# Family Practice Grand Rounds

# Placement Decisions for the Elderly: A Family Crisis

Wilson D. Pace, MD, and Richard E. Anstett, MD, PhD
Denver, Colorado

DR. WILSON D. PACE *(Assistant Professor, Department of Family Medicine)*: Today we have assembled a panel of individuals involved in different aspects of the care of the geriatric population to discuss long-term care options and consequences.

When an elderly individual begins to need help with his or her day-to-day care, many people see a nursing home placement as the only option. We will explore some of the other options today. Many physicians think that a large percentage of the elderly live in nursing homes. This is a fallacy. At any one time, only 4 to 5 percent of individuals over the age of 65 years are in a nursing home. Between 35 and 45 percent of all people over 65 years old, however, will spend some time in a nursing home prior to death. There is no estimate of how many families look at a nursing home for a relative and decide not to go through with the placement, but at least one half of all families have to face the placement decision at some time. It is incumbent on physicians to learn how to help these families during this very difficult time. I would like to start by asking Dr. Zimmerman what he considers the most common problem that faces a family thinking about a nursing home placement.

DR. DAVID ZIMMERMAN *(Practicing family physician specializing in geriatrics)*: The most common problem is the unresolved conflict that develops when separating a parent from the family. Many times the parent does need to be separated from the family because of the inability of the family to care for the parent. The family members realize a nursing home theoretically could give better care, and families are not sure whether placing a family member in a nursing home represents abandonment, a concept fraught with emotional conflict.

MRS. GAYLE ANDRESEN *(Adult nurse practitioner, Montclair Manor Nursing Home)*: Understandably, the emotions seem to usurp the practical points of view. It is very hard to be realistic about nursing homes.

DR. PACE: A frequent question families ask is, "Can Mom (the elderly individual will commonly be referred to as female during this discussion to reflect the 70 percent of nursing home residents who are women) live alone?" How does one person evaluate whether another person still can live alone?

MRS. HELEN TOLL *(Nursing director of a home health care agency)*: You have to determine what kind of problems the individual is having, how well she functions at home, whether the medical problems are under control, what kind of support system there is, and what kind of support is needed.

DR. PACE: What is the most common set of medical problems that result in a nursing home placement?

MRS. TOLL: The most common problem is incontinence. When someone is incontinent 24 hours a day, it becomes a problem that families cannot face. Also, an immobile patient who needs help getting in and out of bed and going to the bathroom can exhaust a family.

DR. RICHARD E. ANSTETT *(Assistant Professor, Department of Family Medicine)*: For the person who lives alone, what are the risks involved in terms of accidents? Is there any way of taking a preventive approach?

DR. ZIMMERMAN: That depends on the patient and her mental status. Falls are primary risks. I am surprised I don't see more accidental

Continued on page 34

From the Department of Family Medicine, School of Medicine, University of Colorado, Denver, Colorado. Requests for reprints should be addressed to Dr. Wilson Pace, University of Colorado School of Medicine, Department of Family Medicine, 1180 Clermont Street, Denver, CO 80220.

*PLACEMENT FOR THE ELDERLY*

Continued from page 31

overdoses; usually I see underdoses or mixed medications. I don't see burns; I would expect to see that more often. Elderly patients living alone are much like children. Their patterns of care are a lot like those you would apply to children.

DR. MITCHELL BERDIE *(Psychologist, Geriatric Resource Center)*: The assessment for independent living takes in a lot more than the specific medical condition. There are a number of assessment teams around the country that help families make these decisions. They look at medical factors, social supports, family commitment, and the financial resources that allow people to bring in social supports. A member of that assessment team is often an architect, who goes to the home and studies architectural problems, such as obstacles that would not allow the use of a walker. The teams reflect the important point that assessment is a multidimensional process.

MRS. ANDRESEN: The patient in question is also part of this assessment process. If the patient's thinking is clear, she has the right to make the choice, even if the family isn't delighted with the results. An assessment team can help resolve that issue.

DR. FRANK MARSH *(Professor, Departments of Community Medicine and Philosophy)*: We are speaking about maintaining some degree of patient autonomy, a major dilemma in family medicine. The family has brought the mother in because she is considering nursing home placement. There are obligations to the patient and the family because the physician is treating the whole family. You cannot judge from a medical standpoint whether a person has lost her autonomy.

MRS. ANDRESEN: The elderly person should make the choice. If she knows she has a potential for falling, she should choose whether she wants to take that risk.

DR. ANSTETT: When a patient is involved in the decision-making process, some of the stigma or guilt is taken away from the family members who are involved in the decision.

