn 2013a). A more contentious question can arise in states where a patient's substitute decision-maker, whether a healthcare agent under a power of attorney for health care or another legal surrogate, may authorize revised POLST

orders if the patient loses decisional capacity. There can be ethically sound reasons for this practice, especially when the patient's condition changes. At the same time, it can raise red flags for healthcare professionals protective of patient autonomy or wellbeing. Chaplains who know the participants and their perspectives may play a helpful mediating role.

More on the chaplains' role

The chaplain's involvement with the POLST process begins with awareness of the POLST paradigm and the form used in the chaplain's state. If a state newly adopts POLST, chaplains should take responsibility for learning ASAP about the form and process in their state. They should not take it for granted that their healthcare organization will immediately provide information or education about POLST. They should be proactive in inquiring how their organization plans to handle the POLST process and forms. If the organization plans to treat the chaplains' role with POLST just like their role with "other" advance directives, the chaplains should advocate for a distinctive multidisciplinary approach along lines discussed here. Similarly, if a state's POLST statute or form changes, attentive chaplains can help ensure that their organization integrates the changes in its practice.

The chaplain's constructive role begins with self-education and participation in training about POLST and facilitated advance care planning/POLST conversations. Often, chaplains are already veteran participants in advance directive conversations and advance care planning processes. With their training and experience, and especially with training in POLST facilitation, they can be especially well equipped to engage patients in conversations about the values and goals that inform specific decisions about POLST. Chaplains can also be alert to the issue of patient selection, i.e., whether a particular patient may benefit from POLST orders now or whether, perhaps, the timing for that patient is not yet right. Chaplains can also be alert to concerns about POLST that may arise in local religious and "pro-life" constituencies. Particularly in the Roman Catholic community, there have been vocal critics and even opponents of POLST. The overriding fear of some has been that POLST opens the door to hastened death and even "stealth euthanasia" (Wickman 2010). The perception that POLST is a national movement with political interests, and that it is supported by groups such as Compassion and Choices (formerly the Hemlock Society), has helped to stoke such fears (Brugger et al. 2013).

The sense among some of a POLST conspiracy has been bolstered by specific questions about the POLST paradigm and by theologically based moral objections to it (Brugger et al. 2013) that are more widely shared—even by some states' Catholic bishops (Johnson 2012). In brief, there have been concerns that POLST orders may be "provided ... to patients who are not near death, particularly in nursing homes; that social workers and others without medical training are counseling patients about their use; and that the training materials emphasize withholding rather than providing care" (Johnson 2012), or stress the burdens of life-sustaining treatments while minimizing their potential benefits (Nairn 2013a). Some have even claimed that the real aim of POLST is to reduce the costs of end-of-life care (Johnson 2012), especially in a time of shrinking reimbursements. It is always possible that abuses of a process like POLST will occur, and there may be a grain of truth in some of the criticisms. At the same time, each has been plausibly answered if not refuted by thoughtful Catholic writers (Nairn 2013a; Coleman and McLean 2012). As one article summarizes the matter, "in themselves, advance directives and POLST not only do not contradict Catholic teaching but [they] also facilitate communication, difficult decision-making and patient-centered care" (Coleman and McLean 2012, p. 62). Non-Catholic chaplains who have contact with Catholic patients or residents—and especially those who serve in Catholic facilities—will at least want to be aware of the concerns and the discussions surrounding them. The advent of POLST provides another avenue for patients to state and implement preferences for care near the end of life. Rightly used, the POLST paradigm promotes enhanced respect for patients' preferences and patient-centered care at the end of life. POLST orders and, especially, the discussions that lead to their formulation can help people feel that their dignity and worth have been—and will be—respected in the care they receive. Chaplains can play an important, even vital, role in this process.

Note

¹ Illinois' form, with POLST orders embedded in a "DNR Advance Directive," is arguably an exception.

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Caring Connections Volume 11 Number 2

[Home](#)

[Editorial](#)

[Advance Directives:
Relieving End of Life
Anxiety for Individuals and
Their Families](#)
Kris Maser

["Physician Orders for Life-
Sustaining
Treatment" \(POLST\)](#)
Dave McCurdy

[Advance Directives: An
Important Part of Pastoral
Care and Counseling](#)
Kevin Voss

[FIVE WISHES - The
Advance Directive "With
Heart"](#)
John Schumacher

[Advance Care Planning:
Caring for Patients and
Families](#)
Pat Tadel

[A Sandy Story](#)
Melody Meeter

[The Chaplain as Educator
Regarding Advance
Directives](#)
Russell Belisle

[A Note From The
Trenches: Ten Things I
Wish Everyone Knew
About Advance Directives](#)
Heather Bumstead

[About Caring Connections](#)

Advance Directives: An Important Part of Pastoral Care and Counseling

Kevin Voss

As many people enter middle age, they begin to think of what might happen after they leave this earth to be with their Lord.

Christians ought to undertake advance planning, not from the perspective that they want to be in control of events surrounding their death or to leave a "legacy," but with an attitude of love and concern for those whom they leave behind. Believers should take the time to write a will, leaving earthly possessions to those who need them to make their way in the world and to those who will carry on with the Lord's work after their passing. In his booklet *How to Live a Christian Life*, Martin Luther notes that St. Paul established a simple guideline for living by saying that everything a Christian does "should be for the advantage of others."¹ That motto is incredibly fitting as we prepare for the end of life.



As wills are written and plans are being made, many feel the need to write an advance directive (AD), which is a document that states how prospective patients would like medical decisions to be made at life's end if they are no longer capable of making them. Contrary to popular belief, ADs are not just for the elderly. Many of the most controversial end-of-life cases in the United States involved young people. For instance, most people over the age of 30 remember the national controversy generated by the Terri Schiavo case. Terri was a 26-year-old woman who suffered a respiratory arrest in 1990, was deemed to be in a persistent vegetative state, and kept alive for 15 years with a feeding tube (after she was stabilized she did not need a ventilator). Because she had written no advance directive, a controversy arose about whether or not Terri would have wanted to remain alive if she had severe mental disability. Highly publicized legal battles ensued between her parents and husband. No matter what anyone's views are concerning the ethics of prolonged life support for those in a persistent vegetative state, few want family members involved in expensive litigation over control of their medical care.

Contrary to popular belief, ADs are not just for the elderly.

A contemporary AD has two parts: a section indicating whom the principal (i.e., the person creating the advance directive) wants to make health care decisions if that person no longer can. This decision maker is known as a "power of attorney for health care," "health care agent," or "proxy." Another section of the AD indicates to the attending physician and health care agent the principal's preferences regarding the provision of feeding tubes, ventilators, and other treatments, limitations on mental health treatment, admission to nursing homes, and health care decisions made for incapacitated pregnant women.

