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Advance Care Planning: Ensuring Your Wishes Are Known and Honored If You Are Unable to Speak for Yourself

Did you know...

- ✓ Most people say they would prefer to die at home, yet only about one-third of adults have an advance directive expressing their wishes for end-of-life care (Pew 2006, AARP 2008). Among those 60 and older, that number rises to about half of older adults completing a directive.
- ✓ Only 28 percent of home health care patients, 65 percent of nursing home residents and 88 percent of hospice care patients have an advance directive on record (Jones 2011).
- ✓ Even among severely or terminally ill patients, fewer than 50 percent had an advance directive in their medical record (Kass-Bartelmes 2003).
- ✓ Between 65 and 76 percent of physicians whose patients had an advance directive were not aware that it existed (Kass-Bartelmes 2003).

Advance care planning is about doing what you can do to ensure that health care treatment you may receive is consistent with your wishes and preferences should you be unable to make your own decisions or speak for yourself. There are several written documents available for us to express our care wishes and/or appoint a surrogate decision-maker if we become unable to make our own decisions. Equally important is making sure that our surrogate knows and understands our care preferences.

WHAT IS ADVANCE CARE PLANNING?

“Advance care planning is about planning for the ‘what ifs’ that may occur across the entire lifespan.” — Joanne Lynn, MD

Whether someone is facing an acute illness, a long-term chronic illness or a terminal illness, advance care planning can help alleviate unnecessary suffering, improve quality of life and provide better understanding of the decision-making challenges facing the individual and his or

her caregivers. An advance care plan can be used at any stage of life and should be updated as circumstances change.

“Advance care plans can be developed at any time, whether you are sick or well,” said Joanne Lynn, MD, a geriatrician and hospice physician who heads the Center on Elder Care and Advanced Illness for the Altarum Institute. “Once you are sick and disabled with a progressive illness that will last until death, you really need a comprehensive care plan that considers your social supports, your preferences, and your likely course. Advance care planning is an essential part of such a plan.”

Advance care planning is about planning for the “what ifs” that may occur across the entire lifespan, such as being maimed in a motorcycle crash at a young age, and not just for older adults approaching the end of their lives, Dr. Lynn said. Those plans can be revised and updated throughout the person’s life as health status and living circumstances change, she added.

Comprehensive advance care planning involves discussion of disease trajectory and multiple conditions, said Kathleen Tschantz Unroe, MD, Assistant Research Professor of Medicine, Indiana University Center for Aging Research. “The patient and family need to understand the patient’s medical and functional condition and what that might look like over the next months or a year and try to anticipate events that can happen. The goal is to try to more proactively make decisions and understand patient values rather than just reacting to changes in condition,” Dr. Unroe said.

Advance care planning is especially important if a patient does not want aggressive treatment, Dr. Unroe said. “The default in our medical system is aggressive care unless there is a clearly written, in-your-face, advance directive.” Otherwise, “a 95-year old who is unresponsive is getting coded [a reference to a “code blue” patient status in a hospital when a team quickly moves to revive a patient without a heartbeat]. If they can get a pulse back and get them into the ICU, that is what is going to happen. That is the American culture and the American medical culture,” she said.

BARRIERS TO ADVANCE CARE PLANNING

“Denial about death does a disservice of not dealing with life-review and life-closure issues that some people would choose to do if they were thinking about dying as part of this last phase.” — Judith Peres, MSW

So why have only one-third of adults prepared an advance directive?

Lack of Awareness. While advance directives are supported by state laws, there is still no clear process to allow an individual’s wishes to be known and ensure that care is tied to those documents. The SUPPORT study, sponsored by the Robert Wood Johnson Foundation, found

that nearly a third of terminally ill participants did not want cardiopulmonary resuscitation (CPR), but less than half of their physicians knew of their preference. Even when patients had written advance directives, their instructions had been discussed with a physician in only 42 percent of the cases (Teno 1997).

Denial. A key part of the problem is our society's denial of death and dying, and of being in a circumstance in which we are unable to make our own decisions and speak for ourselves. "We don't really acknowledge the waning days of life like we do with a birth," Peres said. "Denial about death does a disservice of not dealing with life-review and life closure issues that some people would choose to do if they were thinking about dying as part of this last phase," Peres said. "Instead, if we obfuscate it and talk around it, like the elephant in the room, people really don't get the opportunity to deal with it."

Confusion. Despite a strong preference for quality of life at the end of life, many Americans worry about potential conflicts between palliative care and doing whatever it takes to extend a patient's life, a Regence Foundation/National Journal poll found (Regence 2011). Almost half (47 percent) of respondents said they worry that emphasizing palliative and end-of-life care options could interfere with doing whatever it takes to help patients extend their lives as long as possible.

One way around end-of-life denial has been to discuss palliative care (which may or may not involve end-of-life care) much earlier in a person's disease process or life. "If we move palliative care way upstream through symptom management, communication and inclusion of patient-centered care earlier, then by definition it would include what people needed at the end," Peres said.