DR. MARSH: Too often we try to impose, from a subjective sense, what we think is best. This act denies the autonomy of the patient. Because the older person may have difficulty getting around an apartment, preparing proper meals, or maintaining personal hygiene, we tend, both as parents and as health care professionals, to interpose what we see as the ideal state of health. We become paternalis-

tic, and the older the person grows, the more paternalistic we become.

DR. RAYMOND GEIS *(Third-year family practice resident)*: How do you decide when a patient is in real danger?

DR. MARSH: A patient is in danger when she can't get around or take care of herself. It is difficult to let a patient be autonomous when you know that she might hurt herself.

MRS. ANDRESEN: It is interesting that we allow a child autonomy more readily than we do an older person. The youngster has to learn the lessons of life, but the elderly person has to be protected.

DR. PACE: Some families who are having a difficult time with the placement decision may ask the physician to take a different perspective, taking away from the family the decision to place a parent in a nursing home.

DR. BERDIE: It is always difficult for the physician to know when to exercise some of the authority inherent in the physician's role. The request often occurs in families that have been disengaged for a long time and because of the situation are asked to come together and make a decision. There may be problems because of sibling rivalry or guilt about putting the mother in a nursing home. It is important for the physician to indicate that this decision is a family responsibility, but he can help the family clarify their decision. The physician can help the family look at criteria they can use to make this decision: "Your mother is liable to have a fall; her judgment and eyesight are impaired. What is going to be the best thing for your mother?" The physician does not necessarily make the decision for the family, but can help them go through the decision-making process. That assistance can be important for the family. It can be therapeutic without taking away the family's sense of responsibility.

DR. ZIMMERMAN: I have found that families either come to the office having made the decision and looking for approval, or come to the office saying, "Make the decision for us," which usually implies a corollary: "We really think she needs to be in a nursing home, but we are unable to come to grips with the decision. Make that decision for us so that it is off our shoulders."

DR. PACE: My feeling is that younger physicians have a hard time making decisions for people. We are more comfortable saying here are the options, now you make the decision. Are there ways to help physicians become more comfortable with the role of having to make a difficult decision for someone?

DR. MARSH: The physician must get in mind what type of role he is going to play at the start. You describe what Veatch[1] calls the engineering role, which is the easiest role for the physician to assume. In this role, the physician tells everything to the patient, then disengages himself and lets the patient make the decision. The moral burden is on the patient. The paternalistic role, really the old traditional role, is currently much criticized. Many young physicians are leaning toward the contractual role. I'm not talking about legal contracts; I'm talking about a moral relationship in which the patient is encouraged, insofar as the patient is autonomous, to continue to make the major decisions in his or her life with the physician's assistance. Because the choice of role is up to the physician, one way to feel comfortable about it is to decide from the beginning what kind of role will be assumed.

DR. PACE: What should a physician discuss with a family who decides to take a parent into the home?

DR. BERDIE: The family is going to face a lot of changes. The caring couple is often 50 or 60 years old, and at a point in their lives where they enjoy being without their children and having their own lives. Suddenly, another person moves in. A structural change may be created in the family that may present some major difficulties. Part of your job as a physician is to assess what the family is like and what their established patterns of living are because that will indicate how they are going to respond.

DR. PACE: Mrs. Falco, would you comment on what it is like having your grandmother-in-law live with you? What kind of change has it been for your family?

MRS. GERRI FALCO *(Licensed practical nurse, Department of Family Medicine)*: It's been hard. It has caused financial problems and problems with the children because she tries to influence us with the way she has raised her children. The children are concerned about what they would do if they came home and found she had died. They complain about what she's doing. She complains to my husband, and we complain to each other. She has made up her mind that she is not going to do certain things "come hell or high water," and she won't do them, whether it's for her good or not.

DR. BERDIE: We will likely see more of what you're going through in the coming years: adult grandchildren taking over the role as caretaker. In previous decades, because of the shorter longevity of generations, you wouldn't see adult grandchildren take on primary responsibility for aging grandparents. Previously, the grandchildren wouldn't be old enough to do that. As a family physician, when you assess the resources that an elderly person has, don't forget that they probably have grandchildren who could be involved in the placement process.

DR. ANSTETT: When an elderly person comes into the extended family, is there any way the physician could counsel or prepare her for what it will be like now that other people are making decisions?

DR. ZIMMERMAN: Part of the problem is who you're telling this to, the oldest person in the family. There is the sense that they have been around longer than anybody else and deserve respect. Intellectualizing the problem of control is fine, but it tends to break down in day-to-day living.