Having an AD has several advantages. Chiefly, an advance directive allows people to state their wishes about stopping or maintaining specific treatments at life's end. Many Christians were opposed to early versions of ADs because they saw them as attempts to end treatments inappropriately, even if physicians might be inclined to maintain those treatments. That certainly can be one use for ADs; however, in today's health care environment another use for ADs is to make clear the principal's wish that ventilators and/or feeding tubes should be maintained to sustain life unless the patient is terminally ill and close to death. In other words, principals can declare that they do not want the withdrawal of feeding tubes or ventilators to be the immediate cause of their death.

Christians could also indicate that they want their health care agent to consult or involve their pastors when significant medical decisions are made.

Another advantage of an AD is that it decreases stress on health care professionals and the patient's family. Family members, for example, do not have to argue about how grandma would have wanted things handled at the end of her life. Finally, an AD can serve as a wonderful witness to the Christian faith. Physicians, nurses, and family members must read that document. Believers can state in clear terms how important the Lord is for their lives and that decisions about their care should be based on the biblical view that all human life is valuable and a gift from God. Christians could also indicate that they want their health care agent to consult or involve their pastors when significant medical decisions are made. Some individuals include statements reminding their families that they love them. Here is an example of a statement included in an advance directive written by Christian Life Resources:

My philosophy regarding the health care decisions I would make, if I were able to participate in medical treatment decisions, is based on my belief in the inherent value of human life and that life is a gift from God. It is my desire that all reasonable efforts be made to sustain my life and health.

I believe that death is the normal end of earthly life, and that God takes life by His decision. Therefore, I reject any attempt to end my life when God would sustain it, regardless of any diminished state of quality to my life, even if I have a disability. Similarly, I reject any attempt to lengthen my life when it is clear God intends to take it.

I believe life begins at conception. Therefore, if I have been diagnosed as pregnant and my physician knows of this diagnosis, I request that every effort be made to save the life of my unborn child in full recognition that two lives are at stake, both equal in value and worthy of protection.²

Advance directives do have limitations.

On the other hand, advance directives do have limitations. The most serious limitation of ADs is that not everyone has one. On average, only 25% of all patients have written advance directives. Even if someone has an advance directive, end-of-life dilemmas do not always magically disappear. Bernard Lo, the author of a leading medical ethics textbook, wrote, "People do not always mean what they say; they do not always say what they want; and they do not always want what they say they want."³ Sometimes advance directives use vague terms and cannot apply to all situations. That is why the designation of a good health care agent is so important. Principals should take care to choose someone they know shares the same Christian values about care at life's end. Many people write ADs without the input of their physicians, resulting in directives that are unworkable at the bedside. For example, some ADs indicate that no antibiotics or other treatments are to be administered if the patient is mentally impaired. Unfortunately, this instruction does not take into account the fact that many cases of pneumonia are easily treatable with antibiotics and that treatment, while it will not improve mental clarity, may ease patient discomfort. This directive also does not appreciate that the degree of dementia may vary. Patients with mild senile dementia can often live pleasant lives.

The worst thing someone can do with an AD is to lock a single copy away where no one can get access to it!

Another issue with advance directives is that sometimes people change their minds about specific treatments after they have written their AD. Advance directives are not etched in stone; they may certainly be rewritten. An attorney is not required to execute an AD, although people may find it wise to use one. If ADs are revised, all previous copies should be destroyed, and up-to-date copies should be given to the health care agent, relatives, the patient's primary care physician, local hospitals, and to the principal's pastor. The worst thing someone can do with an AD is to lock a single copy away where no one can get access to it!

What if someone is chosen to be a health care agent for a family member or friend? The best thing the prospective agent can do is to have a discussion with the principal beforehand so the agent knows how that person feels about end-of-life care. If the prospective health care agent cannot in good conscience carry out the principal's wishes (e.g., remove a feeding tube from someone who is not terminally ill), then that person must respectfully decline to be the agent. If the health care agent does accept, and the time comes when that person has to make serious end-of-life decisions, the agent must first try to determine the patient's wishes according to conversations held with the principal while that person was still capable of making decisions. Lacking that information, the agent should try to follow the patient's AD, making the same decisions the patient would have made if decisional. If there is no way of surmising what the patient would have wanted in a specific situation, then the proxy should make health care decisions based on the patient's best interests. Gilbert Meilaender argues that treatments may be legitimately refused or withdrawn at the end of life if they are useless or excessively burdensome for the patient.⁴ Ideally, all serious treatment decisions should be made in collaboration with the health care team, the family, and the patient's pastor.

When a patient or the health care agent faces serious, end-of-life decisions, it is comforting to know that "in all things God works for the good of those who love him."

When a patient or the health care agent faces serious, end-of-life decisions, it is comforting to know that "in all things

God works for the good of those who love him" (Romans 8:28a, NIV). Sometimes the best decision is to simply wait. The Lord often reveals his will to us in his own good time. If decision makers are ever in doubt about whether or not to withhold or withdraw a treatment at life's end, I urge them to err on the side of life, life that we graciously received from God and has been redeemed by Jesus' suffering and death. What a great comfort the Christian faith can be when we are facing death ourselves or forced to make life and death decisions on the behalf of others! We have the confidence of knowing that physical death is only temporary and that we will see fellow believers again in heaven.

If you are a pastor, counselor, or other spiritual advisor, you can walk your parishioners through the reasons for an advance directive as given above. Most important, however, you can share the love of Christ with them even as they prepare to join their Lord in paradise.

Notes

¹ Martin Luther, *How to Live a Christian Life*, 2nd ed. (Minneapolis, MN: Lutheran Press, 2006), 69.

² Christian Life Resources, "Wisconsin Power of Attorney for Health Care Christian Version," p. 6, Christian Life Resources, Inc., www.christianliferesources.com (accessed January 23, 2014). Paragraph divisions are found in the original document.

³ Bernard Lo, *Resolving Ethical Dilemmas: A Guide for Clinicians*, 4th ed. (Philadelphia, PA: Lippincott Williams and Wilkins, 2009), 91.

⁴ Gilbert Meilaender, *Bioethics: A Primer for Christians*, 3rd ed. (Grand Rapids, MI: William B. Eerdmans Publishing Company, 2013), 74.

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Caring Connections Volume 11 Number 2

[Home](#)

[Editorial](#)

**Advance Directives:
Relieving End of Life
Anxiety for Individuals and
Their Families**
Kris Maser

**"Physician Orders for Life-
Sustaining
Treatment" (POLST)**
Dave McCurdy

**Advance Directives: An
Important Part of Pastoral
Care and Counseling**
Kevin Voss

**FIVE WISHES - The
Advance Directive "With
Heart"**
John Schumacher

**Advance Care Planning:
Caring for Patients and
Families**
Pat Tadel

A Sandy Story
Melody Meeter

**The Chaplain as Educator
Regarding Advance
Directives**
Russell Belisle

**A Note From The
Trenches: Ten Things I
Wish Everyone Knew
About Advance Directives**
Heather Bumstead

About Caring Connections

Five Wishes - The Advance Directive With Heart

John Schumacher

It was love at first sight.

