

# Supporting End-of-Life Decisions

*The Social Worker's Role in Advance Directives*

BY JULIANN SCHAEFFER

**N**o one wants to think about end-of-life care, but a 2011 survey shows that it is not far from most people's minds and that the vast majority of people understand the importance of discussing end-of-life decisions.

Eighty-one percent of respondents admitted to thinking about end-of-life issues, according to "Living Well at the End of Life: A National Conversation" (*National Journal*/The Regence Foundation, 2011). Furthermore, 97% agree that patients and their families should be educated on palliative and end-of-life care options.

But understanding the value of end-of-life planning does not equate with putting in place such documents, broadly called advance directives. Estimates vary but suggest that approximately two-thirds of Americans do not have any form of advance directive documenting their personal wishes and goals of care in the event they're unable to speak for themselves. Without such planning in place, should someone be involved in a tragic accident or experience a serious medical event, a mish-mash of family members, caregivers, and health care personnel suddenly become responsible for making care decisions on the patient's behalf—often without knowing what he or she would want.

"[Completing advance directive documents] is really a chance for people to essentially elect a second voice for themselves prior to them actually needing it," says J. Donald Schumacher, PsyD, president and CEO of the National Hospice and Palliative Care Organization (NHPCO). "Every person in the United States should have an advance directive because you never know when something could happen where you would be in the midst of a medical difficulty and not be able to speak for yourself."

While Schumacher and other experts agree that it's best to prepare an advance directive before a health care crisis, elder law attorney Marty Burbank, JD, LLM, says it's typical

to create directives upon admittance to hospice or another health care facility. "By law, any facility that accepts Medicare must at least offer to do one for a patient upon admission," he says. That law is the federal Patient Self-Determination Act, which was enacted in 1990 and directs Medicare-participating health care facilities to broach the topic of advance directives with all patients and provide relevant education on health care decision-making rights (Anderson, 2012).

In a hospice or palliative care setting, social workers tend to be the team members most concerned with psychosocial care. Stein and Fineberg (2013) and Black (2005) assert that social workers' knowledge base and communication skill set make them uniquely suited to take the lead in addressing and guiding patients through effective advance care planning. "Social workers should promote advance care planning by encouraging communication among patients and their families about preferences and values for care, assist patients in completing legal documents, and support family and other surrogates in respecting and advancing their loved ones' wishes," Stein and Fineberg wrote.

## Advance Directive Documents

To effectively usher patients through advance care planning, social workers must first possess a solid knowledge base of basic advance directive documents.

As mentioned previously, advance directives are a general term describing the various legal documents people prepare to explain their health care-related wishes in the event they are unable to speak for themselves (American

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The logo for Crossroads Hospice features a stylized green figure with arms raised, resembling a person or a plant, above the text "Crossroads" in a cursive font and "HOSPICE" in a bold, sans-serif font below it.

Hospital Association, 2012). But there are a few other terms social workers must understand to effectively educate patients on the topic.

State laws and legal language vary—some specify advance directives and others use the term living will—yet both identify which medical procedures a person does or does not wish to be performed on them in the event they're unable to communicate their wishes. Social workers working in this area must understand the specific advance directive planning requirements in the state where they work.

The document generally called a living will details a person's choices for treatments to be performed or withheld in the course of his or her care. Patient preferences for procedures such as cardiopulmonary resuscitation (CPR), ventilator-assisted breathing, dialysis, and tube feeding are commonly described in a living will. Properly communicated to health care providers, a living will becomes part of a patient's medical record.

The second key document important to end-of-life planning is a durable health care power of attorney, which gives another person (also referred to as a health care proxy) the authority to make health care-related decisions when the principal (patient) cannot do so personally (American Hospital Association).

"It is important to note that the principal does not give up their authority to make their own decisions [when designating a durable health care power of attorney]; it is only if they can't that their agent steps in," Burbank adds.

The durable power of attorney designates someone only as the legal decision maker and doesn't actually stipulate details of what the patient desires those decisions to be. Utilizing a durable power of attorney to designate someone to represent a patient's interests and a living will to document what those interests are form the core of advance directive planning.

A health care proxy appointment is particularly important when a patient wishes to appoint someone outside of the legal definition of family, "such as same-sex partners in states where those relationships are not legally recognized, or close friends" (Stein & Fineberg).

## Other Documents

Also of note is the HIPAA waiver, which specifically allows named people to get information from the health care provider that would otherwise not be shared because

of the privacy law. The waiver does not give any authority to a named person to make health care decisions.

"[A HIPAA waiver] can be important, especially if there are estranged or dysfunctional family situations and the person with authority under a health care power of attorney may not be communicating well with other family members," Burbank explains.

