The spiritual dimension of facilitating advance directives planning: the congregational setting as a vital resource

**Kathleen Blanchfield, PhD, MPS, RN**

Lewis University, Romeoville, Illinois

**Introduction**

As a registered nurse, chaplaincy intern, and faith community nurse, I have been privileged to assist in advance directives planning and implementation in the congregational setting. A blessing of working as a faith community nurse is the ability to engage others in the subject of advance care planning in a protected environment strengthened by support from clergy and fellow congregation members. Nurses who practice in this setting can provide vital assistance in calming fears and in facilitating spiritual discussions surrounding care at the end of life.

Advance care planning can cause distress because end-of-life discussions and forms can cause confusion. Loving, well-intended family members can sometimes experience conflict when facing decisions about advance care directives for their loved ones. Unfortunately the forms, frequently known as advance directives (AD), can also become a source of discomfort that overshadows the serious questions surrounding end-of-life fears and concerns. ADs include a living will, which is a document that lists instructions for how the person desires to be treated at the end of their life. An AD also includes a health care power of attorney (HCPOA) which designates a person to act as a decision maker if the individual cannot make decisions regarding their care (Crisp, 2007).

Nurses are a vital resource for providing information about end-of-life care to the members of their congregations. The following scenario illustrates the role that the nurse and the congregational setting can play in alleviating the discord that may arise in end-of-life care discussions within families. Names and some information have been changed to protect confidentiality.

**Peg and George**

The anguish in Peg’s voice was real, but her request was vague, “Can you meet with George and me to discuss our advance directives? We’ll tell you more when you get here.” When I arrived at their home, I found them hopeful, determined, and fearful. A lifetime of accord, discord, and compromise behind them, they were a positive couple who faced life with practicality. Peg and George explained that their adult children had not been prepared to discuss their parent’s end-of-life plans, let alone accept that their individual plans were quite different from each other.

Peg and George had just hosted a party to celebrate their 55 years of marriage with their four adult children and many grandchildren. Because getting everyone together was rare, they decided that, after the celebration, they would introduce their advance directives to the family. Following dinner, they explained that the advance directives provided detailed descriptions of the care they desired if they were no longer able to speak for themselves. However Peg and George each described very different requests regarding advanced care planning. Peg wanted nothing medically extraordinary done for her. Once it was determined that she was near death, she wanted to be allowed to leave in peace with no medically artificial interventions such as ventilators or tube feedings. She felt no need to prolong her life: God was in charge, and she looked forward to a life in heaven. George felt that he had never given up throughout his long life, and he trusted his physicians, so he wanted all that could be done for him medically, including advanced life support. He believed that God asked him to never give up on life.

Little did they know that this topic would cause great disagreement within their family. They tried to persuade their children of the legality of this process and of the medical necessity of having advance directives. This tactic was no match for the distressed questions they faced: “Why do this now?” “Can’t your doctor make decisions for you?” “Why would only one of us make these decisions?” None of their children would agree to be a health care power of attorney. The celebration ended in confusion and stormy silence.

Peg and George spoke with their physician and attorney. Their advance directives were in order, but each sill required an agent to act as the healthcare power of attorney. The couple needed more help explaining their decisions to their children, and so they turned to me, their faith community nurse, for assistance.

Our meeting opened the way for a discussion about the spiritual dimensions of end-of-life planning. As numerous authors on the subject have noted (Johnson, 2004, Kessler, 2007, Kiernan, 2006), many spiritual questions arise with the discussion of advance directives and end-of-life planning. Many of these questions surfaced over the course of our discussion: What is the meaning of my life? Does my religion consider advance directives moral? How can I find meaning in planning for the final days of my life? How will advance directives give me peace of mind? How will advance directives benefit my loved ones? Who can I rely upon to carry out my advance directives in a way that is true to my wishes and respectful of my religious and spiritual beliefs?

Sheehan, both a physician and a priest, states one of the major questions each person needs to answer is: “How does one live spiritually in hope of dying well?” (Sheehan, 2000). Once Peg and George were able to fully discuss their spiritual concerns with a knowledgeable member of their congregation, this became the focus of Peg and George’s discussion with their children. Rather than highlighting the medical and legal reasoning behind their advance directives, they were ready to share their spiritual importance and how their advance directives helped them face the end of their lives with deep meaning and peace. They expressed their lifelong devotion to their family and how their children’s conflict over their end-of-life plans spiritually distressed them and left them feeling unsupported and misunderstood.

Fortunately, this new spiritual focus to the discussion helped Peg, George, and their family to explore the life-giving nature of advance directives. This discussion allowed their children to share their own spiritual beliefs and how each of them wanted to support their parents during their last days. They talked about the meaning of death and the need for hope and peace within the family as they were challenged with difficulties ahead. Having alleviated their children’s fears, each parent was able to designate a health care power of attorney. Peg and George reported a sense of relief, having completed a necessary task for themselves and their family.

**Conclusion**

George died a few years later with his wife and family at his side. His children supported both George and Peg during this sorrowful time. The children had been enlisted into supporting their father’s wishes and cooperated to ensure that his wishes—as described in his advance directive—were followed. Peg is secure in knowing that her children will now respect her advance directives. In the meantime, she has become a source of wisdom for others in the congregation who are concerned about expressing their wishes for end-of-life care to their families.

The process of planning for advance directives needs time, spiritual reflection, and support from trusted family members, friends, clergy, physicians, lawyers, and others. With all the fear about “death panels” that has been generated by the discussion of Medicare reimbursement for end-of-life planning, it is comforting to know that congregations can be a vital and effective resource for facilitating the advance directives discussion. Not every congregation has a faith community nurse, but congregations do have the resources, knowledge, time, and skills to draw from their faith traditions to facilitate end-of-life planning.

In helping individuals grapple with these issues, clergy and congregational staff who have the time and education can effectively facilitate the process of developing advance directives. This can be done through educational programs, individual meetings, and bedside visits either in the home or at healthcare facilities. Numerous studies have indicated that when individuals complete advance directives they have a sense of peace and believe they have removed a burden from their loved ones (Crisp, 2007; Feldstein, Grudzen, Johnson, & LeBaron, 2008; Fried & O’Leary, 2008; Medvene, Base, Patrick & Wescott, 2007). My experience with Peg and George, as well as many other families in my congregation, has shown me how positive the end of our lives can be when we facilitate the discussion of our spiritual concerns as a part of our advance directive planning.

[**KATHLEEN BLANCHFIELD**](mailto:blanchka@lewisu.edu)**,** PhD, MPS, RN is an associate professor in Nursing at Lewis University. She is also affiliated with Advocate Health Care as a network nurse in the Parish Nurse Ministry. She has a master’s degree in Pastoral Studies as well as a PhD in Nursing Administration. Spirituality in Nursing is a topic she has written about and presented in professional education programs throughout the country. She is a member of the Hektoen Institute’s “Nurses and the Humanities” program series advisory board.