I first encountered FIVE WISHES in the mid-'90's at the "Last Acts Conference" in Washington, DC, funded by the Robert Wood Johnson Foundation. At that time the document, created by the Florida State Commission for Aging with Dignity, was an Advance Directive legal only in the state of Florida. However, FIVE WISHES was introduced at the Conference with a plan to modify it to meet the legal requirements of every state where that might be possible. When I returned to Chicago, I suggested to our Chief Executive Officer that when FIVE WISHES meets the legal requirements for the state of Illinois, we should embrace and distribute it in our communities. The rest is history.



What is FIVE WISHES?

FIVE WISHES has been described as the Advance Directive "with heart." It is a user friendly document now recognized as a legal document in 42 states and the District of Columbia. When completed, signed, and witnessed it designates a health care agent and alternate agents (Wish 1), provides direction for medical treatment (Wish 2), and address a variety of spiritual, emotional, and psychosocial issues (Wishes 3,4,5) not considered in most other Advance Directive forms. It is now distributed by 35,000 organizations in the United States on behalf of Aging with Dignity, an independent non-profit agency which continues the work begun in the '90's. The document is available in 27 languages. More than 20 million copies have been distributed in the 15 years that FIVE WISHES has been a national resource. My own agency, Rainbow Hospice and Palliative Care, in partnership with Advocate/Lutheran General Hospital and Resurrection (now Presence) Health Care has been the largest distributor of the Advance Directive in the state of Illinois.

Why am I "in love" with FIVE WISHES?

FIVE WISHES is written in non-intimidating "people language." It is not necessary to be a lawyer or doctor or to have a graduate education to understand the document. It is often a challenging task to begin the process of discussing and completing health care directives. FIVE WISHES gently invites people into the process.

There are many things in life that are out of our hands. This Five Wishes document gives you a way to control something very important – how you are treated if you get seriously ill. It is an easy-to-complete form that lets you say exactly what you want. Once it is filled out and properly signed it is valid under the laws of most states.¹

The introductions to each of the five wishes use similar gentle and inviting language.

If I am no longer able to make my own health care decisions, this form names the person I choose to make these choices for me. This person will be my Health Care Agent (or other term that may be used in my state, such as proxy, representative, or surrogate). This person will make health care choices if both of these things happen: My attending or treating doctor finds I am no longer able to make health care choices AND another health care professional agrees that this is true.²

I believe my life is precious and I deserve to be treated with dignity. When the time comes that I am very sick and am not able to speak for myself, I want the following wishes, and any other directions I have given to my Health Care Agent, to be respected and followed.³

The next three wishes deal with my personal, spiritual and emotional wishes. They are important to me. I want to be treated with dignity near the end of my life, so I would like people to do the things written in Wishes 3, 4, and 5 when they can be done.⁴

FIVE WISHES is literally easy to read. The Illinois Statutory Short Form Power of Attorney for Health Care – and I

would assume, the similar forms used in other states – is a vision test. The print is small and difficult to read. The very appearance of these documents only serves to heighten the stress of those who use them. FIVE WISHES uses a large type and allows white space as it stretches the text across a 12-page workbook.

FIVE WISHES allows for customization. Each Wish includes a number of bullet points which specify powers granted to the agent or actions that he or she may take. The person completing the document simply crosses out the bullet points with which he or she disagrees and lets stand those bullet points which describe the powers to be granted or actions to be taken by the agent. There is also space provided for the individual to write in specific instructions to the agent.

We chaplains and counselors know that the discussion with the agent and circle of support is just as important as the execution of the document.

FIVE WISHES encourages conversation. There are frequent references in the document to conversation with the agent, doctor, family and friends. We chaplains and counselors know that the discussion with the agent and circle of support is just as important as the execution of the document. I have a colleague who had the experience of calling the person who she understood to be the patient's agent. The agent was not aware that he had been selected, could not recall any significant conversation with the patient about her health care preferences, and did not wish to accept responsibility for decision making. At Rainbow Hospice, we refer to FIVE WISHES as a "kitchen table" document, a conversation starter for the time when we gather those closest to us. *Chicago Tribune* writer Barbara Brotman echoed a similar sentiment in a recent column when she reported that the pre-announced topic of conversation when her adult daughters came home for Thanksgiving this year was the completion of Advance Directives.⁵

FIVE WISHES provides in Wish 1 and Wish 2 a clear and simple process for the "nuts and bolts" of any Advance Directive, selecting an agent and providing guidance to that agent. As noted above, it provides opportunity for customizing the powers and directions given to the agent. It gives the individual opportunity to discuss and define his/her own understanding of "life-support treatment." Wish 2 also provides four medical situations which are invitations to discussion about the medical treatment the individual would wish to receive.

FIVE WISHES offers wishes which allow chaplains, social workers and other members of the psychosocial team to engage individuals in exploration of those issues which truly define who each of us is and what is really valued. It is in addressing Wishes 3, 4, and 5 that I have experienced the tears, laughter, and deep insights of the clients with whom I work.

Wish 5, "My Wish For What I Want My Loved Ones To Know," is the most deeply spiritual of the wishes.

Wishes 3, 4, & 5

Wish 3, "My Wish For How Comfortable I Want To Be," is a wish very familiar to those who work in hospice. It is a request for dignity. The bullet points might seem self-evident, but it is important to state the obvious because sometimes the obvious can be overlooked. Wish 3 requests that pain and symptoms be addressed. Pain can be managed at end of life. Unfortunately, myths and misunderstandings among care-givers and family members (and even medical professionals) can get in the way of good pain management. It is important to have this wish clearly documented. Wish 3 also addresses good personal care – bathing, massage, shaving, hair-brushing and the like. This wish is a gift to family members who may experience a sense of helplessness and a desire to do something. Wish 3 provides very clear direction for them.

Wish 4, "My Wish For How I Want People To Treat Me," is a wish which moves to a consideration of the community a person wishes to gather. Should the faith community be informed? Is there a wish for prayer? For others to be present – to hold a hand and talk? For family photos and other significant mementos in the room? For death to occur at home?

Wish 5, "My Wish For What I Want My Loved Ones To Know," is the most deeply spiritual of the wishes. Ira Byock, a nationally known and respected hospice physician, in his book, *The Four Things That Matter Most*, has captured and concretized the end-of-life spiritual work which many chaplains have facilitated and witnessed. Byock reports that he teaches his patients to say four things, "Please forgive me," "I forgive you," "Thank you" and "I love you."⁶ Wish 5 provides opportunity to say these four things, and as I remind those with whom I work, you are not just saying these things on your death bed; you are saying these things next weekend when you sit down with your family to discuss your health care wishes and complete this document. What more important gift could anyone give to loved ones than an expression of love and a commitment to forgive and seek forgiveness NOW?

Completing the FIVE WISHES

At the end of Wish 5 there is a minimal amount of space for funeral planning. It has been my practice to encourage people to either use additional sheets of paper to adequately respond to the funeral planning questions and attach them to the FIVE WISHES booklet or to turn to their faith community leader who probably can provide a funeral planning

resource more appropriate to their faith tradition.

The completed document is signed in the presence of two witnesses who also sign to verify witnessing the signature. Four states (Missouri, North Carolina, South Carolina, and West Virginia) require that the document be notarized.

