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# Preserving Patient Dignity When Surrogates Step In

Marla Fern Gold



**M**ary, a breast cancer survivor, was proud of her successful battle with the disease 25 years later. Her family assumed that if she were ever diagnosed with cancer again, she would want the same aggressive treatment that had saved her life the first time.

But when she was diagnosed in her 80s, she was not able to decide whether to fight the disease, because by then she had become afflicted with Alzheimer's disease and no longer had the capacity to make decisions concerning her medical care. Those decisions fell to her daughter, who elected not to fight but rather to ensure that her mother remained as comfortable and pain-free as possible for the rest of her life.

Such is the power of surrogate decision making, or decision making by someone other than the individual, in matters big, like life and death, and small, like whether to shower in the morning or at night.

## The Complexities Of Decision Making

More and more people are entering long term care—assisted living and nursing facilities—with diminished capacity for making important health care decisions. Some arrive with advance directives in hand, giving the power for decision making to a trusted relative or friend, while others show up with a trusted relative but no legal papers at all.

How, then, do long term care providers meet their twin mandates of providing the highest practicable level of care and maintaining patient and resident rights, while turning over some of their residents' most important decisions to others?

"The default position is that each resident has capacity until proven otherwise," says Howard Tuch, MD, director of long term care programs with Hospice of Southwest Florida.

In Mary's case, her physician's evaluation determined that she was not capable of understanding the medical questions and left the decision making to her daughter, Mary's surrogate decision maker. Her daughter decided that Mary's dementia was so advanced that even successful treatment of the new cancer would not improve her quality of life and might, in fact, diminish it and that Mary would never opt for treatment in this situation.

Because of the growing complexity of health care decision making, it is essential for long term care providers to work with residents and their families even before the time of admission to ensure that advance directives are completed, surrogates are named, and that all relevant family members and friends are contacted. But just as important, it is up to health care providers to ensure that residents make their own decisions whenever possible, and that the right decision



When patients are no longer able to make their own health care decisions, they should still be able to make daily, quality-of-life choices.

maker is making the right decision when it is not possible.

### Surrogate Decision Makers

Simply put, a surrogate decision maker is an individual who makes decisions in another person's stead. A court-appointed surrogate is called a guardian. According to health care attorneys, very few elderly nursing facility patients have court-appointed guardians.

For a court-appointed guardian, the court must deem an individual incompetent—legally unable to make informed decisions on his or her own behalf. Frequently, court-appointed guardians are named for people with mental retardation. Therefore, residents in intermediate care facilities for

people with mental retardation almost always have them (*see sidebar, below*)

For a long term care resident, a “declaration of incompetence is a radical step,” says Msgr. Charles Fahey, senior associate and Marie Doty professor of aging studies at Fordham University's Third Age Center. “It is a device that's contrary to human dignity, because it strips individuals of various rights and opportunities,” he says. In the rare case where legal guardianship is sought, it is usually because either no one can be located to act on a resident's behalf, or because family members cannot come to consensus, despite facility intervention.

Residents of long term care facilities are more likely to have surrogates named through an advance directive or

durable power of attorney, or a proxy appointed in the absence of any surrogacy documentation. In such cases, a resident would not be declared “incompetent,” which is solely a legal term. The resident would be evaluated by at least one physician and found to be incapacitated, or lacking capacity to make an informed decision or provide informed consent.

According to Karen Goldsmith, partner at Goldsmith and Grout, in Winter Park, Fla., most states have proxy or surrogate statutes that allow individuals to designate another person to make health care decisions for them if they become unable to make their own decisions or choose not to. In addition, Goldsmith says, almost every state has additional statutes that allow

## The Power of Guardianship

The 63 residents at Wendell Foster's Campus, an intermediate care facility for people with mental retardation (ICF/MR) in Owensboro, Ky., are governed by court-appointed guardians. Most of these residents have cerebral palsy and severe cognitive impairments that make even simple decision making a legal step-by-step process.

For staff, decision-making authority is clear. “If a resident has a guardian, there are very few situations where a resident can make their own decisions,” explains Cynthia McCollum, chief financial officer. For instance, “If a resident no longer wants pureed food, we cannot make that change unless the guardian agrees,” she says.