DR. ANSTETT: I don't mean a laying down of rules. Are there ways that we can divide up responsibilities, obligations, and control with a person who is used to having control?

DR. BERDIE: Incorporating a grandparent into the family is similar to the blending phenomenon when two parents who had previously been married and have children by their previous marriages move in together. When those families blend in a different environment they have to figure out different roles. In some cases family therapy could be helpful for those families. It's difficult to refer older persons to therapy of any kind because of the stigma therapy carries for them. There are other ways to approach the family by getting them involved with someone who can help them deal with issues they may never have worked through. It's a different situation when you include an older member. If you seek out some assistance, you can enhance the quality of everyone's life.

DR. MARSH: The question of giving up control is important. Stake out some territory for an older person who comes into the home. When my mother was living with my sister, they were able to designate two rooms for her, and nobody could go in there unless invited. She maintained a modest amount of autonomy. Even dying people stake out some area around them to maintain their sense of dignity and autonomy, even though it's gone everywhere else.

DR. ANSTETT: Apart from space, are there other elements of control that you can offer to the older person?

DR. MARSH: Yes, a part in making family decisions. My mother was 85 years old when she died despite having smoked heavily. My sister complained that mother would get sick from smoking. I felt at that age it didn't matter, it was her decision. So, even though the smoking was worsening her emphysema, we didn't say anything about her smoking. We let her know that we didn't want her smoking around us because it bothered us, and she still maintained dignity and respect.

MRS. FALCO: Before our grandmother came to live with us, she had a problem disciplining our children. She has improved a great deal since we've given her responsibility. If the children get out of line and bother her, we expect her to handle it. I expect her to make her own appointments with her doctor and arrange for her Red Cross rides. I check on her to make sure she has done it.

DR. ANSTETT: How do you deal with your children when for them it means one more person telling them what to do? Is that hard?

MRS. FALCO: Yes, it's very hard. I tell them I understand what they are going through, but she's old and deserves respect. I'm a firm believer in respect for age, and I have tried to teach them that.

DR. ZIMMERMAN: This issue is more important than it may appear on the surface. Current trends indicate that in ten years there are going to be fewer nursing home beds available. Those who will get nursing home beds will be either very poor or very rich. The great middle class will have to care for the elderly themselves, which used to be common in this country and will become more common again.

DR. BERDIE: It is already increasingly difficult to find nursing home placement for those with Alzheimer's disease. The payment regulatory agencies don't consider that enough of a functional impairment.

DR. MARSH: You've raised the key issue in all medicine—the allocation of resources, a major responsibility put upon all health care professionals, particularly a physician who is going to help put someone in a bed. One must decide which patient will benefit most by a bed, particularly when we're talking about state funds. The very rich will

Continued on page 39

Continued from page 36

always have a bed. In England a patient cannot receive renal dialysis after the age of 65 years unless he can pay for it. The government does not have enough money to go around. Similar conditions will prevail with nursing homes. In the future, a physician may have to decide who will get those beds.

DR. PACE: What are some of the emotions a physician can expect a family to express once a member of the family is put into a nursing home?

DR. BERDIE: You can expect to see almost anything. At this time it is good to bring up the notion that nursing home placement is a part of a passage into death for the older person.

DR. MARSH: It is generally interpreted as the first stage of social death.

DR. BERDIE: It may be a difficult stage in the dying process for different families. For the family that has been very supportive and managed to keep the parents at home for a long period of time, it can be a deathwatch period.

DR. LORRAINE WOOD *(Third-year family practice resident)*: We just placed my mother-in-law into a nursing home. Part of what she does on a day-to-day basis has to do with what happens in the nursing home. If one of her roommates dies, she becomes profoundly depressed. We try to deal with a person in an environment over which we have little control. We try to visit her frequently and try to deal with her feelings surrounding many issues, but what she feels and how she reacts to us often has to do with what is happening in the nursing home. We are only part of that whole social environment.

DR. ZIMMERMAN: There is one predictable theme. The family will initially almost always react negatively toward the nursing home personnel. A physician can expect to hear such comments as "the nurses aren't giving Mom enough water, they're not taking care of her bowel movements" or "they're not doing" one or another thing. If you respond to all the complaints, something else comes up. This phenomenon usually lasts about four to six weeks and then suddenly dissipates. It's part of the grief work and the unresolved conflict that the family experiences when they put a parent in a nursing home. They finally realize that the nursing home cannot take care of the family member as well as they think it should, but they also realize this is what they want, and it's better than any other alternative.