I then encourage that the document be photocopied "until it fades." Copies should be given to the agent and alternate agents, close family members, primary care physician, attorney, faith community leader, and anyone else who might be concerned about the person's care at end of life. The original should be kept in an accessible place – not in the safe deposit box.

The completion of FIVE WISHES does not mean that the conversation about health care decision making is over. An advance directive, like a will or financial power of attorney should be reviewed periodically to be certain it is still accurate. I recently learned about the "5 Ds". An advance directive should be reviewed when there has been:

- Death – has the agent died?
- Divorce – has the relationship with the agent changed or ended?
- Diagnosis – a new diagnosis which might prompt reconsideration
- Decline – a change in health status
- Decade – at least once every ten years

If FIVE WISHES (or any Advance Directive) needs to be revised, the original should be destroyed, those who were given copies should be informed, and the process of creating a new advance directive should be started. The document with the most current date is always the one which will be honored by the medical community.

The simplicity, gentleness, and spiritual focus (especially Wish 5) of FIVE WISHES make it an excellent resource for chaplains and faith community leaders in initiating conversation about health care decision making in end-of-life care.

How can I use FIVE WISHES?

While an Advance Directive is not required for hospice admission, Rainbow Hospice encourages patients who are able to complete FIVE WISHES. One of my favorite hospice stories is about our patient who in Wish 3 had reported that she wished to receive massage and hear harp music. We sent a music therapist and massage therapist and with the family's permission video recorded the time together as the massage therapist taught the family appropriate touch and the music therapist invited the family to sing hymns to the patient. FIVE WISHES enables us to know and honor the patient's wishes.

Our social workers and chaplains will assist family members, care givers, and bereaved clients who wish to complete an advance directive. We also provide FIVE WISHES to our staff and volunteers and periodically do an inservice on Advance Directives.

In the community we present FIVE WISHES to senior groups, Chamber of Commerce breakfasts, caregiver support groups, community clergy gatherings, Stephen ministry trainings, CPE groups, Eucharistic ministry groups, faith community adult classes, chaplain inservices, and to any other group which expresses interest in beginning the conversation about health care at end of life.

The experience of working with community clergy prompted us to create a check list of ways in which faith community leaders can use FIVE WISHES:

- Offer a FIVE WISHES presentation to parishioners/congregants.
- Offer a FIVE WISHES presentation to the professional staff and their significant others.
- Offer a FIVE WISHES presentation to one or more groups within your faith community – women's group, men's group, etc.
- Hold a workshop for your ministers of care, bereavement volunteers, or other lay ministers and teach them how to use FIVE WISHES with those they visit.
- Offer a program to parishioners/congregants on funeral planning (invite a local funeral home representative) and include FIVE WISHES as a part of the program.
- Offer a program on stewardship or estate planning and include FIVE WISHES as a part of the program.
- Make sure your Parish Nurse is familiar with FIVE WISHES.
- Introduce it to individuals you are serving.
- Introduce it to families with whom you are working – facilitate a family gathering with mom and/or dad and the adult children to discuss and execute FIVE WISHES.
- Conduct a congregation/parish campaign to encourage people to complete FIVE WISHES and report results on a regular basis.
- Establish a file of advance directives and funeral plans in the parish/congregation office (if one does not exist). Create a "tickler system" so that people can be encouraged to review these documents periodically with a staff member or trained volunteer.

- Incorporate advance directives planning in pre-marital counseling.

The simplicity, gentleness, and spiritual focus (especially Wish 5) of FIVE WISHES make it an excellent resource for chaplains and faith community leaders in initiating conversation about health care decision making in end-of-life care. The increasing complexity of medical care and bewildering information presented in the time of crisis make it more important than ever that health care conversations take place before the surgery is scheduled, the therapy is initiated, or the frantic trip is made to the emergency department. FIVE WISHES is a tool which serves well the conversation which begins in the sanctuary, the parish hall, the pastor/priest/rabbi's office or at the kitchen table.

For more information about FIVE WISHES and to order the document, please contact Aging with Dignity at www.agingwithdignity.org or 888-594-7437.

Notes

¹ FIVE WISHES, pg.2

² FIVE WISHES, pg. 4

³ FIVE WISHES, pg. 6

⁴ FIVE WISHES, pg. 8

⁵ Barbara Brotman, *Chicago Tribune*, 12/9/13

⁶ Ira Byock, *The Four Things That Matter Most*, Free Press, NY, 2004, pg.3

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Caring Connections Volume 11 Number 2

[Home](#)

[Editorial](#)

[Advance Directives:
Relieving End of Life
Anxiety for Individuals and
Their Families](#)
Kris Maser

["Physician Orders for Life-
Sustaining
Treatment" \(POLST\)](#)
Dave McCurdy

[Advance Directives: An
Important Part of Pastoral
Care and Counseling](#)
Kevin Voss

[FIVE WISHES - The
Advance Directive "With
Heart"](#)
John Schumacher

[Advance Care Planning:
Caring for Patients and
Families](#)
Pat Tadel

[A Sandy Story](#)
Melody Meeter

[The Chaplain as Educator
Regarding Advance
Directives](#)
Russell Belisle

[A Note From The
Trenches: Ten Things I
Wish Everyone Knew
About Advance Directives](#)
Heather Bumstead

[About Caring Connections](#)

Advance Care Planning: Caring for Patients and Families - The Gunderson Story

Pat Tadel

A great deal has changed in healthcare over the past 60 years or so.

Medical and scientific advances have made significant differences in our lives. As a result, the kind of decisions that need to be made by individuals as they move through their lives regarding health and illness are multifaceted and complicated. It may not always be clear how these decisions fit in with who one is, what one wants for oneself, what the benefits will be, or what the burdens are that would be attached. This situation will not go away. Decisions will continue to become more and more difficult, more complex. It may not always be clear how to sort out not just what the decisions are, but how the possible answers will impact one's life and the lives of those one loves.



Whether or not we have had to make such decisions for ourselves or our loved ones, many of us have sat with patients and their families and witnessed the struggle that occurs when decisions need to be made. At times, these choices impact how, when and where a person dies. The anguish and doubt which accompanies such decision-making situations has not gotten less frequent. This is so, even though the Patient Self Determination Act (PSDA), signed in 1991, assured that patients could have their voice heard and their preferences written down "just in case" they were in a situation where they could not speak for themselves due to a medical crisis or serious illness. Most adults know about Advance Directives (AD), know what they are, and may even know how to fill one out, but the number of those who actually do it is very small. I would expect that most of you reading this have not completed such a document yourselves! So, even though these documents exist, even though we know their purpose, and are aware of the doubts present when making another's decisions in crisis, they are not completed, or are unavailable, or ambiguous, and not very useful. Only 18% - 36% of individuals have completed an Advance Directive.

Most adults know about Advance Directives (AD), know what they are, and may even know how to fill one out, but the number of those who actually do it is very small.

