
Caring Conversations — PATHWAYS' Consumer/Patient Initiative

by Linda Johnson

Imagine for a moment that you are a fifty-year-old beginning to experience occasional aches and twinges, sure signs of age and mortality. Imagine at the same time that you are the primary caregiver and health care decision maker for two or more parents in their seventies who have increasingly frequent episodes of chronic or serious illness. Imagine, finally, that you are the parent of two children in their twenties who are remarkably nonchalant about their own health and future, occasionally uninsured, and entirely too comfortable depending on you for advice and money. That you may find yourself, sooner or later, in similar straits, is very likely — we all will — and it was to help us face such moments that Caring Conversations was developed.

As the Center began the PATHWAYS project, we believed strongly that without a shift in the cultural perspective on death and dying, we would not succeed in improving end-of-life care in our community. Dying can never be easy in a culture that believes that healthy living, taking megavitamins, and relying on advances in medicine and technology will, if we also refuse to think about mortality and our own impending death, enable us to live forever.

We also knew that a key component in shattering this myth depended on friends and family members being able to help each other when age and frailty or unexpected illness become the first signs of our mortality. Providing effective tools to the fifty-year-old caregiver described in the abstract and other men and women whose lives are similarly burdened became the focus of *Caring Conversations*.

Background

PATHWAYS' various strategies fell into three broad categories: those strategies directed toward organizational change; those directed toward professional education and development, and those directed toward consumers. The third, and some of us believed the most important, part of the

strategic plan to implement PATHWAYS consisted of activities aimed at consumers of health care services: citizen-patients and their families and friends. An attempt to shift the entire community's culture and expectations for good end-of-life care requires, perhaps even depends on, the consumer/patient who is facing serious illness and the dying process. *Caring Conversations* is a key component of this strategy.

Caring Conversations is a model of advance care planning that shifts the focus from the completion of documents to the conversations that may evolve from or precede the documents. *Caring Conversations* was initially conceptualized as a workshop planned for middle-aged women who were often taking on the role of caregiver for elderly parents; whose own children were reaching adulthood, having children, and moving away from home; and who were noticing the first signs of mortality in themselves and their friends. We believed that they were often the first and primary decision makers for, and communicators with, other family members or friends about health care. We also believed that these women were acutely aware of the network of relationships within family systems, and of the need for discussing or planning for the care needs of each other.

The title of this program reflects a delight in alliteration, and an awareness of the multiple and complicated meanings inherent in both words. *Caring* not only refers to certain behaviors that parents provide to children, or adult children to elderly parents; it also refers to a gentleness of thought about those who are important to us. Yet another layer of meaning describes the “care” that we receive from professional providers of health care services.

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Conversation, too, is a somewhat complex word. While at one level it may simply mean an exchange of words, ideas, or pleasantries, it also suggests a mutual dialogue in which both parties are invested in a civil, engaging interchange. It suggests a give and take — a process that may not have a specific beginning and end, but one that may recur and be ongoing. This particular combination of words seemed to capture both the essence and the essentials of the process we believe is critical to improve end-of-life care. We wanted ordinary citizens to be given the tools and the encouragement to think about their own end-of-life preferences, and to practice talking about their thoughts with family or friends. We believed that using the workshop as a starting point, and the *Caring Conversations* workbook as a continuing guide, would encourage both the caring and the conversations that are needed to improve care at the end of life.

We also believed that advance directives have not always lived up to their promise. Although they developed as a mechanism that a person could use to help limit the overuse of health care

technology and medicine’s ability to extend the dying process, there are several reasons why they have not been effective.

In the SUPPORT study, providers of care often did not know that the patient they were caring for had an advance directive. Even when an advance directive was recognized and available, they were infrequently used to guide clinical decision making. Both families and professional caregivers reported that advance directives can be confusing, and often don’t address the specific situation that the patient is experiencing.

