

A Different Kind of Holiday Gift

Advance Directives: Conversation that is Courageous and Caring

Aunt Sarah is dying. She knew it first, even before the doctor broke the bad news about cancer that was caught too late and had spread too far. Sarah knows and is talking about dying, about forgoing resuscitation attempts, feeding tubes and chemotherapy. She talks to her daughter about the quilt she wants to finish, even about what songs would be nice at her funeral—though she doesn't want to plan it.

But Sarah's husband is devastated and hopes for a miracle. It is hard to talk with Uncle Joe about what's happening to his beloved wife of fifty years. It's hard for him to hear Sarah. Still she tries. It will be her last holiday gift.

Death is a natural part of life. But for many of us, talking about death doesn't feel natural, especially during the holidays. Isn't this season all about being merry, happy, and joyous, about gift giving and receiving? Indeed, it is, while death is sad. Yet dying happens, even during the holidays. Or death has happened, and the holidays are a sad reminder of what happened, and how. Was it anything like a "good death"? Will it be so for Aunt Sarah? What could make dying better, or worse?

One thing that might ease Aunt Sarah's dying is if she has communicated her wishes and worries, her "do's and don'ts," regarding end of life care options. Designating a trusted family member or friend as legal agent for health care decisions is especially important, because many of us won't be competent to make our own decisions while dying. Letting loved ones know our preferences is an invaluable gift to them. Receiving such a gift, by listening, is invaluable to the giver.

As difficult as this is, both giving and receiving such a gift may be easier before the dying begins. In the later stages of a terminal illness, families are faced with trying to determine what medical things their loved one would want. Gut-wrenching decisions must be made in the midst of an already painful and emotionally charged time.

When Aunt Sarah had to be a decision maker for her own father, many years earlier, it was “the hardest thing I ever did.” She says this tearfully even now. He had given no advance directives. There had been no end of life conversations or designated agent. Had he wanted someone to attempt resuscitation when his heart stopped, or to let him go peacefully? Would he accept greater dependency if it came with longer life—exchange quality for quantity? How could she know what her 93 year old Daddy would say about ventilator support or antibiotics for his pneumonia?

Sarah wants to make sure that her husband and doctors know as much as possible about what she does and doesn't want.

A discussion about the end of life brings us face to face with fears of dying and death. It takes care and unusual courage to initiate this conversation. But because holidays are times when families gather, it can be an opportune time to begin the conversation. It's a different kind of holiday gift.

Resources:

- **Courageous Conversations** is a booklet containing information about advance directives and other end of life issues. It is available as a free download from **St. John Health**, at: <http://www.stjohn.org/Documents/CourageousConversations.pdf>
- **The Duke Institute on Care at the End of Life** provides an annotated list of other helpful websites: <http://www.iceol.duke.edu/resources/index.html>
- **Caring Conversations**, a similar booklet to **Courageous Conversations**, is available in English and Spanish, in versions appropriate for youth and adults. Download from the **Center for Practical Bioethics**, at: <http://www.practicalbioethics.org/cpb.aspx?pgID=986>
- More information is available from the **National Hospice and Palliative Care Organization** (NHPCO), at: <http://www.caringinfo.org/PlanningAhead.htm>
- **To access this article, please visit** <http://www.stjohn.org/PalliativeCare/>

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