That is, except for one area of the country where, instead of only about 30% of those that die having an AD in place, over 96% do. This culture shift was the result of a community groundswell that started over 20 years ago in La Crosse County, Wisconsin. In the mid-1980s, Dr. Bud Hammes, in his role as ethicist at Gundersen Health Systems (GHS) faced three situations over several months that called for new ways of thinking about how the healthcare system cares for patients. All three of these cases involved patients with end-stage renal disease who suffered devastating strokes. The clinical team expected these patients to survive for some time if dialysis treatments were continued, but they did not expect the patients to regain awareness of self, others or their surroundings. In all three situations, the patients would be dependent on others for care and require dialysis three times a week. The families struggled with what to do; they did not know what their loved one would have wanted. It had never been discussed. The complexities of deciding what to do would require much time and effort to sort through for the clinical team and leave lasting distress with the families. Dr. Hammes saw that changing the way we plan and engage in healthcare decisions could be different, could instead be a model of caring, a gift of love we leave the ones we love.

At the same time, La Crosse area leaders recognized that the "usual" way of educating and encouraging individuals to fill out an AD was not making enough of a difference. They were unsettled, knowing that there were still families who were making decisions that left them wondering if it was what their loved one would have decided. Families were unsure of the patient's goals and values, had never had discussions, and sometimes did not even know they were named as healthcare surrogates until they needed to step in and be the "voice of the patient." There were still too many who were not motivated to complete an AD. This shift from the usual way of doing things included changing the

language, no longer focused on filling out a form—an AD—but about creating a plan which fit with one's goals and values, engaging instead in advance care planning (ACP). Changing the focus from filling out a form to inviting individuals and their loved ones into a conversation about what was important to them to live fully was the focus of the community action. This included two major health organizations collaborating to form one language, included community engagement, ACP facilitation skills training, designing systems to honor patient preferences, and quality improvement.

The religious community was involved from the very beginning in the work. The work in the La Crosse County area engaged spiritual and religious leaders from a broad spectrum of faith groups. One of the Task Force members, a Lutheran minister who was a well-respected and established pastor in the area, was a significant spokesperson regarding the importance of ACP. She viewed ACP as a natural part of ministry, consistent with how faith and values guide one's life when illness may require significant ongoing medical support. Many times people turn first to religious leaders for guidance when discussing end-of-life decisions. As part of holistic care it fit perfectly as part of this initiative.

After two years of full implementation of the educational intervention and system change, the La Crosse project appeared to have had a significant impact on end-of-life planning and decision making. An extensive research study was conducted, with results showing that of 540 adult deaths in the La Crosse community from April 1995 to March 1996, an AD had been written by 85 percent of those who died. Of all those with documents, 96 percent were located in their medical records. Treatment preferences expressed in an AD seemed to be known by family and physician, and were typically followed. A repeat study was done about 10 years later, looking at the impact of the Respecting Choices® model of ACP. In this study, all adult deaths in La Crosse County from September 2007 to March 2008 were reviewed for evidence of ACP. The study showed the following results: at time of death 90% of adults had a written AD, and 99% had an AD in the health record, demonstrating both the prevalence and availability of AD, a significant increase from the results of the 1998 study. This was compelling, as it gave evidence that such a program was not only sustainable, but could show improvement over time.

The powerful significance of pastoral care in ACP as part of the intra-disciplinary care model gives a clear message of holistic care for patients and families at GHS [Gundersen Health Systems], care that includes spirituality as part of the facilitated conversation.

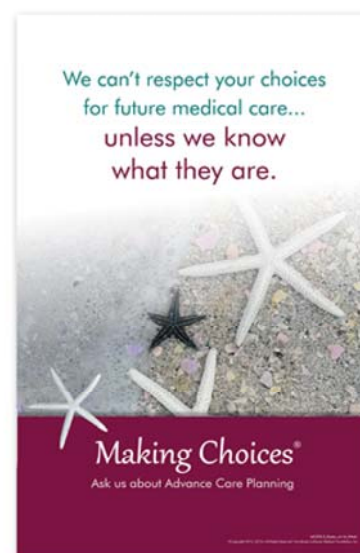
This planning process uses standardized tools as the foundation of the Respecting Choices model. The culture shift moved the conversation from asking the question, "Do you have an advance directive?" to really engaging in a conversation. The Latin root of the word "conversation" means "to come together among." This conversation, by skilled facilitators trained in specific research-driven interview skills and using key research-tested questions, allows individuals and their families to do just that. It is not uncommon to see the individual and agent turn to each other in conversation, sharing and dialoguing. The discussion, as part of the routine of care, follows the individual through the trajectory of illness, with ACP as stages of planning specific to the complexity of healthcare needs and possible shifting goals and values that are part of one's lived experience. The facilitator directs the questions in a guided fashion that allows individuals to explore their understanding, reflect on what is important, what living well looks like, and what possible "bad outcomes" might look like. The facilitated conversation invites patients to discuss with others, in their own voice, what is important and how potential healthcare decisions fit with their expression of self. This discussion helps to frame these goals and values in a way that lets the clinical team know what these goals and values are in relation to possible clinical decisions that might need to be made in a crisis, identifies possible needs for coordination of care, and builds trust as the family and clinicians talk together during sometimes painful expressions of what illness feels like, what goals and values are important, what their hopes are for living well, and for dying how and where they want to.

The individual, during the facilitated interview, is learning how to express him/herself in a way that allows for continuing the discussion when they are with other family members. There is no research that shows how often this happens, but anecdotally, time and again sons and daughters, wives and husbands, and other loved ones tell us that this structured conversation opened them up to rich and deep ongoing discussions with their loved ones. These rich conversations do not stop after the facilitated conversation, but continue when they leave. They learn to express their wishes in ways that enrich their lives. This added benefit is what has been called by one patient's son the "enduring conversation." This patient's son, Greg, asked to share this in the recent book edited by Dr. Hammes, *Having Your Own Say*.

"The conversation was eye-opening for me. With a third party present, I learned things I never knew about my dad – not only his wishes for his healthcare but also things about his career and how he raised his children. What became very clear throughout the conversation was that Dad never wanted to go to a nursing home – he considered it the 'kiss of death' and he did not want to put himself in that place. He also did not want a drawn-out death. Looking back, I see that this was very critical ... The choice was his; the facilitation just provided the road map. That meeting triggered multiple follow-up conversations with my father. The last few years of his life we had more father-son talks than we did for the first 60 years of my life. I wish we could have had those types of conversations earlier." (p. 153)

Research done by Detering, et al. (2010) also points to a less traumatic grief experience by caregivers and family when such a conversation has taken place. In the published research responses by families post-death speak of the death of the loved one as "peaceful," "having a clear plan so we could just relax and enjoy time with dad," and "great to be given the opportunity to talk about it and get it out in the open" (p. 1351).