### Ensuring Residents' Rights

To safeguard residents' rights, every suggested change, no matter how minor, must go through the facility's Resident Rights Committee for a recommendation, then to the guardian for approval. “If we want to change anything, it is a rights violation if it does not go through our committee first,” says McCollum.



A resident at Wendell Foster's Campus in Owensboro, Ky., smiles for the camera.

Though the law is pretty clear, there are still gray areas, says Carol Rolf, senior partner with Rolf and Goffman, in Cleveland. “Facilities struggle with the balance of rights of the individual and rights of the guardian. Many regulatory agencies support embracing individual rights, but in most cases, courts will enforce guardian rights.”

She says typical scenarios can include a young person who is diabetic and wants to eat candy, or who wants a sexual relationship, or who wants to smoke, actions the guardian prohibits. “Who has the final say?”

While ultimately the guardian may be the final decision maker, “legal guardianship does not remove the facility from a moral obligation to try to enhance the capacity of the individual,” says Msgr. Charles Fahey, an ethicist with Fordham

University's Third Age Center. For that reason, staff at Wendell Foster's work hard any time they have a new admission with a public guardian. Residents can have two types of guardians. A public guardian is an individual who works as a professional guardian for a fee. This guardian ►

may have dozens of charges and may not know any of them well. The other guardian, and the one McCollum much prefers, is a family member appointed by the court. "When a resident comes to us with an outside guardian, our social service person works with our parents' support group and board members to try to find people we know to act as a guardian. We don't feel that state guardians have the best interests of residents in mind. State guardians don't have the time to dedicate to our residents, they can't visit, they can't send cards," McCollum says. Certainly, newspaper articles detailing financial mis-handlings almost always center on state guardians.

Often, McCollum says, a guardian for one resident is willing to become guardian for a new resident.

### Resolving Differences

McCollum says that ongoing and open communication between facility staff and guardians leads to very few dis-



agreements. In fact, she says, "The only time we've had any problems is when we get strong feelings from a guardian that they want their family member to live on their own, but there are times when residents cannot take care of themselves even in a supported community living program." Wendell Foster's supported community living program has admission criteria, and it is up to staff to determine whether a resident fits the criteria.

In the event that staff do not think a guardian is acting in the best interests of a resident, the facility can write a letter to the probate court indicating the facility's concerns. "The court then, on its own motion, can institute a look into the appropriateness of the guardianship," says Rolf.

"As an advocate for the resident, you sometimes may want to assist them in challenging guardianship," says Rolf. But first, she says, make sure they really want the change. "They may grouse about something but be willing to do it, or they may really want a change."

proxy decision makers to step in when people have not designated another person to act on their behalf. The hierarchical list of proxy decision makers varies by state, but it usually starts with a person's spouse, then adult children, then competent siblings, other relatives, and close friends. However, proxy decision makers may have more difficulty than surrogates in making certain decisions, says Tuch. "In some cases, a proxy may have much more difficulty than a surrogate to request no feeding tube."

Though the law may be clear, in reality, there are myriad ethical, legal, and practical issues that come into play when a surrogate is installed as a decision maker. "From an ethical perspective, the issue is pretty clear. You have to go along with the wishes that a resident expressed. From a legal perspective, the issue is pretty clear as well, that you have to go along with the living will. But from a practical standpoint, that's where it gets tricky," says Tuch.

The first issue providers must evaluate with any resident is whether they are competent, says Carol Rolf, senior partner with Rolf and Goldman, in Cleveland. "If a physician documents that a resident is not able to make a decision for himself or herself and the

resident has an advance directive and durable power of attorney in place, it is at that point that the durable power kicks in, and it is at that point when the facility can start talking to the surrogate decision maker, the 'attorney in fact,' to make health care decisions."

"Until then, the facility should not be asking the surrogate. Automatically, a lot of providers are deferring decisions to the durable power even when residents are able to make their own decisions," Rolf says.

To determine capacity, facilities can use a global deterioration scale, the brief cognitive rating scale, or other diagnostic tools to evaluate a resident's ability to make decisions. Explains Tuch, "An individual has to be able to understand the procedure being discussed and the consequences of the procedure, as well as the consequences of refusing the procedure, to be able to make an informed decision."

