



## CASE STUDY



## From the Caregiver's Perspective

*(This case is written by a caregiver; all remarks are direct quotes from her. At the end of the column, a physician comments on the issues raised by the article.)*

### The Case

PG, 83, lives in western New York, 60 miles south of Buffalo. While visiting her daughter and son-in-law for Christmas in 2004, she was hospitalized with pneumonia. After discharge, she recuperated for a few days at her daughter's and then, although weakened, returned to her home. Early in January, she slipped from her recliner, broke a hip, and was hospitalized for a hip prosthesis. From there she went to a nursing home for rehabilitation but shortly after became ill and was hospitalized in Erie, Pennsylvania, where she eventually required a colectomy and ileostomy. From late December to mid-February, her daughter, SH, was by her side. In mid-February, PG came by ambulance to a nursing home in Syracuse for further rehabilitation. She was able to go back to her home in early April 2005. In the following paragraphs, PG's caregiver describes the various dilemmas that can beset both patient and family as they try to navigate the health care system.

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## Culture and Caregiving

The challenges of working with diverse patient populations extend to the patients' families and caregivers. It is important for health care professionals to recognize possible problems or issues that might arise when preparing to treat or discharge patients who do not share the Western perspective of illness and its accompanying expectations.

### CULTURAL BARRIERS

For a patient whose language of origin is not English, the medical encounter in the emergency room or physician's office can be bewildering and frightening. If the physician is not aware of cultural norms, the simplest of introductory procedures (a direct eye-to-eye greeting, a handshake, a vague question) can ruin the chance for an honest and thorough examination. If the patient does not understand English, the physician needs to know that certain family members may not be the proper ones for translation regardless of their speaking abilities or presence in the room.

Discharge planners need to take into account what levels of care are available at home. Many cultures do not believe in the concept of assisted living or nursing home care; they see family as the only place where the ill person should go. But does the family fully understand what the care will entail? Is there someone at home who can read

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# Bioethics *in brief*

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## COMMUNITY OF CARING



# When the Primary Caregiver Is Not Family

While the nuclear family is often assumed to be the ideal source for caregiving, the fact remains that many in the U.S. who are ill or disabled live alone and cannot turn to family members for help. In addition, simply having family members does not guarantee that they are available or that they want to give care when it is needed. Filling in the space on forms that ask whom to contact in case of emergency is easy for a patient with a healthy partner. For those who live alone, it can serve as a painful reminder of their isolation and vulnerability. On the other hand, it can be an opportunity: a chance to broaden our definition of community and turn to friends for aid and companionship.

According to a *New York Times* article ("Alone in Illness" by Jane Gross, published on August 26, 2005), "in 2003 nearly twenty-seven percent of American households consisted of one person living alone, up from eighteen percent in 1970, putting a premium on friendship, a relationship without the legal status or social standing of kin."

Hospitals planning discharges can encourage patients who live alone to work out a care relationship with a reliable friend or neighbor. Friendship and a mutual commitment to care and support can make all the difference to a single person with illness or disability. A friend may be better at taking notes and asking important questions than a family member, who may be emotionally overwhelmed by the experience.

## THE VALUE OF FRIENDS

The *New York Times* article describes one woman who relies on a group of friends rather than just one person: "Barbara chose friends

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### **When the Primary Caregiver Is Not Family**

who had cancer to join her at doctors' appointments when she was assessing treatment options. She chose those who shared her love of art and theater to keep her distracted with outings...while awaiting the pathology report." Gross also found a group of neighbors (more acquaintances than friends) who organized themselves to provide a network of support: "Their purpose is to be available to one another in times of need, like when someone requires a companion for the trip home after a colonoscopy."

#### **THE MYTH OF INDEPENDENCE**

Americans take great pride in being self-reliant and independent; we are encouraged to keep our troubles to ourselves or at least within the family. Illness, aging, and their attendant problems, however, will dispel these myths of independence. We need to be open-minded about asking for help and realistic about who will be there for us. Thinking creatively about a network of care that extends beyond current social and legal definitions of "family" is a good way to begin this process.

—Rebecca Garden



## **Patients, Families and Organ Donation**

Health care professionals and students alike have long been both puzzled and troubled by the apparent authority of family members to veto a dying patient's expressed wish to be an organ donor. Technically the law grants no such power. The Uniform Anatomical Gift Act, adopted in some form across the 50 states, specifies that family members may decide to donate a loved one's organs upon death "absent contrary indications" of the patient's wishes. But for many years the law offered little or no guidance as to how to resolve a conflict where the patient says yes but the family says no. The result has been a de facto veto power in the family, sometimes even in the face of clear evidence of the patient's wishes in the form of an organ donor card or driver's license designation. A frequent observation explains but does not justify this practice: families upset by organ retrieval over their objection may sue, but failure to honor the patient's donative intent poses no such risk.