The difference between AD and ACP is important in other ways. As mentioned previously, ACP is a commitment to ongoing stages of planning, not just a onetime conversation. It is a process, not an event. It requires the interdisciplinary team to engage with the patient on a regular basis, as illness progresses or at times of health crisis, to assure that individual goals and values are honored. This is an important component, because one's sense of what is valuable, what one's goals of care are, and what bad outcomes might look like change over time for individuals as chronic illness develops or other diseases compound one's fragility. It assures that the individual receives the care they want, as well as being able to express what care they do not want. In this way, the team and the patient and/or agent can work together in developing strategies for communicating these choices to those who need to know what they are. This approach to ACP makes a positive difference for patients and families. Studies have evaluated the impact that such an individualized approach to ACP can have. These studies have demonstrated improved quality of life for patients, reduction in stress and anxiety for healthcare agents, and increased satisfaction with the overall healthcare experience.



Today, the model at GHS includes chaplains who play an important role as certified facilitators for the initial stage of planning, called First Steps®. The standardized training for First Steps certification is embedded in the CPE program here. Pastoral care's involvement early on as part of engaging in the health trajectory of individuals supports the goal that the planning process has. In particular, it adds value to the following focus areas:

- identifying and exploring fears, concerns, and gaps in understanding of each patient and helping with coordination to address them;
- exploring patient experiences of illness and medical decision-making and considering lessons learned in these experiences;
- reflecting on individual's values, goals, beliefs, and spiritual considerations, and looking at these in depth relative to the stage of illness;
- identifying questions that individuals may have and helping develop a plan, whether it be medical, religious/spiritual, legal, etc.;
- providing a safe and open forum for discussion between the patient and those who are close, so that they can be openly and fully discussed.

The powerful significance of pastoral care in ACP as part of the intra-disciplinary care model gives a clear message of holistic care for patients and families at GHS, care that includes spirituality as part of the facilitated conversation.

Changing the way we communicate with individuals about their goals and values before they are unable to speak for themselves, having these dialogues documented in a way that the family and interdisciplinary team can formulate care decisions and having these documents readily available are all goals that must be met. These goals will not be accomplished without a culture shift. This involves a shared commitment to changing the systems of care delivery and embedding it in the routine of care. Respecting Choices has developed the components of a systems approach that includes community engagement, professional education, and the development of organization and community standards of practice. Attending to only one of these areas will leave gaps in a system, as many organizations and communities have discovered. Respecting Choices has used these goals as its framework. As a result, ACP has become the routine, expected care model that is woven into wellness visits, revisited at the time of discharge from the hospital, and transferred across care settings. The facilitators are trained using a standardized skill-based approach which guides the individual through specific questions and dialogue focused on understanding, reflection and discussion.

The Respecting Choices model has been replicated in over 80 communities or organizations across the country.

This comprehensive curriculum has become known as "GHS Respecting Choices Organization & Community Advance Care Planning Course." Respecting Choices is an internationally recognized, evidence-based ACP program that is dramatically different from other programs. Since 2000, Respecting Choices has assisted organizations nationally and internationally to replicate the Respecting Choices model through training, consultation and specific materials. The Respecting Choices model has been replicated in over 80 communities or organizations across the country. In August 2002, Respecting Choices was presented for the first time in Heidelberg, a suburb of Melbourne, Australia, where it has since become the model for end-of-life care in all of Australia. Other international Respecting Choices initiatives are now underway in Germany, Singapore, and Spain. In addition, RC has provided extensive consultation and education for multiple Canadian health initiatives. At this time, researchers from seven European countries are conducting a 5-year, 8.5 million dollar study based on the Respecting Choices model. This study will involve 1,200 patients and 20 different hospitals in England, the Netherlands, Denmark, Belgium, Italy, and Slovenia. It has undergone extensive

research testing on adolescents, with a variety of cultures, across care settings, and has demonstrated positive impact.

If you are interested in more in-depth information about Respecting Choices ACP model, would like to watch some of the video clips available, or pull some of the research I have cited for review, here is the link: www.gundersenhealth.org/respecting-choices. The website is a rich resource for the stages of planning that make up the spectrum of care when planning healthcare decisions. I also welcome comments and questions, and can be emailed at pmtadel@gundersenhealth.org.

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Caring Connections Volume 11 Number 2

[Home](#)

[Editorial](#)

[Advance Directives:
Relieving End of Life
Anxiety for Individuals and
Their Families](#)
Kris Maser

["Physician Orders for Life-
Sustaining
Treatment" \(POLST\)](#)
Dave McCurdy

[Advance Directives: An
Important Part of Pastoral
Care and Counseling](#)
Kevin Voss

[FIVE WISHES - The
Advance Directive "With
Heart"](#)
John Schumacher

[Advance Care Planning:
Caring for Patients and
Families](#)
Pat Tadel

[A Sandy Story](#)
Melody Meeter

[The Chaplain as Educator
Regarding Advance
Directives](#)
Russell Belisle

[A Note From The
Trenches: Ten Things I
Wish Everyone Knew
About Advance Directives](#)
Heather Bumstead

[About Caring Connections](#)

A "Sandy" Story

Melody Meeter

A case manager asked me to visit Charlie, who was dying.

I entered the room to find a tender scene: Charlie's niece, Carol, was bent over her uncle, stroking his face. He was lying on his side, eyes closed, oxygen mask on, breathing slowly and quietly. "I think he's going," she said. "You came at just the right moment." I moved to the other side of the bed and stroked his thick, white, wiry hair. "Would you like me to pray for him?" I asked. "Yes," she said, "He would like that." I said The Lord's Prayer, Psalm 23, and I thanked God for Charlie's life. Then Charlie rallied a bit. Color came back into his face. "Uncle Charlie, can you open your eyes?" asked Carol. He did not; however, he lifted his hand and waved it weakly around until he found Carol's hand.

I knew Carol. She was a nurse on the radiation/oncology unit, and we had served on a palliative care task force together. I sat down and she told me Charlie's story. He was 93 years old and had lived in a beach community in Brooklyn for most of his life. Two years before this his wife had died and his health had been declining since. On the day of Hurricane Sandy the residents of Charlie's community had to evacuate, so Carol picked him up and took him to her home. Since her son was from the same community, he also came to Carol's home that day - with his wife and two grandsons. Suddenly Carol and her husband were hosts to Uncle Charlie, a son, a daughter-in-law and two grandsons. After a couple of months, the son's family was able to return to their home, but Charlie's home had been utterly destroyed. Thus it was that Charlie spent the last 7 months of his life with his niece and her husband.



Surrogates who must make medical decisions for loved ones in the final days and months of their lives are often traumatized by the experience.

It had been a rough ride for both Charlie and his niece ... in and out of hospitals ... in and out of rehab facilities. Carol was prepared, she thought, to be caregiver and decision-maker for someone in Charlie's situation. After all, she'd worked for decades in radiation oncology! She was Charlie's legal health care proxy, and she saw to it that the proxy form went with him each time he was hospitalized. But there were so many decisions to make and Charlie, though conscious and competent, didn't want to discuss the details. He was content to leave it all up to her. As Carol said, "I'm sure my husband and colleagues got sick of hearing me talk about it." She told me about the day, a couple of months before this, when a physician she had never met came into the room to say, with very little preamble, "If his leg is not amputated he will die." Charlie was semi-conscious. What should she do? She did not give permission, was certain Charlie would not want it, but it was agonizing for her. She felt guilty, like she was signing his death warrant, like she was saying she did not want her uncle to live.