DR. STEVEN POOLE *(Associate Professor, Department of Family Medicine)*: Are you ever able to talk with the families about this reaction?

DR. ZIMMERMAN: When I get the chance, I tell the family I expect these feelings to develop. I also tell them I'd rather that they call me than complain to the nursing staff and create a lot of friction. If a family member continues to complain about the way the nurses are caring for a patient to the nursing staff, instead of the staff jumping in with greater vigor, then tend to back off.

MRS. TOLL: My experience has been that either a family will put a parent in a nursing home and completely back off for a period of time, or they act out as you described. The nursing home staff needs to understand what is happening so that they don't respond by giving the patient the kind of care that the family thinks she is getting. This attitude can cause numerous problems between the staff and the family.

DR. BERDIE: There is also a response called relocation shock. When a patient takes up residence in a nursing home, she goes through a period of regression. Quite frequently she may become more demented than she was. The family responds to it with, "What did we do! We put Mom in here and look what happened to her." Schultz[2] looked at ways to alleviate relocation shock and found that by involving the older person in the decision directly, such as having the person go to a couple of nursing homes and make a choice of where she wants to go, relocation shock was lessened. If physicians focused on those kinds of interventions, we could prevent some of the symptoms.

DR. ZIMMERMAN: I have sent families all over town picking and choosing among nursing homes. Once in the nursing home the food is even worse then they thought, it's a little dirtier than they thought, the nursing care is certainly not what they expected. I would emphasize that the physician will invariably become the object of anger unless it is handled carefully.

MRS. ANDRESEN: An internal nursing home problem that often exacerbates patient shock is unnecessary movement of residents, particularly without permission from the residents. It does not help with relocation shock.

DR. PACE: The decision to place somebody often comes after a family has had a parent living with them for two to three years and finally cannot

Continued on page 43

Continued from page 39

deal with the care anymore. I would hope that family physicians would get involved prior to that nursing home placement in helping the family. When the family makes a decision to place a parent, what do you tell a family to look for in a nursing home? How do you evaluate a nursing home?

MRS. TOLL: One should call the state health department to find out how they rate the nursing home. They will tell you which ones are the cleanest, which ones are the most efficient, or which ones are in trouble. That information will limit your choice. The patient's condition plays a role. If she is alert and one nursing home has a very good activities program but the food isn't so great, maybe the person will settle for the activities program. If you have somebody who will need a lot of nursing care, find a nursing home that is putting its efforts into nursing care. One has to consider what is important to the patient.

DR. WOOD: We made surprise visits to many nursing homes, ate the food, sat in the bathrooms, and talked to the patients, nurses, physicians, and especially the religious people who were coming to the nursing homes because religion is often an important part of an elderly person's life. To my mother-in-law, the priest was very important. We also were concerned about autonomy, and we tried to determine whether there was a philosophy of encouraging a person to be more independent. We made many visits and observed on a one-to-one basis how much support was given to people, the feeling about medications, the restrictions on visiting hours, if any, and what support services they provided. The nursing home we picked has a van equipped with a wheelchair lift that we can take whenever we like. They provided us with outreach services that were extremely helpful.

DR. ZIMMERMAN: Dr. Wood's experiences are unlike most in terms of prospective analysis. Most families, because of conflicts, find the process distasteful and are not really interested in doing such a thorough investigation. When I begin with a family, I say, "No nursing home is going to be perfect. Given this, pick one that satisfies your basic needs." The choices usually center on convenience of visitation. It's too bad that one cannot judge the adequacy of a nursing home on the basis of ambiance. Nursing care in nursing homes has nothing to do with how attractive the building is.

DR. BERDIE: Most people do not investigate nursing homes as Dr. Wood did. Seventy percent of people are placed in nursing homes after only one home is looked at. That one half of the people had never been in a nursing home before they made the decision to place a parent reflects how frequently the decision for nursing home placement is defined by the family as an immediate crisis.

DR. WOOD: Availability can be a major problem. Someone in the nursing home dies and the interested party gets a call and is told to bring the family member over right away. Among the choice of nursing homes, this is the one with a bed, take it or leave it. In that sense the family is put in a situation of having to make a crisis decision. You take it if it's satisfactory on most criteria.

DR. BERDIE: That whole business of convenience brings up another issue. I frequently deal with people who have brought their parents to Denver to place them in a nursing home so they could be close to them. People ask me, "Should I bring my parent here or should I find a nursing home back in Iowa?" It's a difficult decision. A lot of people I talk to feel the mother would have been happier left in Iowa. Often the parent says, "I'd rather be close to you." But after a year of being in a nursing home in a strange city, not being able to go any place familiar, both parties frequently wish they had not made the move; they wish they had found a place closer to the parent's home.