Cultural Differences. The majority of Medicare beneficiaries of all racial and ethnic groups say that in the event of a terminal illness with less than a year to live, they would want to die at home and would not want to receive life-prolonging drugs with uncomfortable side effects or mechanical ventilation to extend their life for a week or a month. However, researcher Amber Barnato, MD, MPH, and colleagues have reported differences in the distribution of preferences for end-of-life medical treatment by race/ethnicity even after controlling for potentially mediating or confounding demographic and sociocultural variables (Barnato 2007). For example, compared to whites, blacks are more likely to die in the hospital and to use intensive care and life-sustaining treatments such as mechanical ventilation, hemodialysis and feeding tubes, according to the research reported by Barnato, who is with the Center for Research on Health Care, University of Pittsburgh. Blacks also incur higher medical care costs in their last 12 months than whites. While some of these differences are due to regions with higher end-of-life care treatment costs, some differences may be due to minorities' lower usage of hospice services and advance care planning

documents. Barnato found that, among community-dwelling Medicare beneficiaries age 65 or older:

- Blacks (18 percent) were more likely than Hispanic (15 percent) and non-Hispanic whites (8 percent) to want to die in the hospital.
- More blacks (28 percent) and Hispanics (21 percent) than whites (15 percent) want life-extending drug treatment even if it has uncomfortable side effects.
- Fewer blacks (49 percent) and Hispanics (57 percent) than whites (74 percent) want palliative medications that might be life shortening.
- More black (24 percent) and Hispanic (22 percent) than white (13 percent) respondents said they would want mechanical ventilation for life extension of one week. Asked about mechanical ventilation for one month, the responses in favor were blacks (36 percent wanted), Hispanics (29 percent wanted), whites (21 percent wanted).

CHRONIC CONDITIONS AND ADVANCE CARE PLANNING

Successful public health strategies and medical advancements have contributed to increased life expectancy for Americans, such that now the average person will live to be about 76 years old. While some older adults remain healthy and robust until very close to death, it is more likely that an older individual will have lived for two or more years with one or more chronic diseases and experienced substantial disability before dying. Along the way, he or she, and the family, will have to make what are sometimes difficult choices about health care. Considering those choices, and talking about what should or should not be done, is at the heart of advance care planning (Lynn 2003, IOM 1997).

“Throughout our lives, but especially when we are older and facing increased risk of serious illness, we need a plan about what services are essential to living well and meaningfully,” Dr. Lynn said.

The data below show the proportion of older Americans impacted by health problems:

- 70 percent of Americans (more than 1.7 million) die of a chronic disease (Kung 2008).
- About 62 percent of all deaths each year are due to five chronic diseases – heart disease, cancer, stroke, chronic obstructive pulmonary disease and diabetes (Minino 2011).
- Alzheimer’s disease is the sixth-leading cause of death across all ages in the United States and the fifth-leading cause of death for those ages 65 and older (Xu 2007).
- 42 percent of Medicare enrollees age 65 and over have functional limitations (Forum 2010).
- 25 percent of people receive hospice services at the end of their lives (Casarett 2005).
- 24 percent of noninstitutionalized persons age 65+ report having fair/poor health (CDC 2010a).
- 7 percent of noninstitutionalized persons age 65+ and 19 percent of persons age 85+ report needing help with personal care from other persons (CDC 2010b).

The reality of more people living with, declining from, and ultimately dying of a chronic condition raises complexities and challenges that require new ways of thinking about death and dying. Toward the end of the twentieth century, several news items related to these challenges caught the public's attention. Well-publicized cases of terminally ill people – who were kept alive by artificial means while their families argued over what care options the patient would have wanted – got more people thinking about their own end-of-life wishes.

Gallup Polls conducted in the mid-1990s found nine out of 10 respondents reported they would prefer to be cared for at home if they were terminally ill with six months or less to live (IOM 1997).

Most Americans (71 percent) believe it is more important to enhance the quality of life for seriously ill patients, even if it means a shorter life, than to extend the life of seriously ill patients through every medical intervention possible (23 percent), according to the Regence poll (Regence 2011).

The Regence poll also showed that 97 percent of respondents agree that educating patients and their families about these issues is important; 78 percent believe there should be more of an open debate about public policies regarding palliative care options and 81 percent think these discussions should be fully covered by Medicare.

Professionals in the fields of public health and aging services are in positions to help older adults and their families address important issues related to advance care planning, such as completing legal or other written documents. However, the key responsibility falls on individuals and their families to have “The Conversation” about what care they would like to receive if they become unable to make their own decisions. Thus, the most important tasks are to appoint a surrogate decision maker; ensure that a person's family and caregivers understand the individual's attitude about life, death and dying; and engage in a conversation about the person's wishes for care under various scenarios that might occur.

END-OF-LIFE CARE AS A PUBLIC HEALTH ISSUE

*“Is not the logical conclusion of healthy aging a ‘good’ death?
Is not this an important part of public health work?” — Myra Christopher*

The Centers for Disease Control and Prevention (CDC) recognizes the public health opportunity to educate Americans, and especially older adults, about advance care planning and to improve their quality of care at the end of life. Planning for the end of life is increasingly being viewed as a public health issue, given its potential to prevent unnecessary suffering and to support an individual's decisions and preferences related to the end of life (CDC 2010c).

Advance care planning also meets other criteria that define a public health issue. According to Lynda Anderson, PhD, Director, Healthy Aging Program, Division of Population Health at CDC, advance care planning: (1) can potentially affect a large number of people [2.3 million people die each year (Hogan 2001)]; (2) can reduce unwanted and expensive treatment [the 5 percent of Medicare beneficiaries who die in a given year account for about one-quarter of that year's Medicare spending (Hogan 2001, Austin 2003)]; and (3) can meet public demand to change the way care has been addressed in the past.

Proponents of advance care planning note that it took time for the medical profession and public health community to understand the importance of advance care planning. After all, health care professionals are typically focused on ensuring a healthy long life and saving lives at any cost. Therefore death – or preparing for death – has not been viewed as compatible with what health care providers do.