#### **THE PATIENTS' WISHES RULE**

Recent changes in New York law resolve this dilemma in favor of honoring patient wishes. New York law now clearly states that consent to donation is not rescinded by family objection, unless it is shown that the donor revoked his or her consent. Giving teeth to this more rigorously patient-centered approach, the law establishes primacy of the rights of the transplant recipient. University Hospital policy has been revised to reflect these changes in the law.

A number of other states have moved in the same direction, sometimes coupling donor registries with rules that the patient's "first person consent" trumps family objections. These policy initiatives are a welcome development. Beyond securing respect for patient/donor autonomy, hopefully they will increase the supply of viable organs for transplant. Yet local organ procurement organizations in some states with first person consent laws reportedly still seek family consent. The utility of law to effectuate changes in clinical behavior and practice is worthy of careful study. Sometimes changing rules is easier than changing culture.



## Discharge into an Unsatisfactory Care Situation

What is a nurse to do when an assessment of the status of the patient and the plan for discharge in the face of limited or non-existent home care resources leads to a serious doubt that the discharge will be a safe one?

Mr. Miller, 83 years old, has been hospitalized for over a week. Recovering from a bout of pneumonia, he is still very weak and has a poor appetite, but his infection has been treated and his respiratory status stabilized. He no longer needs acute care. Displaying a rather ornery mood, he tells his nurse that he is anxious to leave the hospital and get back to his home where he can “get a good night’s sleep and some real food.” He still requires a great deal of assistance with all activities, especially ambulation.

The problem is that the only assistance available at home will come from his wife who is also

over 80 years old and has multiple health problems of her own. The couple lives in a remote area several miles from any community. No other family members live in the area. Their only social support is membership in a church located 20 miles from their home. Mr. and Mrs. Miller have always prided themselves on their pioneer life, preferring to live away from traffic and crowds. They have few assets but have needed little because of their simple lifestyle.

### **GOOD INTENTIONS OFTEN INADEQUATE**

Members of the nursing staff caring for Mr. Miller during his hospital stay have assessed not only his ability to care for himself, but also the ability of his wife to adequately assist him at home. They have expressed many concerns with what they see as an unsafe plan for discharge to home. Home care agency resources are very limited in the rural area where the Millers reside. The nurses fear a

bad outcome without adequate care and have concluded that transfer to a rehab facility is the only safe plan for Mr. Miller.

### **HONOR A LIFE’S PROMISE?**

The care coordination nurse suggested to the couple that a short stay at a rehabilitation facility would be beneficial in helping Mr. Miller gain strength before returning home. Mrs. Miller stated that she and her husband exchanged promises that they would never even consider allowing each other to go to a nursing home. She promised that she would always take care of him in the home they have shared for over 50 years. Both she and her husband became adamant that going home was the only acceptable plan.

In this case, two ethical principles of nursing practice come into conflict: the responsibility to protect patients under their care and the need to respect

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## **Discharge into an Unsatisfactory Care Situation**

the autonomy of a competent patient to make his or her own decisions. As they discuss their distress, the nurses agree that it is probably true that Mr. Miller will have both a better appetite and more rest at home. Familiar home surroundings often are more comfortable than the hospital environment for elderly patients. On the other hand, they have legitimate concerns regarding Mr. Miller's many needs and his dependence on his wife to meet all of them. They worry about the effects on Mrs. Miller's own health because being the sole caregiver will create a hardship for her.

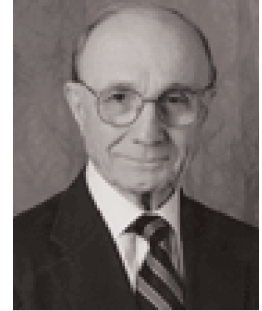
### **LESS THAN PERFECT MAY BE OK**

Cases such as these serve to remind nurses that they are not surrogate parents or guardians for their patients and that they cannot always fix a patient's social support system. The primary responsibility remains the support of the patient in all ways possible. Competent patients who are committed to a less than perfect plan for themselves are entitled to autonomy. Most discharge planning nurses engage in supportive dialogue with patients. The nurse can be honest in stating her or his opinion that this plan is not the best plan but that the team will support the decision. In this way, the nurse leaves a door open by making it clear to the patient and caregiver that they can contact her or him if the plan is not going well.

