

Easing the Loneliness Of Death

BY PEGGY A. SZWABO, RN

Many healthcare providers feel uneasy discussing death with patients who are dying. They do not know how to behave around these patients or what to say to them. Rather than attending to the thoughts and feelings of the dying, care givers often pay more attention to their own uneasiness about death. Persons who are dying feel alienated from the healthcare system because they sense care givers' insecurities about death. This only compounds the pain, suffering, embarrassment, loneliness, and isolation that often accompany the dying process.

Grace was one example of this isolation. At age 72 she was dying of metastatic lung cancer. Grace had to care not only for herself but also for her 76-year-old husband with Alzheimer's disease. The staff at a pain management program had referred Grace to me for counseling and resource referral after deeming her "too geriatric" for their program. This reflects the all-too-often ageist response from healthcare providers who do not see work with the elderly as valuable.

A TROUBLEMAKER

Grace's catastrophic situation did not fit neatly into the U.S. healthcare system. Providers who were unsure about what to do for her felt a sense of failure and frustration. People like Grace are referred to geriatric services for counseling because their needs require a lot of time and because healthcare providers refuse to admit they do not know what to do to "fix" people such as Grace or her situation.

But Grace was a survivor. She was remarkably resourceful, strong willed, and direct—characteristics care givers do not cherish in patients. Grace had the stamina to

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seek out information on her care and treatment options for both herself and for her husband. Although she had been referred to me so I could help her receive additional resources to lessen her care-giving burden, I found Grace was already familiar with all her options. She called these sources frequently.

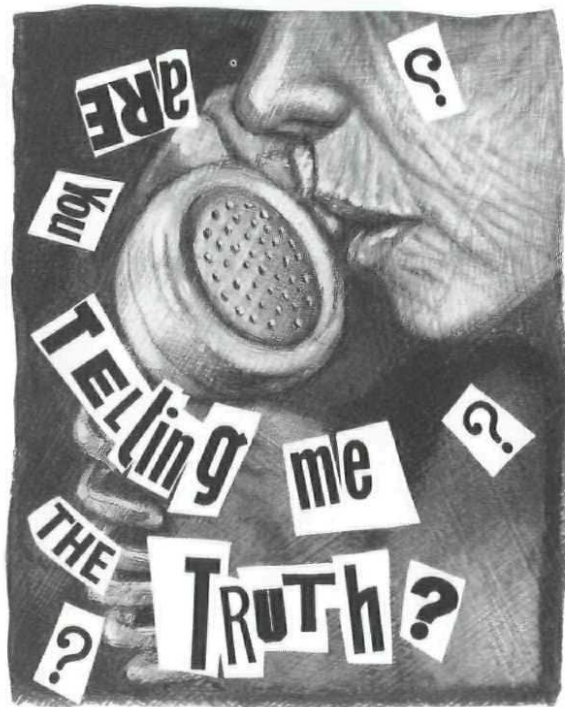
Grace let her physicians know what she had learned in a challenging, provocative way. Not so hidden in her questions about the disease were the real questions: Are you doing all you can? Are you telling me the truth? The healthcare system had abandoned Grace and labeled her as "difficult" because of her questions, telephone calls, and proddings. What she needed was someone to listen and answer her questions. She needed someone to help her through her pain and fears—to help her reconstruct her life.

THE GRIEVING PROCESS

Grace was grieving. Grief is an emotional response to loss. And Grace had experienced many losses—her future; her physical abilities; her control of pain; her autonomy and independence; her husband as a source of support; and perhaps the medical system, which referred her to me to get her out of the way. Her grieving behavior made care givers uncomfortable. Generally, society forces grieving persons to isolate themselves.

I decided that one way to help Grace through the grieving process was to help her make her daily routine as meaningful as possible. Grace was willing to look at what things she could do, ways she could interact with her husband, family, and friends. She began to start telling people good-bye and

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planning for her husband's care.

Grace needed the reassurance that she could reach out and someone would be there. I met with her weekly to talk about anything she wanted. Grace told me she felt angry and frustrated with the medical system for its inability to control her pain and for its fragmentation, which sent her from one specialist to another. Grace's attitude usually mirrored the behaviors her husband was exhibiting. Her feelings were related to her own health and to her role as a burdened care giver of a loved one with dementia.

Grace often felt guilty when she chose fulfilling her own needs before those of her husband. Who should she choose? Grace explained that she had to take care of herself, but she also worried about him. She would not place her husband in a long-term care facility; she did not want to be alone. Grace's fear was that some day she would no longer be able to care for her husband and she would have to put him in a facility—another loss for both.

STOPPING THE ALIENATION

After a time Grace believed she had better pain control because she had been taking a combination of round-the-clock analgesics and antidepressant medication. She admitted that talking about her feelings helped. Grace visited me despite her physical pain and complicated transportation arrangements. She sometimes brought her husband along when he could not be left alone. Grace explained that she would not miss a visit because she could tell me anything and knew I was listening.

Grace taught me what perseverance is all about. Her illness was terminal; her husband's condition was deteriorating. She faced difficult decisions. I continued to help her grapple with her situation until her death in the autumn of 1991.

As the elderly population increases, the number of persons in similar situations will increase as well. These elderly patients require, above all, that care givers listen, understand, and accept them. □

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forces the ministers' relationship with the hospital.

Continuing education is often a top priority of the clergy. Most indicate a need for further training and development to deal with parishioners with medical and psychological concerns. Therefore, as part of the survey, ask if they are interested in programs on subjects such as parish health promotion activities and how to help those with AIDS, chronic and terminal illnesses, chemical dependencies, parenting problems, and so forth. These can be offered by the hospital or held in conjunction with ministerial association meetings. Although the programs would primarily focus on helping ministers in their work, each program could include a brief explanation of a new service and a tour of an area of the hospital. Speakers can be hospital staff or professionals with specialized expertise.

Education should not stop here. Churches and synagogues have many groups (e.g., men's and women's groups, youth groups) that are also seeking professionals to speak at their meetings. Your hospital speakers' bureau could offer free programs at churches and synagogues and even sponsor on-site health fairs, screenings, and other events.

REACHING THE CHURCH COMMUNITY

Churches also represent a tremendous source of potential hospital volunteers. When seeking volunteers or promoting hospital programs or screenings, place notices on church bulletin boards and in their newsletters.

Those who work and volunteer at churches are also important referral sources and marketers for you. Consider an annual luncheon for church secretaries and another for pres-

idents of church groups to recognize their contributions to the community and inform them about hospital programs and services. You may even wish to sponsor a program for these groups on how to do fund-raising, public relations, and special events, using your own hospital professionals or bringing in experts to speak.

When people move to a community, one of their first priorities is to locate a place of worship. You could coordinate a newcomers' program with churches and synagogues to provide packets of health information for new members. Include such items as first aid charts, emergency telephone stickers, wallet health cards, flyers on upcoming community educational programs and screenings, and information on a physician referral service. Include these newcomers' names in your marketing data base to receive future hospital mailings.

Catholic and other religious schools are another focus for public relations. Many of these schools require their students to volunteer a number of hours before graduation. The schools can be an important source of volunteer assistance, a place to promote health careers, and a way to provide early orientation to your hospital for students' and their families' future healthcare needs.

THE NEED FOR COLLABORATION

The key word here is "collaboration." With diminishing dollars for marketing and public relations, hospitals must identify methods of collaborating with local clergy and religious leaders to educate and help those in the community. Through research, orientation, education, increased involvement, and continual dialogue, we can strengthen these relationships for the benefit of both the hospital and the community. □