“Is not the logical conclusion of healthy aging a ‘good death’? Is not this an important part of public health work?” commented Myra J. Christopher, the Kathleen M. Foley Chair of the Center for Practical Bioethics.

A 1997 Institute of Medicine (IOM) report defined a “good death” as “good care at the end of life.” This good death “depends on strong interpersonal skills, clinical knowledge and technical proficiency, and it is informed by scientific evidence, values and personal and professional experience” (IOM 1997).

WHAT ARE CARE NEEDS AT THE END OF LIFE?

“People need to be comfortable, people need to be respected and people need to be told the truth.” — Judith Peres, MSW

Defining end-of-life care needs is not easy because “We are still essentially a death-denying culture,” said Judith Peres, MSW, a policy consultant in palliative care and long-term services and supports who serves on the board of the Social Work, Hospice and Palliative Care Network. “People don’t want to have an honest conversation, nor are the acute care providers used to having the conversation.”

In addition, people vary greatly in what they want at the end of their life. Some patients want to continue aggressive treatment up to the time of death. Others are willing to endure treatment side effects and hospitalization in the hope of gaining weeks or months of additional life. Some prefer to focus on their quality of life. They may choose to concentrate on closure; comfort care in familiar surroundings, including pain control and relief from uncomfortable disease symptoms; and retaining their dignity.

A survey (Steinhauser 2000) of more than 1,400 patients, family members or professionals involved with end-of-life care revealed that their most important goals are:

- Pain and symptom management
- Preparation for death
- Achieving a sense of completion
- Decisions about treatment preferences
- Being treated as a “whole person”

In addition, patients strongly rated the importance of being mentally aware, having funeral arrangements made, helping others, coming to peace with God and not being a burden. Participants ranked freedom from pain as most important and dying at home as least important among nine criteria (Steinhauser 2000).

Clearly, “people need to be comfortable, people need to be respected and people need to be told the truth,” Peres said. Some recent research shows that good pain and symptom management control and attention to psycho-social-spiritual needs not only reduces suffering, but also extends life. “This message seems to be getting lost a lot in an effort to coordinate care and save money,” Peres added.

DEFINING ‘PALLIATIVE CARE’ AND ‘END OF LIFE’ CARE

The definitions of and relationship between end-of-life care and palliative care vary among experts, patients and providers (Moon 2002).

End-of-life care and hospice care are for people who are expected to die soon, whereas palliative care provides pain relief and comfort care to anyone who is seriously ill regardless of prognosis. Both palliative care and end-of-life care emphasize relief of suffering and improved quality of life. Palliative care can be offered as part of hospice or end-of-life care, or it can be offered along with treatments meant to cure illness (NINR 2011).

According to the Center to Advance Palliative Care, “Palliative care is a medical specialty that helps people facing serious and chronic illness be more comfortable by alleviating pain, treating a host of other symptoms and focusing on their quality of life. It is appropriate at any age and any stage of a serious illness and can be provided along with curative treatment.”

Findings from a 2011 Public Opinion Strategies survey found that most Americans believe palliative care should be made available at all hospitals. However, the concept of “palliative care” and “advance care planning” are not as well understood by the public as the more-familiar concept of “hospice care.” Once informed about palliative care, 92 percent of respondents said they would consider it for a seriously ill loved one (CAPC 2011).

Another key difference is that hospice care is covered by Medicare for someone who is certified to be in the last six months of life, while palliative care is financed on a physician fee-for-service basis.

MEDICARE HOSPICE BENEFIT

“Greater physician engagement is needed in the process of certifying and recertifying patients' eligibility for the Medicare hospice benefit.” — Medicare Payment Advisory Commission

Medicare began to cover hospice care in 1983 for beneficiaries who have been certified by a physician as having a life expectancy of six months or less (Hoyer 1996). The Medicare hospice benefit offers psychological and social services, pain management, respite care, and spiritual and bereavement counseling on an as-needed basis up to 24 hours a day. It also covers outpatient prescription drugs for symptom relief (but not for treating the terminal illness) with a 5 percent copay, and medical supplies and equipment. Medicare requires hospice programs to have a physician, nurse, a hospice aide, a social worker and a chaplain available to hospice patients. Medicare requires hospice beneficiaries to forego curative prescription drugs and treatments (CMS 2011).

In 2010, 82.7 percent of hospice patients were 65 years of age or older; more than one-third of all hospice patients were 85 years of age or older, according to data from the National Hospice and Palliative Care Organization (NHPCO 2011). They were predominantly white (90.7 percent) and not of Hispanic or Latino origin (91.9 percent) (NCHS 2011).

For-Profit Trend. Since around 2000, there has been a trend of more for-profit hospices programs being created, Peres said. “Fifty-one percent of hospice providers are now for-profits,” Peres said. There are no hard data on whether quality of care is impacted by a hospice’s profit or non-profit status.

Location of Care. Most hospice patients (66.7 percent) receive their care at “home,” which includes private housing, nursing homes and residential facilities (NHPCO 2011). NHPCO data show 21.9 percent of hospice patients received care in a hospice inpatient facility and 11.4 percent received care in acute care hospitals in 2010.

The majority (58.0 percent) of hospices are independent, freestanding agencies (NHPCO 2011). The remaining agencies are either part of a hospital system (21.3 percent), home health agency (19.2 percent) or nursing home (1.4 percent).