—Barb Fero

## **Edmund D. Pellegrino, MD Appointed New Chair of the President's Council on Bioethics**

The White House has appointed Edmund D. Pellegrino, MD to be the new chair of the President's Council on Bioethics. Dr. Pellegrino, 85, is Professor Emeritus of Medicine, founder of the Center for Clinical Bioethics at Georgetown University Hospital, and former Director of the Kennedy Institute of Ethics at Georgetown University in Washington, DC. He has published more than 20 books and 500 articles. His distinguished career was celebrated with a Lifetime Achievement Award from the American Society for Bioethics and Humanities in 1998.



“I am honored to have the opportunity to participate in this very important work,” Pellegrino said in a prepared statement. “The Council has set a very high bar in addressing many of the serious bioethical issues before our country. However, many significant issues remain, ranging from the challenges of ensuring access to health care to meeting critically important needs in end-of-life care.”

The President's Council has taken a number of conservative and controversial positions on such issues as cloning, stem cell research, and aspects of assisted reproduction. Critics of the Council have charged that it has functioned as a “post-hoc think tank” that has provided intellectual support for administration policies. Whether Pellegrino's leadership will set a new course or a new tone will be keenly watched by bioethicists and policymakers alike.

—Edgar Dahl

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## **Websites of Interest**

### **[www.nofec.org](http://www.nofec.org)**

NOFEC is the National Organization for Empowering Caregivers. It provides assistance, education, support, referrals and respite volunteers for informal family caregivers, and promotes public awareness about the realities of caregiving.

### **[www.care-givers.com](http://www.care-givers.com)**

A related and interactive website that features chat rooms, message boards and a vast number of resources.

### **[www.nlm.nih.gov/medlineplus/caregivers.html](http://www.nlm.nih.gov/medlineplus/caregivers.html)**

The MedlinePlus website is a service of the US National Library of Medicine and the NIH and has a major section on caregiving.

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## **From the Caregiver's Perspective**

### **THE DAUGHTER SPEAKS**

*SH (PG's daughter and caregiver):*

When my mother arrived for Christmas, she was much weaker than usual. She had not been eating well and had not been able to do her exercises to maintain her strength. Her mind was not as sharp as usual. When Mom is sick she gets lethargic, sleeps a lot, and doesn't "participate" as she usually does. I suggested that she see a doctor here but she did not want to spoil Christmas. On my husband's birthday, Mom noticed that her heart was beating fast and she was short of breath. My husband (a physician) took her to a hospital; she was admitted with serious pneumonia and a very high white cell count. My job was to visit Mom and to care for her dog.

It was hard to talk with her doctors even if we set an appointed time. They rarely could seem to make those meetings. I am Mom's Health Care Proxy but she made all of her own medical decisions. She has a living will stating she does not want to be resuscitated.

When she came back to our house from the hospital, her legs were tremendously swollen and oozing copious amounts of clear fluid. We had to wrap them in bath towels and change the towels frequently. She mostly stayed in bed and we took her meals to her, made sure she took her medicines, and took care of her dog.

### **LIFE GOES ON HOLD**

We had planned a trip to Europe for the beginning of the year and Mom insisted she be taken to her own home so as not to spoil our plans. I arranged for someone to

come each morning for two hours to get her breakfast and take care of the dog. She already had someone to clean her house and do her laundry and her cousin comes five evenings a week to prepare dinner and keep her company. She also had a companion three afternoons a week to run errands, drive her to appointments, etc. We increased this to five afternoons. Mom now required home oxygen. We cancelled our trip to Europe, which didn't please Mom, but this allowed us to stay with her an additional two weeks. I noticed that there were unpaid bills piled up at the house and I tended to those.

While we were there, Mom slipped from her chair and broke her hip. The rescue squad took her to an ER and then to a bigger hospital in the next town. Her hip prosthesis operation went well and she was walking the next day. She needed inpatient rehab for her hip. She chose a nursing home near her home because there were family and friends there (even though we all had concerns about the quality of care). Although it was very difficult to leave her, I came back to Syracuse after she was settled in the nursing home to return to work.

The next week Mom had bad diarrhea. The nursing home called her doctor and asked for medicine but they never called me or asked her doctor to visit. Four days later, a cousin called us and said Mom looked terrible. We called her physician and insisted that he visit her. He did the next morning and sent her to the ER and then to a hospital ICU in Erie, PA, in critical condition. We immediately drove 240 miles to Erie. Erie is about an hour from Mom's house and I made the trip two or three times a day for the next few weeks,

returning to her home to take care of her dog, to eat, and to sleep. It was snowy and dark for many of the trips. My husband came for the weekends and would spell me for some of the visits so I could rest.

Mom eventually had to have her infected colon removed because it didn't respond to antibiotics. The gastroenterologist and the surgeon disagreed about the urgency of the surgery. As sick as she was, Mom was still making her own decisions—at first to hold off the surgery, and when she didn't improve later, to have it. My job was to make sure she understood what the various doctors were saying so that her decisions were well informed. Mom was quite sure she was not ready to die.