This is such a common story - treatments being offered without taking into account the deeper questions: What is Charlie's prognosis? Is Charlie dying? Are these treatments and tests what Charlie would want if he knew they were not likely to extend his life? Instead, patients and families often get what seem like conflicting messages from different staff. Take a typical morning. The nurse says, "Blood pressure is better today." The medical resident says, "The antibiotics don't seem to be affecting infection X." A physician says, "I want to schedule you for a colonoscopy today."

The Palliative Care Information Act, in effect in New York State since 2010, requires primary care physicians to offer information about palliative care as a treatment option for patients who are terminally ill. I don't know how compliant physicians are being with this law, but I know nobody sat down with Charlie or Carol to talk about what was happening with his body as a whole. If Carol felt intimidated and overwhelmed by the many decisions she had to make, how much more difficult it is for families who know little of hospital medicine, who are afraid to ask questions or do not know what to ask. Our department of pastoral care, along with the patient relations and ethics department, recently completed a study/survey of family members whose loved ones had recently died at our hospital. Our survey of some 60 family members bore out what several other recent studies have shown: surrogates who must make medical decisions for loved ones in the final days and months of their lives are often traumatized by the experience. In fact, some of the other studies reveal that an alarming percentage of the surrogates later suffered from mild to severe post-traumatic stress disorder.

Because of Hurricane Sandy, Charlie spent most of his final six months, not alone, but within his loving family.

Things could have been different for Charlie and Carol. If he had been enrolled in a home palliative care or hospice program, he might have avoided some of the hospitalizations and perhaps even some of the pain and suffering. Then again, I meet many patients who ARE in hospice or palliative care and still end up in the hospital. The intense suffering at home - vomiting blood, seizures, intractable pain, diarrhea and/or shortness of breath - is not always managed speedily by the hospice or palliative care organizations. (I have wondered about having palliative care ambulances.) Even though people always say they want to die at home, when our bodies are in this kind of intense crisis, we know what to do: we call 911. This would seem to indicate that our culture has lost the ability to stay with the intense suffering and the drama of the dying person.

Charlie lived another day or two after I prayed for him. He died in the hospital. Even in the hospital Carol witnessed some final seizures that amplified her suffering. Couldn't they prevent the seizures? Couldn't even the hospital give Charlie a peaceful death? However, there were many blessings as well in Charlie's final months. Because of Hurricane Sandy, Charlie spent most of his final six months, not alone, but within his loving family. Because of Sandy, Charlie got to watch his two great grand nephews growing. One day it happened that Charlie was alone for a few minutes in the living room, watching the one-year-old, Vincent. And it happened that Vince took his first steps with Charlie as the only witness. Carol recalled how much Charlie enjoyed telling people, "I got to see Vincent take his first steps."

Rev. Melody Meeter has been Director of Pastoral Care for Lutheran HealthCare since 2006. She is a board-certified chaplain in the Association of Professional Chaplains, and an ordained pastor in the Reformed Church in America. She completed her residency training at Memorial Sloan Kettering Cancer Center in Manhattan and has been working in the chaplaincy field for 18 years, with wide experience in ministering to patients and families from many religious and cultural backgrounds. She has a passionate interest in end of life issues and palliative care, and serves on the Ethics Consultation Service for Lutheran HealthCare. In 2012 she completed the Certificate Program for Bioethics and the Medical Humanities at Montefiore-Einstein Center for Bioethics. She teaches both CPE students and medical students on many topics. Most recently, she has completed a workshop at Columbia University Medical School in Narrative Medicine..



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Caring Connections Volume 11 Number 2

[Home](#)

[Editorial](#)

[Advance Directives:
Relieving End of Life
Anxiety for Individuals and
Their Families](#)
Kris Maser

["Physician Orders for Life-
Sustaining
Treatment" \(POLST\)](#)
Dave McCurdy

[Advance Directives: An
Important Part of Pastoral
Care and Counseling](#)
Kevin Voss

[FIVE WISHES - The
Advance Directive "With
Heart"](#)
John Schumacher

[Advance Care Planning:
Caring for Patients and
Families](#)
Pat Tadel

[A Sandy Story](#)
Melody Meeter

[The Chaplain as Educator
Regarding Advance
Directives](#)
Russell Belisle

[A Note From The
Trenches: Ten Things I
Wish Everyone Knew
About Advance Directives](#)
Heather Bumstead

[About Caring Connections](#)

The Chaplain as Educator Regarding Advance Directives

Russell Belisle

I have noticed that, as of late, much has been said about advance directives, also known as living wills.

I have noticed that, as of late, much has been said about advance directives, also known as living wills. As a seminary student in the eighties, I recall that we had lengthy discussions concerning this very topic in our ethics class. Back in those days, Do Not Resuscitate (DNR) or Allow Natural Death (AND) were termed "pulling the plug." Today we are at a place where extubations and withdrawing artificial food are commonplace in many hospitals. With the advent of the Affordable Health Care Act, and community hospital care, hospitals throughout the nation are urging patient to complete an advance care directive while they are of sound mind and reason. As a chaplain at a major hospital in Memphis, TN, I am charged with the duty of providing advance directive consults to our in-patients.



I am one of a core of chaplains at Methodist University Hospital. Our staff is comprised of chaplains of various Christian backgrounds. Our spiritual care department is the gatekeeper for advance directives for the Methodist system of hospitals throughout the city. As such, I have met with dozens upon dozens of patients, to lead them through the process of setting up their advance directive within the hospital. In addition to the in-patients, I am a part of the congregational health network (CHN), the part of the hospital that connects with over 500 local congregations. I am one of the chaplains deployed to congregations throughout the city for the purpose of discussing advance directives in that local setting.

I see this type of presentation as a special ministry. I have visited large and small congregations of various denominations. Some of these congregations have been predominantly white, while others were predominantly black. Very few of the congregations that I have visited have been internally diverse racially; however, there has been diversity in terms of economics. Be it black or white, wealthy or poor, I have experienced similar patterns in these congregations. Pattern one: human beings realize that the long-range prognosis for everyone is death (Job 14:1-2, Is. 40:6-8). Pattern two: advance directives are uncomfortable subjects, and people appreciate having someone who is knowledgeable and trusted leading them through the topic. Pattern three: many people had thought about making an advance directive but it just didn't seem urgent to them.

Advance directives are an uncomfortable topic that brings to mind a sense of loss. Because we don't want to face this topic, we need someone to lead us through it. That is where we chaplains come in.