There were more than 3,500 Medicare-certified hospice agencies in 2010 (NHPCO 2011). NHPCO data show the Medicare hospice benefit is the predominate source of payment for hospice care – 83.8 percent of all hospice payments. Other payment sources were managed

care/private insurance (7.9 percent), Medicaid hospice benefit (4.9 percent), uncompensated or charity care (1.5 percent) and self-pay (1.1 percent).

Hospice Utilization. During 2007, there were 1.0 million hospice patients, a 68 percent increase since 2000 when there were 621,000 patients (NCHS 2011). Medicare payments for hospice grew from almost \$3 billion in 2000 to \$12 billion in 2009 (MedPAC 2011).

Length of stay. Ironically, research on hospice patient length of stay at Massachusetts General Hospital showed that lung cancer patients, who received palliative care and hospice care at an earlier stage, lived longer by a couple months (Temel 2010). “Similar longevity has been shown with a number of other diagnoses, such as heart failure and COPD” (chronic obstructive pulmonary disease), said Dr. Anthony Riley, the Medical Director at Gilchrist Hospice Care in Baltimore, Md. “So there is accumulating evidence that hospice care can extend life.” Dr. Riley cited two possible reasons for this phenomenon: (1) hospice protects patients from harmful medical interventions that shorten their life and (2) hospice helps relieve the stress of the medical illness and that translates into survival benefit.

Medicare Payments. Medicare makes a daily payment, regardless of the amount of services provided on a given day and on days when no services are provided, according to MedPAC. Payments are made according to a fee schedule for four categories of care. For 2012, the base payment rates were: \$151/day for routine home (or assisted living) care; \$156/day for inpatient respite care (in a nursing home or other facility when their usual caregiver is unavailable); \$672/day for general inpatient care (in a hospice or hospital hospice for those who are very symptomatic, such as intractable pain or vomiting); and \$881/day for continuous (24/7) home care. The rates are updated annually (MedPAC 2011).

Some providers state that the fixed Medicare daily rate is insufficient to cover services. This is especially true for patients who have short hospice stays with extraordinary expenses. The first and last few days in hospice are the most costly, because that is when the most care is provided, Dr. Riley said. Thus, for shorter stays, there are fewer less costly days to offset the more costly ones, resulting in higher costs for the hospice program (Austin 2003).

Predicting Death. The other problem with hospice economics is the difficulty of selecting patients who will die within the six-month window. “The trajectory for someone with even very advanced dementia, people who are no longer able to walk or speak, could be shorter or it could be a few years,” Dr. Unroe said.

“Most of us die having lived with a set of eventually fatal illnesses that are stable two weeks ahead of death,” Dr. Lynn said. “People living with these illnesses are often just one complication away from death. Planning for what to do when these complications arise is essential to good

advance care planning.” A study looking at more than a dozen prognostic indices used to predict risk of death in older adults in a variety of clinical settings, such as in nursing homes and hospitals, found that there is insufficient evidence to recommend the widespread use of these indices in clinical practice (Yourman 2012).

Concurrent Care. Currently, Medicare patients give up curative treatment to receive hospice services. However, some hospices serving non-Medicare patients provide interventions such as IV antibiotics, radiation therapy, and chemotherapy. In addition, curative treatment and palliative care can overlap. For example, radiation can be used to ease the pain of cancer, yet it is also a treatment for some forms of cancer.

“Additionally, asking patients from certain cultures (Hispanics and African-Americans in particular) to choose comfort care to the exclusion of life-prolonging treatment may be incongruent with their culture and beliefs,” according to the American Society of Law, Medicine & Ethics (Cerminara 2012).

The U.S. Department of Health and Human Services has been authorized to conduct a three-year Medicare hospice concurrent care demonstration to measure the quality of hospice care compared to conventional care. As many as 15 hospice programs nationwide will be participating in the study to determine whether patients benefit when Medicare authorizes payment for receipt of curative treatment at the same time they are receiving hospice care.

DETERMINING QUALITY OF HOSPICE CARE

“Quality in end-of-life care is difficult to measure,” Dr. Riley said. “There are no ready or easily usable tools to measure quality. We can’t use mortality as a measure of quality care,” since hospice patients generally die. “It is hard to use the quality argument if you don’t have any quality numbers.” So measurements tend to focus on hospice utilization, rather than quality of care, he said.

There is currently a movement to ensure more rigorous hospice quality management through metrics such as pain controlled within 24 hours. “That is a clinical, patient-centered outcome that is a meaningful metric that measures how fast you can get the patient comfortable,” Dr. Riley said.

“In recognition of the need for quality measurement and improvement, and in anticipation of the time when payment will be linked to quality hospice care, the Centers for Medicare & Medicaid Services (CMS) has recently requested that hospices submit quality metrics that should be considered for adoption by CMS. Metrics such as patient comfort measures and family evaluation of hospice care and bereavement services are likely to receive the most consideration,” Dr. Riley said.

Another way to analyze hospice care is to look at how programs approach different cultures and communities with regard to having the conversation, Peres said. “The first tenant of social work is ‘begin where the client is.’ So any nurse, social worker, physician, or person working in palliative and end-of-life care, if they are not first soliciting a person’s belief system, then they are going in the wrong direction.”

ADVANCE CARE PLANNING DOCUMENTS

“Advance care planning gives us a way to have a voice, to make a choice as to what we want from the people who will make decisions for us if we are no longer able to.” — Lynda Anderson, PhD

There are two overriding goals for advance care planning: establishing a surrogate decision-maker, which is a legal activity; and expressing your values, treatment goals and wishes, which is a communications task, explained Charles Sabatino, JD, Director, Commission on Law and Aging at the American Bar Association (ABA). “In addition to whatever advance care planning documents someone has filled out, the surrogate decision maker should be guided by information shared during focused conversations between the agent and the patient and family,” according to ABA documents.