### **THE SHIP WAS MISSING A CAPTAIN**

We discovered during this prolonged and complicated hospital stay that her many specialists did not seem to communicate to each other or to the hospitalist who oversaw her case. Fortunately, the hospitalist was generally available to talk to me. Our ship needed a captain.

In all three hospitals there were problems controlling her pain. Mom has a chronic pain problem. We repeatedly had to convince the doctors not to stop or cut back on her usual pain meds and then insist that they address the new pain she had from her pneumonia, hip fracture, and colon problems. I felt extremely fortunate that the first month of her illness occurred during winter break at the University because I was able to manage some of my professional responsibilities via phone and e-mail.

When she was ready for discharge, Mom was very weak and unable to walk; her legs were again swollen

and constantly weeping. This time she chose to get rehabilitation at a nursing home in Syracuse, arriving there by ambulance in mid-February. We hired a private “ostomy” nurse for Mom. They hit it off and from day one we didn’t have to tend to her colostomy. My husband and I took turns visiting every day. I did her laundry, ran her errands, and ordered and picked up the equipment she needed before going home.

### RESTORING INDEPENDENCE

We tried to be there for at least one meal each day to encourage her to eat. I never did meet her nursing home physician in the six weeks she was there. Pain control remained a serious problem. Mom said her physician called her an “addict” at one point. Throughout this whole ordeal, my goal was to help her make her own decisions and to regain as much independence as possible. Mom told me her goal is never to live in a nursing home.

My mom’s illnesses at times left me exhausted. I was naturally anxious when she was not doing well, but my stress also increased over our fairly constant inability to communicate with Mom’s doctors during her first two hospitalizations. The nurses were very helpful and caring at each of the places Mom stayed. But I wonder how caregivers without my resources and ability to take time away from work or without my husband’s medical knowledge are able to manage.

### LACK OF INTEGRATED CARE

Although I seldom felt as though I were in the way or that my questions were unimportant at the hospital in Erie, this was not the case in the other two hospitals. And even in Erie where several doctors spent as much time with me as I needed,

the system was not designed to help caregivers navigate the labyrinth of tests, results, and then prognosis. It was very frustrating that there was at the same time both too much information about test results and yet not enough information about Mom. Each physician was treating just his/her “piece” of Mom.

Caregivers are often the first line of a patient’s defenses. Helping them is smart medicine.

### PHYSICIAN’S COMMENT:

A model for dealing with patients and their families/significant others is useful since patients often need the advocacy of caregivers, especially if they are very sick or lack decisional capacity. The questions asked by caregivers on behalf of the patients should be welcomed by the medical and nursing staff. In addition, the staff might want to ask some questions of their own about the caregiver.

Would it help PG’s physicians, nurses and social workers to know that SH, in addition to facing her mother’s life-threatening illnesses, lives in Syracuse, has to travel one hour each way to the hospital in Erie in the dead of the winter, and is removed from her own support group while she is doing this? Further, should the health team ask these questions: Who is this daughter who stays at her mother’s bedside for varying intervals

throughout the day? Do we know and appreciate her role in her mother’s recovery and well-being? Have we inquired about her well-being in more than a perfunctory way? Is there a system in place to promote daily communication by a responsible physician with the caregivers?

—Joel Potash



*continued from page 1* **Culture and Caregiving**

the prescriptions and properly distribute correct doses?

In the hospital too, culture can impede care if stereotypes are allowed to trump knowledge and sensitivity. For example, certain Asian cultures shy away from organ transplants believing that they prevent the soul in the next life from being whole. Perhaps this is why a Hmong patient or his caregiver might be resistant to the idea of a kidney transplant. However, good care mandates that the physician engage in a conversation with the patient and the patient's caregivers (if the patient wants them present) before assuming that this patient would not want such a procedure done.

The notion of autonomy currently holds primacy of place in our ethical canon in the United States. Other cultures, however, do not want such an emphasis on the individual's right to know and choose treatment. They prefer to involve family and sometimes in a tightly structured hierarchy. Physicians and nurses need to

understand these traditions if they are to involve their patients in their treatment and care. For example, Latino families often incorporate siblings, more distant relatives, and close family friends into decision-making processes. And in their home countries, Asian families often provide care for family members in the hospital rather than nursing staff. Some patients

rely on life partners and friends rather than legal spouses and/or relatives for support and home care. Rather than an annoyance, such traditions can be incorporated into the patient's treatment plan, possibly creating a more optimal outcome with less stress on both sides.

—Deirdre Neilen



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