### Levels Of Decision Making

Many providers maintain that once an individual has been found to lack capacity, all decision making shifts to their surrogate or proxy decision maker. But long term care experts say this is a mistake.

"Capacity is not absolute," says Tuch. "Just because someone lacks

capacity to make complex medical decisions doesn't mean that person cannot make decisions about what to eat, who they have as a roommate, or when they bathe. Many facilities use blanket capacity/incapacity for decision making, and this is just not correct."

In fact, he says, a resident may lack capacity to make health care decisions but still maintain the capacity to appoint a surrogate. "There are different thresholds for capacity for different types of decisions," he says.

Capacity can change from day to day as well, say providers. "Competency is not as simple as being 'in' or 'out.' Competency does come and go—people have good days and bad days, days where they may be very competent to make decisions, or a significant change in status may make them incapable of making an informed decision," says Dave Kylo, executive director of the National Center for Assisted Living.

Capacity also has gradations that must be determined. "There is a tendency for us as providers to assume that a person with dementia does not have capacity to make decisions," says Jeanne Hyde Grubman, director of education and outreach for the Chicago-based Alzheimer's Association. "That is not true. On a day-to-day basis, for example, the resi-

dent can decide, 'Should I wear the red dress or the yellow dress?' Choice is a really important thing that they be allowed in whatever area they are able."

### Ethical Obligations

Deb Choma, director of Shard Villa, an assisted living center in Salisbury, Vt., has one example of how challenging it can be to advocate for a resident with a surrogate decision maker. One resident, a 94-year-old grandmother, was "snuggling" with another resident, a 97-year-old widower. The woman's son, she said, "flipped out when he heard about it." Ultimately, she says, "the son is the one in charge of her and has the power to determine whether she can have this relationship, because she turned over decision making when she entered my home." In the end, through lots of talking and venting, the son agreed that his mother could have the relationship.

In fact, endless potential hazards litter the decision-making path—from issues about end-of-life care to food preferences, to roommates, to bathing habits. Ethically, in fact, Tuch says the biggest problems occur when a proxy makes decisions not consistent with a resident's wishes.

Recognizing the values, preferences, and beliefs of residents is one way to help them maintain some autonomy and choice within the confines of surrogacy and helps to keep ethical responsibility at the forefront of decision making.

Says Ed McMahon, a clinical psychologist and director of Alzheimer's care and quality of life for Ft. Smith, Ark.-based Beverly Enterprises, "Unless a court had adjudicated an individual as incompetent, we would always assume when they come to us that they have a certain amount of capacity. We might look at their capacity as the ability to decide whether they want to get up at 10 a.m., and not at 8 a.m. We may not extend this capacity to make medical decisions."

## Legal Documents

There are a number of legal documents that may come into play when residents are unable to make decisions for themselves. These include:

- *Advance directive* Enables a person to document in advance preferences regarding treatment and care, including end-of-life wishes. Two common forms of advance directives are a living will and a durable power of attorney for health care:

- Living will* States a person's choices for future medical care decisions, including the use of artificial life support.

- Durable power of attorney for health care*. Allows a person to appoint

another individual to make all decisions regarding health care—including choice of providers, medical treatment, and end-of-life care.

- *Durable power of attorney* Allows a person to authorize another to make legal and financial decisions when the person can no longer make them.

- *Living trust* Allows a person to create a trust and to appoint someone else as a trustee to carefully invest and manage assets.

- *Will*. Names an executor and beneficiaries in the event that an individual dies.

*Each of these documents is state-specific. Source: The Alzheimer's Association Web site*

Fahey says the overriding principle must always be to "maintain any shred of the ability of the individual to make an informed decision. Whatever legalities are involved, you always strive for that shred of capacity." It is up to providers, he says, to make that distinction in each situation.

### Knowing The Resident Is Essential

Knowing the resident as a person is elemental when determining capacity for decision making, says Grubman. This allows facility staff to help the resident retain as much autonomy as possible. It also may help staff understand puzzling behavior.

"The nursing facility has an obligation to get to know its residents, not only how they are on that particular day or year, but who the residents were during their lifetimes. Knowing that helps [a facility] to anticipate peoples' needs and know what kind of decisions they may have made about day-to-day life," Grubman says.