As a hospital chaplain going into a strange congregation, I often feel like a stranger. The presentations are always to groups of 25 to 70 people. The pastor gives me an introduction and then I usually begin my presentation with a little bit of background about some of my experiences as a hospital chaplain attending to critical patients. The accounts that I give are real, with the privacy details omitted. I have shared accounts of patients who came into the ER with burst aneurysms. When I share these stories, I tell of how unexpected and sudden the illness was, and that it could happen to anyone. More importantly, I detail what it was like for the family to make a decision concerning beginning life support or allowing natural death. Another account that I may share is of a patient in the cardiac intensive care unit that was unconscious and had no family to speak for him. Life or death decisions had to be made in regards to his care and there was no advance directive to lead the medical team in this process. In this case, an ethics consult was ordered to determine the care of this patient. At Methodist Hospital of Memphis, I believe that the ethics team is just that, ethical—with the patient's best interest at heart. That being said, the ethics team is still a body of strangers making important decisions about your health when you cannot speak for yourself.

During a major medical emergency, the family does not always know how to respond. A person who is the only child of

a surviving parent may want to disconnect from life support, but does not want to live with the feeling that he or she killed his or her one remaining parent. Another possible scenario is that a young husband/father has to decide about the care of his wife, and he wants to make sure that everything that can be done for her is done. A written advance directive would be helpful. At this point I remind the gathering that when we are of sound mind we make arrangements for our possessions, and then I ask if it doesn't make sense to make provision about our care when we can't speak for ourselves. It takes the burden off of our family and loved ones.

At this point I have the interest of the people in attendance. Often I have noticed parents looking at young children and adult children looking at their parents as I discuss the decision-making process. With most groups of people the idea has crossed their minds, but normally it is not verbalized. Let's face it; most people don't know how to approach the subject. Advance directives are an uncomfortable topic that brings to mind a sense of loss. Because we don't want to face this topic, we need someone to lead us through it. That is where we chaplains come in. I have found it helpful to distribute copies of advance directives and then lead the group through the process. We usually use the "5 Wishes" document and the Tennessee state form. Both of these are accepted at every hospital in the state. I recommend that you check if you live in one of the 40 states where "5 Wishes" is used. If not "5 Wishes," I encourage you to have an instrument that can be used to lead the gathering through the process of knowing what choices can be made while you are healthy and well. I have also found it useful to give pointers on how to address spouse, parents, and other loved ones about this topic.

My faith informs me that whether or not I request CPR, a ventilator, or medications to prolong my days upon the earth, I belong to Christ.

I personally believe that having an advance directive is a good idea. However, before you address others about such a directive, it is important that you have one yourself. I had been speaking to groups of people about advance directives for over a year before I finally decided to go through the process myself. I thought that it would only take me a few minutes to complete the form; I was wrong. Once I sat down and began to look at the seriousness of the decisions that I would make it was not easy, or cut and dry. I had to meet the challenge of facing the end of my own life. I believe that this experience has given me a better understanding of the process and a greater respect for those who complete an advance directive. I have found it helpful to discuss how I felt filling one out. It gives me a greater appreciation for the importance of my faith in our Lord and Savior Jesus Christ. My faith informs me that whether or not I request CPR, a ventilator, or medications to prolong my days upon the earth, I belong to Christ. If I live, I live to the Lord, or if I die, I die to the Lord, so whether I live or die, I belong to the Lord!

Russell Belisle is a Pastor of Cross of Calvary Lutheran Church in Memphis, TN. He is also a Chaplain/Navigator at Methodist University Hospital of Memphis, TN..



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Caring Connections Volume 11 Number 2

[Home](#)

[Editorial](#)

[Advance Directives:
Relieving End of Life
Anxiety for Individuals and
Their Families](#)

Kris Maser

["Physician Orders for Life-
Sustaining
Treatment" \(POLST\)](#)

Dave McCurdy

[Advance Directives: An
Important Part of Pastoral
Care and Counseling](#)

Kevin Voss

[FIVE WISHES - The
Advance Directive "With
Heart"](#)

John Schumacher

[Advance Care Planning:
Caring for Patients and
Families](#)

Pat Tadel

[A Sandy Story](#)

Melody Meeter

[The Chaplain as Educator
Regarding Advance
Directives](#)

Russell Belisle

[A Note From The
Trenches: Ten Things I
Wish Everyone Knew
About Advance Directives](#)

Heather Bumstead

[About Caring Connections](#)

A Note From The Trenches: Ten Things I Wish Everyone Knew About Advance Directives

Heather Bumstead

1. Advance Directives are meant to empower you to have your wishes honored when you are unable to speak up for yourself.
2. Advance Directives are not activated UNLESS you are deemed medically unable to make decisions (e.g. you are unconscious). They are only in effect as long as that situation continues. If you regain consciousness, you can make decisions for yourself again.
3. Living Wills are one of TWO kinds of Advance Directives: the Health Care Power of Attorney (HCPA) is just as — if not more — important, and often contains the provisions associated with a Living Will.
4. A Living Will is not just about "pulling the plug." It makes clear whatever your wishes are for critical/end-of-life care.
5. EVERYONE should have an HCPA, not just chronically or critically ill individuals.
6. The BEST TIME to make out an HCPA is when you're perfectly healthy ... in other words: NOW.
7. Whether you have an HCPA or not, speak to those close to you about your wishes NOW. It makes the conversation a great deal easier on everyone and is a gift to those who love you.
8. When a family is faced with making critical health decisions for an individual without Advance Directives, they usually need a little more time than health care staff do to see their way to the right decision for themselves (especially if they have no idea what the patient would have wanted).
9. It is often helpful to ask family members of patients without Advance Directives what they think the patient would have wanted. It's simple and obvious, but true.
10. Each patient and each family needs to be empowered to make and be supported in making the decision that is right for them. While this may seem obvious to Spiritual Care Givers, it is helpful for us to remember — especially when staff (out of their own concern and caring) feel passionately about the "right" decision.



The Rev. Heather Bumstead, M.Div., BCC, has had a Living Will and an HCPA since 1997 when she started helping patients execute those documents as a Chaplain Resident at Wake Forest University Baptist Medical Center in Winston-Salem NC. She still helps execute such documents at Froedtert & The Medical College of Wisconsin: Froedtert Hospital Campus in Milwaukee, Wisconsin where she is a chaplain. She is also part-time pastor of Bethania Lutheran Church in Racine, WI..



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Caring Connections Volume 11 Number 2

[Home](#)

[Editorial](#)

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Melody Meeter

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Regarding Advance
Directives**
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[About Caring Connections](#)

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Caring Connections: An Inter-Lutheran Journal for Practitioners and Teachers of Pastoral Care and Counseling is written by and for Lutheran practitioners and educators in the fields of pastoral care, counseling, and education. Seeking to promote both breadth and depth of reflection on the theology and practice of ministry in the Lutheran tradition, *Caring Connections* intends to be academically informed, yet readable; solidly grounded in the practice of ministry; and theologically probing.

Caring Connections seeks to reach a broad readership, including chaplains, pastoral counselors, seminary faculty and other teachers in academic settings, clinical educators, synod and district leaders, others in specialized ministries and — not least — concerned congregational pastors and laity. *Caring Connections* also provides news and information about activities, events and opportunities of interest to diverse constituencies in specialized ministries.

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