Advance directives can only work if the individual understands the document, his or her surrogate understands the individual’s wishes, the physician is aware of the document’s existence, the physician complies with the surrogate’s instructions, and the document is revised as an individual’s condition and goals changes.

“Everybody approaches the topic of advance care planning in a very personalized, unique way,” Sabatino said. “Fortunately there are a lot of tools, such as the CDC advance care planning training course [*see section below on Role of CDC*], that are helping people to know how to have structured discussions and help them think through what all the issues are in connecting with those discussions, so that they do more effective advance care planning.”

Living Will. The first planning documents were proposed in 1967 (Glick 1991). The living will was based on the legal premise that a patient cannot be subjected to treatment without his or her consent. A living will provides a way for an individual to instruct a physician or other health care provider as to when to use, withhold or withdraw life-sustaining treatment when that person no longer has the capacity to make decisions about life-sustaining treatment.

Durable Power of Attorney. Because living wills only applied to a narrow range of decisions, lawyers and others began recommending durable powers of attorney, which designate someone else to make health-care decisions when you cannot do so. The document states the types of treatments that you do and do not want, but allows the decision-maker to make decisions

beyond those listed in the document. To create a stronger document that would be directly applicable to health care, states enacted statutes creating durable powers of attorney for health care. By the end of 1997, every state had enacted some version of a health care power of attorney statute (ABA 1998).

Do Not Resuscitate Order. In the early 1990s, the need for additional legislation for do-not-resuscitate (DNR) protocols became apparent to address the unwanted resuscitation of terminally ill patients. Without this document, emergency medical service providers were obligated to try to resuscitate someone whose heart or breathing had stopped. By the end of 1999, 42 states had statewide DNR protocols in place, usually created by legislation (Sabatino 1999).

Communications Approach. Instead of relying solely on legalistic documents, a 1997 Institute of Medicine (IOM) report on end-of-life care said that people were beginning to adopt a communications approach that involved “discussions with family members and physicians about what the future may hold for people with serious illnesses, how patients and families want their beliefs and preferences to guide decisions ... , and what steps could alleviate concerns related to finances, family matters, spiritual questions and other issues that trouble seriously ill or dying patients and their families”(IOM 1997).

Useful, consumer-oriented materials based on communication-based approaches were developed for individuals and their family members. Among these were the Five Wishes “living will” created by the organization Aging with Dignity, and the *Caring Conversations* workbook developed by the Center for Practical Bioethics to help individuals and their families share meaningful conversation while making practical preparations for end-of-life decisions (*see Resources list*), among other similar models.

“In most situations, having the conversation and coming to some conclusions is more important than worrying about how you document it,” Dr. Lynn said. Sometimes patients just write a letter to their kids, she said. “No judge is going to overturn a parent’s final letter to the kids.” The communications approach – having the conversation – allows people to address things that are not in an advance directive and other standard forms, such as a living will, Dr. Lynn said. “You might want to address other issues, such as your desire that the family make peace, that you don’t want to bankrupt your surviving spouse, that you don’t want to incur excessive medical costs when there is no hope for a cure.”

POLST. Oregon was the first state to develop the Physician Orders for Life-Sustaining Treatment (POLST) Paradigm Program for seriously ill patients (Sabatino 2010). This tool does not serve the same purpose as an advance directive and is best supplemented with other advance care planning. It is a tool that requires a discussion between the patient and/or surrogate with the

treating physician to determine the patient's end-of-life care goals and wishes, which are then incorporated into the physician's orders regarding resuscitation; artificial nutrition and hydration; and issues of comfort care versus more aggressive treatment. Some states include additional decisions such as whether to use antibiotics or ventilation. These orders are reviewed and updated as needed when the patient's condition changes. One of the primary benefits of the POLST form is that it moves with the patient through various institutions (hospital, nursing care, home care) and is to be recognized by all health care professionals.

About 15 states and cities have authorized the use of POLST forms, Sabatino said, and many more are developing similar programs.

Default Surrogates. Meanwhile, states are gradually adopting ways to make decisions in the absence of any kind of advance directive. Today 44 states and the District of Columbia have default surrogate consent or family consent laws, although the laws vary considerably among states (ABA 2009a). These laws create a list of permissible surrogates, usually starting with the spouse and then a next-of-kin (child, sibling, etc.) priority list. Many states also allow a domestic partner or close friend to make health care decisions for someone who is unable to do so.

Advance Directive. The multitude of complex documents and options outlined above led many states to try to merge their various documents into one advance directive. As of the latest data available, 25 states had statutes expressly recognizing such documents (ABA 2009b), but regardless of one's state, it is common to use a single, comprehensive advance directive. The main purpose of an advance directive is to appoint a surrogate to act on your behalf when you cannot. "You also can give instructions about the kind of health care you do or do not want," according to ABA.

In addition, in 1993, the National Conference of Commissioners on Uniform State Laws adopted the Uniform Health-Care Decisions Act, which created basic rules for recognizing almost any kind of written or oral statement as an advance directive. States that have adopted this model law have added a requirement that the statement be witnessed.

Congressional Action. The Patient Self-Determination Act passed in 1990 requires Medicare and Medicaid providers to educate staff and patients about health care decision-making, to ask patients whether they have an advance directive, and to comply with the requirements of state law respecting advance directives. The law stops short of actually requiring providers to assist in completing an advance directive (Sabatino 2010).