And lastly, social workers should know about so-called POLST (physician orders for life-sustaining treatment and MOLST (medical orders for life-sustaining treatment) end-of-life medical order forms that many states have instituted for people facing serious and terminal illness. These documents are designed to complement other advance directives by providing the weight of a signed physician's order. They become part of the medical record pertaining to treatment

for a current medical condition, according to POLST.org, which hosts a list of states with POLST programs. These orders contrast with living wills that are designed to plan for future medical situations. POLST orders address treatment for current known health problems.

In the states that have adopted POLST, this form now has replaced the older do not resuscitate (DNR) order. "Both of these are doctor's orders," Burbank says. "The POLST covers more options than does a DNR, but both must be signed by the doctor." The authority of a signed physician's order increases the likelihood the patient's wish will be carried out.

Burbank noted that many physicians are not familiar with POLST documents, but are familiar DNR

orders. He says social workers can provide that education to physicians and that describing POLST orders as next-generation DNRs is a good analogy.

## State by State

Each state has its own laws regarding advance directive documents, and some states have reciprocity agreements with other states to allow a document's validity in more than one state. While state laws differ, "no law or court has invalidated the concept of advance directives, and an increasing number of statutes and court decisions support it" (American Hospital Association).

While most states don't require a lawyer to finalize advance directives, Burbank says social workers may find multiple benefits from initiating a relationship with a local elder law attorney. In addition to being a trusted source for advance care planning legal questions, "Most elder law attorneys won't charge when a social worker calls for a

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patient, but if the patient calls directly, there may be a fee, so this can be very good for the client families," he explains.

Social workers should educate themselves on their own state's requirements to ensure they're able to answer patients' questions or help complete advance care planning documents. Individual state requirements can be found at state government office or other websites, such as the NHPCO's CaringInfo.org or National Healthcare Decisions Day's [www.nhdd.org](http://www.nhdd.org).

## Plan the Discussion

According to Gary L. Stein, JD, MSW, an associate professor and the vice chair of the Social Work Hospice & Palliative Care Network in the Wurzweiler School of Social Work at Yeshiva University in New York, the topic of advance care planning should be broached with all patients, not just those with serious illness, and the sooner, the better. "Advance care planning should be a part of medical care for all patients," he explains. "You want to discuss advance care planning when people are relatively well and not wait until they're in a crisis state of illness. The hospital is not a great time to be addressing these questions because people are in a crisis situation due to their illness. It's better to be able to think through these issues when [patients are] relatively well."

Precisely when to address the issue depends on each patient's unique circumstances, Stein says: "Social workers should use their practice skills to determine when the best time is to bring this topic up. In terms of timing, it needs to be adjusted to the type of setting social workers and patients are in, how long they're likely to be in that setting, and how sick they are.

"In terms of comfort, these discussions shouldn't be rushed; there should be adequate time for discussion," he adds, noting that such a sensitive discussion can go more smoothly if social workers establish a rapport with patients beforehand. "Hospice social workers get the opportunity to spend a considerable amount of time with clients and can establish a relationship before they bring up advance care planning. It's best when there's some kind of preexisting relationship between the social worker and the client, so there's a sense of trust and patients can feel comfortable making known their concerns."

Tulsky (2005) notes that effective communication can benefit patients in the advance care process much more than simple assistance with filling out documents: "Advance care planning remains a useful tool for approaching conversations with patients about the end of life. However, such planning should occur within a framework that emphasizes responding to patient and family emotions and focuses more on goals for care and less on specific treatments."

Stein and Fineberg agree that communication about advance care planning is the most important piece of planning, and social workers are apt health care professionals to facilitate those discussions.

According to Grace H. Christ, PhD/DSW, a research scientist and professor emerita at Columbia University School of Social Work, social workers should not view advance care planning as a one-time discussion with patients but a topic to be revisited whenever necessary. "Serious illness and its treatment today often requires that patients and families confront the possibility of dying multiple times throughout what can be a long disease process," she says. "Patients' and families' awareness and stress is heightened at times of change in the illness, decrease in functional status, or at points of transition to different treatments or changes in their caregiving network.

"Social workers provide critical consultation during these stressful times of transition and change, engaging patients in a conversation about their reactions and plans for future care," she adds. "They are skilled in 'planting seeds' at different transition points that encourage consideration of what if the treatment is not effective or inquiring whether they have discussed their thoughts with family members about their care wishes, as examples. Such questions allow for thinking about what patients hope for in this process and what is most important to them as the illness progresses without forcing unwanted closure and decision making unless they are ready to do so."