Other reports indicate that some people are fearful about completing an advance directive because they fear that by so doing, even appropriate care may be limited. Particularly those who have experienced a lack of respect or access to necessary or appropriate care from the health care system are justifiably suspicious about completing a “document” that purports to direct providers to limit inappropriate or unnecessary care in the face of death.

Sometimes the document can’t be located, or its directions are unclear. Sometimes family, friends, or health care providers disagree about the meaning or intent of statements made in the document, or are uncertain about the person’s preferences.

As advance directives have evolved from early living wills to more comprehensive health care directives, and even more recently to advance care planning, the emphasis has increasingly been placed on the importance of communication between family and friends, and between patients and providers, about personal preferences that can guide care when people have lost the capacity to communicate or decide. *Caring Conversations* recognizes the importance of this emphasis. It is a process for thinking about and discussing end-of-life care preferences, and then documenting those conclusions or decisions in an effective way. The advance care document that results from this process can be understood by the agents capable of serving as spokespersons and advocates for the patients’ preferences.

Implementation

The initial *Caring Conversations* workshop or pilot program consisted of stories and exercises to encourage workshop participants to think about their own preferences and wishes for care should they lose decisional capacity when facing serious illness or death. Our goal was to enhance awareness of the need for conversations with those we care about by listening to stories told by those who had faced serious illness or the death of a family member without having had these conversations. These stories are compelling; they “testify” to the value and importance of communicating the values, preferences, and choices that are important in life and in the dying process. Another goal was to provide participants of the workshop with tools and techniques to help them begin these important conversations with their loved ones and use the information they gain from them to shape or direct care.

To meet the first goal (enhancing awareness), we invited a caregiver or former caregiver to share his or her personal story about the death of a family member. Each speaker was asked to talk about the ways in which conversations had been important and helpful and to describe those instances in which the lack of conversation had created difficulties or tension. We believe that this storytelling is the key to demonstrating the model and importance of caring conversations in the process of advance planning. Storytelling also provides examples of the many ways these conversations can evolve:

To address our second goal (providing tools or techniques that might be helpful in initiating or conducting the conversations), each participant received a resource book, an advance directive document (this document is now included in the *Caring Conversations* workbook), and a wristband that was to be worn after the workshop until the participant had had a caring conversation. The resource book offered yet another personal story about the importance of conversation in good end of life. It also contained a values survey that could be used by participants to clarify their own thinking about their beliefs and preferences.

Of the three breakout sessions that were part of the workshop’s activities, one provided the sharing of alternative tools that might be helpful to initiate or conclude the caring conversation, such as letters to family members, videos, a box of important or favorite things, and various types of advance directives. Another of the three workshops introduced Midwest Bioethics Center’s currently distributed advance directive, encouraged attendees to complete their own, and provided a notary public to finalize the document. The third workshop focused on how to be an effective advocate or communicator for family or friends who are in the process of being cared for in a health care organization.

The advocacy issue was also addressed in the resource book with a section on “What to do when caring conversations aren’t enough.” While we

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believe and promote the idea that caring conversations between family members, friends, and care providers are critical and important, we also realize that effectively articulating and getting the wishes of the citizen/patient recognized and respected (implemented) in health care treatment decisions is difficult within health care organizations as they currently exist. Therefore, we wanted to teach and support participants in how to be effective advocates for themselves and for their loved ones. We also wanted them to be aware of ethics committees and other conflict resolution mechanisms that may be available within health care organizations.

The initial workshop was held on a cold Saturday morning in January 1998, with 120

participants, many of whom brought a friend or family member (as had been suggested in the brochure). The energy and enthusiasm throughout the morning were palpable. Many who had previously completed an advance directive form became engaged in conversations with family members that “shed a whole new light on what Mom really meant.” Follow-up surveys three months after the workshop indicated that most participants did have a caring conversation during the next three months, or used their newly acquired information in an experience with someone who was seriously ill or dying.