In 2008, Congress added "end-of-life planning" to the "Welcome to Medicare" physical exam available to newly enrolled Medicare beneficiaries. The term "end-of-life planning" is defined as verbal or written information "regarding an individual's ability to prepare an advance directive in

the case that an injury or illness causes the individual to be unable to make health care decisions; and whether or not the physician is willing to follow the individual's wishes as expressed in an advance directive" (42 U.S. Code §1395(x)(3)).

Bare Bones Power of Attorney. State law variations make it nearly impossible to have a national advance directive, Sabatino said, but in 2011 the American Bar Association developed a guide that is usable in all but five states. ABA's Commission on Law and Aging released a "bare bones" healthcare power of attorney document, applicable in 45 states, in an effort "to make the legal side of this more manageable and understandable," Sabatino said. It is designed to focus more simply on the single most important task – naming a health care agent. The form contained in the ABA guidance document, *Giving Someone a Power of Attorney for Your Health Care*, is designed as an easy-to-use legal form for all adults and avoids specific instructions about medical treatments. (*See Resources list.*)

"Only five states have laws so inflexible and cumbersome that the bare bones power of attorney will not work – Indiana, New Hampshire, Ohio, Texas and Wisconsin," he said.

The ABA document requires the individual to do three things: 1) think carefully about whom you want as your health care agent; 2) provide guidance to the agent through more effective communication resources than a legal form; and 3) fill out the power of attorney form and sign in the presence of two witnesses.

Resolving Conflicts. Advance care planning is not perfect and sometimes family members will disagree over what a loved one would have wanted. "The best defense is having a good offense and that means having good support services in the health care environment that constitute good counseling and support for the family" to help them get through the situation, Sabatino said. Hospitals vary a lot in how much support they provide family members. "Some are pretty good at it and some leave family members hanging in the lurch," which means more problems are likely to occur. "For some families, there is nothing you can do and in the end litigation may be the only course of action, but that doesn't happen a lot and it shouldn't happen a lot." Many institutions and all hospitals have some form of ethics committee that can provide consultation and support to both the doctor and hopefully the family."

Unfortunately, "thirty years of research shows that even if you have an advance directive, most of the time it doesn't get into the patient's medical record," Sabatino said. "Even if it gets into the medical record, it is not very visible and is not likely to be consulted when decisions need to be made. The most important task is the appointment of an agent to ensure your wishes, in whatever way they are communicated (via an advance directive or verbally), are carried out."

Not all of the advance-directive compliance problems are due to poor communication with health care providers. “We now hear more anecdotes of providers who want to go along with a patient’s wishes, but the agent or family says ‘No, we want all treatment’,” Sabatino said. That puts the provider in both an ethical and legal dilemma. “Ethically their first obligation is to respect the patient and the patient’s wishes, but legally the health care agent may have legal authority, yet they are not acting properly in the fiduciary role that they have, because the agent is obligated to follow the patient’s wishes.”

ROLE OF CDC

“We are seeing a lot of multiple chronic conditions that people are dealing with and, as they learn to manage those, advance care planning should be a natural and logical part of effective chronic disease self-management.”

— Lynda Anderson, PhD

With its focus on disease prevention and health promotion, CDC would like to see advance care planning become part of the self-management approach to living with multiple chronic diseases. “We are seeing a lot of multiple chronic conditions that people are dealing with, and, as they learn to manage those, advance care planning should be a natural and logical part of effective chronic disease self-management,” Anderson said. “Just as we plan for how to manage a chronic condition – go to a physician, learn about the treatment, learn how to improve our quality of life – advance care planning is part of that, not something separate.”

For example, the Chronic Disease Self-Management Program (Stanford 2012) – a facilitated workshop that teaches patients how to manage their disease – discusses advance directives. With the Administration on Aging and the Arthritis Foundation promoting the Chronic Disease Self-Management Program (CDSMP), it has reached 50,000 people (HHS 2010). Among participants in the CDSMP, durable power of attorney completion increased from a rate of 48 percent at baseline to a rate of 58 percent three years after completion of the course, according to a research paper (McGuire 2007).

Public Health Education. In 2002, CDC collaborated with the National Association of Chronic Disease Directors to identify public health priorities for addressing end-of-life care issues. More than 200 stakeholders from a variety of disciplines participated in a “concept mapping” process that led to the identification of two priorities that focus on public health education: (1) educate the public about the importance of advance directives and (2) educate the public about the availability of hospice and palliative care.

Advance Care Planning Module. In fall 2011, CDC's Healthy Aging Program, in partnership with Christopher at the Center for Practical Bioethics and with the Directors of Health Promotion and Education, developed a modular, online course on advance care planning specifically designed for public health and aging network professionals. ("Advance Care Planning: An Introduction for Public Health and Aging Services Professionals," www.cdc.gov/aging/advancecareplanning/index.htm.) Offered free of charge, the course addresses the importance of advance care planning, describes the unique role of public health and aging services professionals and defines key terms and types of documents. The course, using content provided by Christopher, was piloted in workshops hosted by the local AAAs in Wichita, Kansas (2009) and Seattle, Washington (2009), and by the state health department in Boston, Massachusetts (2010). As of the end of 2011, almost 90 health professionals had completed the course and 40 more were registered to take it (CDC 2010d).