Social workers should be prepared to help patients and their families with advance care planning from start to finish. That process includes educating the patient and family about benefits, documentation requirements, and the importance of communication. "Communication requires helping patients understand the benefits of letting others know what they hope for in this process and the documentation that will assure that their wishes are respected," Christ says. "Social workers are experts in implementing communication as an ongoing, multidimensional process rather than a one-time event. By multidimensional, I mean it has informational, emotional, psychological, and instrumental aspects."

Stein sees helping patients select and document a health care proxy as the most important part of advance care planning. "I think designating a person to be someone's advocate and representative in a complex health care system is more important than guessing what types of situations one's going to be in at a future time," he says.

Social workers also may be well positioned to discuss the realities of CPR and other life-support measures with patients near the end of life. "Many people have seen movies and TV shows where someone gets CPR and they have complete recovery," Burbank says. "In reality, it is much different. If a hospice patient receives CPR, the likelihood is that they will die in an ICU with several hoses and tubes placed in them and at great financial expense as well.

"Social workers are also in the best place to describe the effects of tube feeding and IV fluids," he adds. "Lay people's beliefs about these life support measures do not usually reflect a patient's experience."

## Communication and Distribution

So once social workers have assisted patients in creating appropriate and complete advance directives, is their job done? Just the opposite—as experts assert, the real key to effective advance care planning is not creating these documents but communicating and distributing them. Without those key steps, a patient's wishes easily can go unheard in their time of need "because, should it happen that there's no copy of an advance directive there [when it's needed], patients may have things done to and for them that they don't wish," Schumacher explains.

Several issues can prevent a patient's wishes from being followed, the most significant of which is when the document is not readily accessible to providers. But who should receive advance care documents?

As soon as they're signed, Burbank says any patient and health care agent as well as close family members and health care personnel should be informed about the documents' details. However, simply distributing these documents to all appropriate family members and health care personnel is insufficient. One of the greatest acts a social worker can do for a patient is explain these documents in an efficient manner so that the patients' wishes are more likely to be understood and therefore honored.

"The most important thing is not just having the document but having a conversation with those people so they understand [the patient's] wishes and concerns," Burbank says, "not only the person who is given the authority to make decisions for a patient but others who will be around so that they support that person rather than question them at a very stressful time."

When an end-of-life choice is well communicated, it's more likely that the choice will be respected. Social workers' skill sets also make them well suited to address various issues relating to patients or their families related to advance directives. One such issue involves the cultural differences that can complicate advance care planning for some patients.

Different cultures treat death and dying in different ways. The report "Cross-Cultural Considerations in Promoting Advance Care Planning in Canada" (Con 2007) looked at how various cultures across Canada deal with advance care planning and found myriad ways people of different cultures look at the issue. For example, many Chinese respondents said discussing death was seen as unlucky and was essentially inviting it in, whereas many in the country's black community reported "that [advance care planning] was not practiced in their culture because planning for their death would mean that there was no more hope for the person." Respondents of South Asian descent saw death as a "wish from God," thus viewing any advanced planning as unnecessary.

In such instances, Stein says the social workers' role is to allow each individual to make clear what in his or her culture or religion personally is important "instead of making

assumptions about what's important to someone based on their religion or their culture."

"It's always helpful to bring in cultural leaders/community leaders to help understand the issues generally important to people from diverse communities. They may also be able assist in individual cases," Stein adds. "For example, nearly all health care facilities, including hospices, have pastoral counselors and clergy available to assist patients and their families with religious and spiritual matters and to help members of the health care team, including social workers, understand religious customs and rituals associated or implicated with end-of-life care or decisions or after-death practices."

According to Burbank, getting the patient alone can help ensure his or her wishes are being heard accurately. "A patient's faith may have different guidelines than what the patient really wants. It may be hard to express their wishes if there are others in the room who may try to pressure someone into following their church doctrine rather than their personal wishes," he explains.

Effective communication also is integral in times of family conflict, which isn't an uncommon occurrence, according to Stein.

"Sometimes family members want to impose their own values, spiritual beliefs, or views about end-of-life care on their loved one," says Judith Peres, MSW, LCSW-C, a social worker in private practice and a consultant for the Altarum Institute's Center for Elder Care and Advanced Illness. "Conversations about end-of-life care issues are emotionally charged. Social workers, trained to encourage conversation through open-ended questions or empathetic responses when inquiring, can help diffuse family conflict at the bedside. Paying attention to the feelings associated with the content of the conversation is key to resolving communication difficulties."

## Conclusion

Accurate and timely discussion of advance directives helps patients communicate with family and loved ones, and provides patients with a real opportunity to have control in their end-of-life choices. By educating patients on the topic of advance care planning and effectively communicating and distributing the appropriate documents to all parties involved, social workers are in a prime position to offer patients the best chance at ensuring their end-of-life decisions are honored.

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