This initial four-hour workshop was later replicated in cooperation with four of the local Shepherd’s Centers. These workshops used Shepherd’s Center volunteers, mostly retired community leaders, and were held at Shepherd’s Center sites (typically churches), in December 1998, and reached an additional 300 people. Again the survey responses were positive.

In addition to positive feedback, however, we gratefully received suggestions for improvement. Some participants felt they wanted an opportunity to attend all three breakout sessions, and were frustrated they couldn’t attend every aspect of the workshop. Others expressed a need for more specific medical or disease information so they could better understand and assess the implications of the disease process. They wanted to be better prepared to have conversations with health care providers, and thereby be more knowledgeable and involved in taking the initiative in their own health care decisions.

Future Indications

Since 1989 MBC has taken community leadership in developing and distributing health care treatment directives that meet specific requirements of Kansas and Missouri. The directives of the Center are the advance care documents most commonly seen in our community health care settings. Following the success of our *Caring Conversations* efforts in 1998, we determined to use this program and concept to enhance the process of advance health care planning in our community.

The program has now evolved into a multi-component effort to better meet the needs of a variety of groups with a range of programming requests.

The current program includes a *Caring Conversations* workbook that guides persons in thinking about their own end-of-life care. The workbook consists of a series of open-ended questions or statements that encourage people to

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think about their lives, including the values, attitudes, and beliefs that will help shape their response to a terminal prognosis or serious illness. Also included in the workbook is a two-sided advance directive that allows persons to summarize their conclusions about their care, and to name their surrogate decision maker.

It seems more convenient for most health care providers to keep the one page form on file, rather than the entire workbook. The one page document and a brochure containing frequently asked questions will still be available to health care organizations through a local printer. It is, however, the workbook that the Center will promote, and send to anyone who calls and asks for an advance directive. People will be encouraged to review and complete the workbook questions, discuss them with friends and family, and then complete the brief, concise advance directive that summarizes their preferences. They will also be

especially encouraged to share their workbook with their agent, that is, their durable power of attorney for health care decisions.

Speakers are now being trained who are knowledgeable about *Caring Conversations* and who will present this concept to groups throughout the community. Their presentations may be from twenty minutes to more than an hour in length. The workbooks will be provided at these presentations, and a handout of additional resources will also be available.

A facilitator's notebook and resource booklet is available to enable community organizations, churches, or other groups to hold a three-to-six hour *Caring Conversations* workshop. The kit includes a program script and suggested resources and tools that will help attendees consider and document their own preferences; activities to facilitate effective conversations; a wristband, workbook, and other handouts to be given to each participant to encourage further consideration and conversation after the workshop.

Also included in the facilitator's notebook is a video of an intergenerational caring conversation to use as a model or sample for participants. Other video and curriculum resources are available to those health care providers who may benefit from a program that will not only encourage them to consider and communicate their own preferences and document them in an advance directive, but will also educate and support them in their role as information providers to citizen/patients.

The curriculum for a five-session *Caring Conversations* educational series first published in the educational resources section of the *Compassion Sabbath* Resource Kit has been adapted for use in the *Caring Conversations* program. This curriculum is accompanied by two videos and will be useful to groups who want to provide five sessions of a one- or two-hour program over a period of time, such as at a weekly church gathering or other adult study group. A study group may encourage reflective conversation and more introspective, spiritual contemplation than is possible in the one-session workshop.

In addition to these resources, the Center will continue to be available for consultation and to provide other resource materials that will encourage all members of our community to think about their end-of-life preferences, initiate caring conversations with family, friends, and health care providers, document their thinking in a workbook and their conclusions in an advance directive, and be prepared to speak up knowledgeably and advocate for each other as health care decisions are being made.

As each of us considers or nears the "last chapter of life," our ability to clearly and honestly think about our own preferences within the context of our important relationships may be the most important thing we can do to facilitate a "good death." To the extent that those we care about understand the wishes and values that we want to maintain through the dying process, the more comfortable they will be living with and advocating for the care they know we want and need.