Annette Graham, LCSW, Executive Director, Central Plains (KS) Area Agency on Aging (AAA), one of the early sites for pilot-testing the course, described it this way: "The training educates the professional about the topic, why it is important, the details and intricacies involved." Attendees included senior volunteers and parish nurses, as well as representatives from the Alzheimer's Association, county health departments, Kansas Health Ethics, senior centers, wellness centers, Wichita State University, medical services bureaus, mental health centers and area agencies on aging. "By bringing this diverse group together – a group that often didn't cross paths – this was an opportunity to make some connections and have a better understanding of what the other organizations did," Graham said.

"The course was so much more in-depth and provided a higher level of knowledge than they had ever encountered. It allowed for discussions about the factual stuff and data around end of life, what really happens, how many people are cognitively able to make their own decisions, what are the medical treatments that are available, how it impacts quality of life, and discussion about your own thoughts, and how to have this discussion with other people." Following the course, the AAA provided advance care planning education to its staff, did presentations on the topic, issued press releases and newspaper articles that reached 80,000 households, and participated in a proclamation for National Healthcare Decisions Day. The AAA notified local senior centers that health ethics professionals were available to discuss advance care planning.

DEMENTIA CARE

People with dementia often die with inadequate pain control, with feeding tubes in place and without the benefits of hospice care (Sachs 2004). More than 50 percent of residents in assisted living and nursing homes have some form of dementia or cognitive impairment (AA 2007), and

67 percent of dementia-related deaths occur in nursing homes (Mitchell 2005). Yet only 6 percent of people admitted to hospice care in 2008 had a primary diagnosis of Alzheimer's disease (60,488 people) and an additional 11 percent of people admitted had a primary diagnosis of non-AD dementia (113,204 people) (AA 2011c).

For an individual with Alzheimer's disease, advance planning is essential to fulfilling end-of-life care wishes, according to the Alzheimer's Association. Physicians and other members of the health care team play an important role in initiating discussion with the individual and family regarding these wishes (AA 2011a). The association recommends discussion of these issues at an early stage – when the individual's cognitive and communication abilities are least impaired – to help to clarify the person's wishes. "Discussions about end-of-life care are ongoing and always involve the person, proxy decision maker and family to the degree possible," Elizabeth Gould, MSW, Director of State Programs at the Alzheimer's Association, said. "Regular advance planning discussions with the care team provide an opportunity to revisit care decisions that have been made to see if they are still appropriate." The recommendations are based on evidence-based care guidelines resulting from the association's quality of care campaign, and are endorsed by 30 leading health and senior care organizations (AA 2011b).

People with early-stage Alzheimer's disease may be living well with dementia and be in denial that Alzheimer's is a fatal disease, according to Mike Splaine with Splaine Consulting. "Taking control of our own lives and charting your own destiny are classic boomer culture," he said. "You can't ignore the invasion of culture into these attitudes. So one of the benefits of earlier diagnosis is people being able to provide direction and input for future health care decisions," said Splaine, who is a former Director of State Affairs for the Alzheimer's Association.

In addition, once a person has moderate-to-severe dementia, it is difficult to assess whether they have decision-making capacity for advance directives and other end-of-life care. "When do people living with Alzheimer's have capacity to make up their minds about an advance directive, and when are they no longer able to do so? Capacity is a judgment call, and a legal call in some cases when doing surrogate decision making," Splaine said.

The unpredictable course of dementia "renders it a poor fit for the six-month life-expectancy requirement of the Medicare hospice benefit," Diane Meier wrote in a 2010 issue of "Health Affairs" (Meier 2010). Meier is a professor of geriatrics and palliative care medicine at Mount Sinai School of Medicine, New York City. She argues that regardless of life expectancy, palliative care should be offered to people with dementia and other chronic or life-threatening illnesses.

FUTURE DIRECTIONS

“We are moving in the right direction, for all the wrong reasons, but we are going where we need to be.” — Myra Christopher

Most Americans living today will cope with one or more chronic conditions for an extended period of time, spend some years living with disabilities (functional and/or cognitive impairment) at the end of life, and face decisions that will affect the timing and quality of death (Hogan 2001, Lynn 2004). Public policy and health care systems must continue to develop more effective ways to ensure that advance care planning is routine for all adults, addresses the various communication styles of individuals, and ensures that patients’ goals and wishes are reflected in treatment plans (Lynn 2004).

Clearly the public needs better education about the terms palliative care and advance care planning. While the Regence Foundation/National Journal poll showed most people understood the terms “end of life care” (65 percent said that term was familiar) and “hospice care” (86 percent), the newer term of “palliative care” was familiar to only 24 percent of those polled (Regence 2011).

Advance care planners must teach others to embrace dying as part of life, Peres said. That would include defining what a good death looks like, and trying to use the other parts of the system to make it clear that the high-tech care that we are able to deliver is not necessarily the care that is needed at the end of life.

Future of Hospice. Hospice care has become more integrated with mainstream medicine, and “we don’t need it in the way we have known it in past years,” Christopher said.

“Some say ‘hospice is dead.’ Hospice has accomplished what we set out to do in the mid-70s, to help people understand that there is a better model for caring for people at the end of life, than the intensive-care, acute-care, full-court press approach,” she explained.

But the Hospice Association of America argues that “The need for hospice services will continue to rise due to the growing aging population and the rising health care costs. More importantly, medical professionals, as well as the general public are choosing hospice over other forms of health care delivery because of its holistic, patient-family, in-home centered philosophy.”