DR. PACE: Meeting a family at the nursing home and finding they haven't told the mother that she is being placed is another common occurrence. The elderly parent thinks she will be there a couple of days. How should one deal with that?

DR. MARSH: The minute you enter into a relationship with a patient who is going into a nursing home, you have moral and legal obligations, one of which is fully informed consent. One way to handle it is for the physician to talk with the family immediately to find out what the patient knows. Has the patient been told? If not, then the family should tell the patient. You can't deal with the patient unless she is fully informed. If she says, "I want out of here, I didn't want to come here," you should hand that back to the family or you're really caught.

DR. DAVID STEINMAN *(Associate Professor, Departments of Family Medicine and Pre-*

Continued on page 46

Continued from page 43

*ventive Medicine)*: I once had a problem in which a spouse caretaker no longer wanted to care for his ill wife. A scenario like this developed: "Doctor, you've got to place my wife in the nursing home. I just can't take it anymore." His wife called the next morning saying, "My husband wants to put me in a nursing home, but you know how I feel about it. He shouldn't be permitted to do this." The physician has to stand back, air the conflict with both spouses, and make them make the decision. If you're party to premature placement, you no longer have a family as your patient. You have to be willing to listen and let people work things out. Don't be too ready to place someone to see how it works out. You're not doing that family a service.

DR. PACE: Nursing home placement isn't always the end of the line, and people do leave nursing homes. How do you decide when a person is ready to leave a nursing home? These people are in a protective environment, and it may be hard to decide how capable they are of living alone again.

MRS. ANDRESEN: The answer lies with the support systems to which they return or that can be provided when they do return home. Nursing homes will be used more often for rehabilitation purposes. Patients will come out of hospitals, spend a month or two in a nursing home for rehabilitation, and then go back to their own home. The clients we have had at Montclair Manor who have done well have often been living in a retirement apartment where there are some resources for help, such as panic buttons or a maid service. Occasionally a client has gone back home to a spouse and has deteriorated in a matter of days or weeks. The outcome is not based solely on physical function, but on family dynamics.

MRS. TOLL: Most of the patients we have discharged from the nursing home have had home health care or live-in help 24 hours a day. Home health care can supplement a family's care by providing a housekeeper, physical therapist, or nurse.

DR. PACE: The majority of patients do not return to independent living once they enter a nursing home. It eventually becomes necessary to decide on appropriate medical intervention.

DR. MARSH: Mrs. Andresen, how often have you found that a "no code" has been talked about with the family?

MRS. ANDRESEN: Not nearly enough.

DR. MARSH: It is a delicate question. Also the ethical question of how many times a patient who has physically and mentally deteriorated should be resuscitated is quite powerful. The physician and everyone else connected with the family is responsible for thinking that through and deciding what to do.

MRS. ANDRESEN: I would like to see the beginnings of such a discussion take place on admission to the nursing home. You can't resolve the issue overnight, but it should be brought up at that time.

DR. BERDIE: It's becoming clear that the nursing home is part of the dying process.

MRS. ANDRESEN: In reality, that is exactly what it is. The nursing home staff faces death several times a week.

DR. ZIMMERMAN: I have a little scalp vein needle in my office. When I get a chance to talk with a family member prospectively about resuscitation, I hold up this needle and point out that this is the heroic measure we're talking about, not artificial ventilation, not advanced cardiac life support. Ampicillin might be a heroic measure in the patient who is a chronic aspirator. The family then begins to understand what the question really is: How many times do we send mother to the hospital to improve her creatinine or rebalance her electrolytes or clear up her minor infection? I start them thinking about it that way. I let them know they don't have to decide immediately, but eventually when I get a call from the nursing home about mother having a fever again, I'm going to ask them, "Do we draw the line here?"

DR. STEINMAN: We need to have a clear sense of the natural history of illness and to realize that health cannot necessarily be bought with a $2,000 acute hospital admission.

DR. PACE: Today we have explored several aspects of elderly long-term care. The panel has indicated that this decision should involve and will affect the entire family. They have pointed out the common problems the physician may face and supported the concept of anticipatory intervention for the family facing this crisis. It is incumbent upon us, as family physicians, to lend informed guidance to our patients through this process.

**References**

1. Veatch RM: Death, Dying and the Biologic Revolution. New Haven, Conn, Yale University Press, 1978
2. Schultz R: The Psychology of Death, Dying, and Bereavement. Menlo Park, Calif, Addison-Wesley, 1978