“The lines that we have tried to create between community-based palliative care, hospital-based palliative care, hospice, acute inpatient hospice – those lines are blurring and as we see the emergence of accountable care organizations and bundled payments, those lines are going to get fuzzier and fuzzier. This has really intellectually and conceptually been embraced and now the economics will

drive it,” Christopher said. “We are moving in the right direction, for all the wrong reasons, but we are going where we need to be.”

Palliative Care Movement. “The palliative medicine movement is good for hospice because it brings attention to end-of-life issues and broadens the definition of end-of-life beyond the six months that makes a patient eligible for the hospice benefit.” Dr. Riley said. However, he expressed concern that patients and families may choose to be “palliative” and never get to the “hospice” stage. In those cases, referrals to hospice will end up being made too close to the time of death and prevent the patient and family from receiving counseling, bereavement and other benefits of hospice.

Better support for those trying to navigate advance care planning is a goal of a recently formed organization, the Coalition to Transform Advanced Care (C-TAC), a nonprofit, non-partisan organization based in Washington, D.C. It is funded in part by grants from the Peter G. Peterson Foundation, the SCAN Foundation, and its members. Members include experts and organizations in all fields that affect advance care planning, including national patient and caregiver advocates, leading provider groups and health systems, innovative health plans, hospice and palliative care organizations, home care, long-term care, clinicians, faith-based organizations, and academia.

The Center for Practical Bioethics is enthusiastic about this new organization and believes that it will help ensure for those who do advance care planning that their goals and values will be integrated into care and treatment plans regardless of their ability to speak for themselves, Christopher said.

C-TAC is calling for reforms to make it easier for people to navigate the complex issues related to advanced illnesses, such as cancer, heart disease, COPD, diabetes, stroke, and dementia.

Nursing Homes. Since 25 percent of Americans die in nursing homes, and that number is predicted to increase with an aging population, nursing homes need to be in the business of providing high quality palliative and end-of-life care, Dr. Unroe said. “There is an assumption that patients in long-term care have robust advance care planning, that their care preferences are clearly documented and followed, and that nursing homes would be very adept at caring for and managing dying patients and managing distressing symptoms like pain. But this is absolutely not standard practice. Some facilities are excellent at end-of-life care and palliative care and some are not.” While many nursing homes partner with hospices for end-of-life care for their patients, “there is a lot of opportunity for facilities to develop internal expertise in providing this care,” she said. “Broad segments of the nursing home population would benefit from comprehensive

palliative care, including understanding disease processes and prognosis, setting goals of care and symptom assessment and management.”

Role for Aging Services Network. Aging services professionals “could help promote the need to do advance care planning and clearly articulate your wishes for what you want toward the end of your life,” Peres said. Events held at senior centers or publicizing National Healthcare Decisions Day (April 16th each year) can be used to promote the importance of advance care planning. “The whole aging services network could step up and be leaders in that sort of thing,” Peres said.

Graham suggested that advance care planning could be built into the Options Counseling services now offered by the Aging and Disability Resource Center Program (AoA 2011), a collaborative effort of the Administration on Aging and the Centers for Medicare & Medicaid Services. Options Counseling helps people look at their long-term care options.

This document is available online at www.cdc.gov/aging/publications/briefs.htm. It was written by Nancy Aldrich. William F. Benson was senior editor and project manager. This brief should be cited as follows: Benson WF and Aldrich N. Advance Care Planning: Ensuring Your Wishes Are Known and Honored If You Are Unable to Speak for Yourself, Critical Issue Brief, Centers for Disease Control and Prevention. 2012. www.cdc.gov/aging.

STORY IDEAS FOR JOURNALISTS

- 1) Interview people who have and have not completed advance care planning documents and write about why or why not they took that action. Interview families who have been involved with a hospice program when someone in the family died. Write about how hospice services helped them.
- 2) National Healthcare Decisions Day is observed in mid-April each year to inspire, educate & empower the public and providers about the importance of advance care planning. Write a story on advance care planning to be published near the time of that event (April 16 in 2012). (For more info, go to www.nhdd.org/.)
- 3) National Hospice and Palliative Care Month is observed in November. That can also be an opportunity to write a story about advance care planning.
- 4) Look at the state-by-state report card on palliative care (prepared by the Center to Advance Palliative Care and the National Palliative Care Research Center) and write about your state’s data and how it compares to other states. Examine ways that care in your state could be improved. Go to www.capc.org/reportcard/. The key findings from the study were published in the October 2011 issue of *Journal of Palliative Medicine*.
- 5) Write a story about your state laws on advance care planning and explain how they differ from other states. Investigate whether the laws could be improved.

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ADDITIONAL RESOURCES:

- Advance Care Planning & Advance Directives, www.healthinaging.org/public_education/pef/advance_directives.pdf
- Advance Care Planning Conversation Guide, www.coalitionccc.org/_pdf/Conversation_Guide.pdf
- Advance Care Planning: An Introduction for Public Health and Aging Services Professionals, CDC course, www.cdc.gov/aging/advancecareplanning/about.htm
- Aging with Dignity (Five Wishes), www.agingwithdignity.org
- Agency for Healthcare Research and Quality, www.ahrq.gov/research/endliferia/endria.htm
- Alzheimer's Association HelpLine, 800-272-3900, www.alz.org
- Center for Practical Bioethics, <http://practicalbioethics.org/about/model-and-methodology/making-your-wishes-known-for-end-of-life-care/>; Caring Conversations, www.practicalbioethics.org/FileUploads/FINAL.Caring%20Conversations%20Workbook%202010.pdf
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