"I believe there needs to be some extensive work done preadmission when working with residents with dementia, in particular, to find out what the person did for a living, what

their personality was like, what their interests were, and what their current capabilities are," says Grubman. "This information impacts care tremendously, but it often does not take place."

In one instance, staff had gone through numerous futile attempts to deal with a resident who was constantly trying to organize, manage, and "keep things under control," says Grubman. "It was very bothersome to staff until they realized that this was a good thing, because the resident was a former school principal, so these behaviors were consistent with what she had done her whole life. It was critical that staff understand who this resident was." Minor decisions, such as knowing whether a resident would choose chicken or a hot dog are just as important to discern, she says. "These pieces of information help staff keep decisions about day-to-day living consistent with who the person is," she says. Grubman and others say this is an ethical necessity, not a choice.

### Following The Paper Trail

Before any surrogate decision making can take place, providers must ensure that the appropriate papers have been

filed that outline all surrogacy or proxy decision-making authority, any legal documents that accompany these issues, and other relevant data (*see box, page 33*).

For Choma of Shard Villa, this process begins with the first meeting or telephone call from a prospective resident or family member. "I encourage all prospective residents to have advance directives in place prior to admission," she says.

At facilities operated by Cleveland, Tenn.-based Life Care Centers of America, specific policies and procedures spell out the protocols for obtaining advance directives. "As part of our admission process, we let people know about advance directives, living wills, and durable powers of attorney," says Cathy Murray, senior vice president of operations. "If a resident is entering the Alzheimer's unit, we will try to set up in the very beginning a discussion among the resident, the family, staff, and the physician and get

a surrogate decision maker in place. Even if the resident enters the facility at a point where they can make their own decisions, we try to get them thinking in the direction that if they become less able to make their own decisions, they should appoint someone now who can make decisions for them later."

That's why, says Tuch, it is so important to stress to capable residents that they choose a surrogate who knows their values well enough to speak in their stead. "Someone who knows your values, that's who you want to have sitting across the table from the clinicians," he says. "When you write a living will, you cannot always anticipate the enormously complex situations you may be confronted with 20 years down the road. You need a surrogate who could say what you would have wanted."

Murray says that with the rise in assisted living of Alzheimer's specialty units, nursing facilities are admitting

patients in later stages of the disease who are already at the point where they need another decision maker. She hopes, therefore, that the assisted living facility where the resident lived previously had advance directives completed when the resident still had the capacity to make health care decisions.

### **Advance Planning**

Beverly Enterprises, Fort Smith, Ark., follows similar protocols for working with residents and their families to get advance directives in place prior to admission. Says Andrea Ludington, senior vice president for professional services, "One of the things we work really hard at is that as soon as we are contacted by a family or resident, our admissions folks have checklists to ask the family or resident about advance directives. That's really important."

Beverly staff also discuss advance directives and living wills at quarterly care plan meetings or after a change in condition.

## Taking Ethics Home

**G**uardianship and ethical issues are not exclusive to the long term care facility setting. For many patients and providers, the same issues are just as relevant in the home care environment. While Alzheimer's patients participate in day care programs at facilities, they may also be receiving care from home care providers after hours; the same ethical issues are prevalent in both settings. In many cases, home care situations are more vulnerable to risks because home care providers work under less supervision. "For a home care provider, there is a definite risk of crossing the line," says Allen Hager, legislative chair for the National Private Duty Association (NPDA). "The bond between the patient and the home care employee can become very personal. If not properly managed, the relationship could lend itself to a negative situation."

### **Educating Consumers**

As more consumers turn to home care as an alternative to institutional care and greater numbers of Americans are suf-

fering from chronic or debilitating health conditions, the home care industry is booming. With this boom come the risks of unqualified home care providers "tainting" the industry and consumers who are left unaware of the legal risks involved with hiring registry providers or independent home care workers.

"It is imperative that the consumer understand what kind of services are provided and who is providing the services," Hager says. "There is a very specific difference among home care agencies: Do they hire their workforce? Or do they simply place independent contractors?" If an agency hires its workforce, the agency is responsible for employee screenings, wages, taxes, and liability issues—relieving the consumer of many risks involved with home care. The independent home care provider who is not affiliated with an agency is not so easily monitored.

Many times, it may be the institutional health care provider recommending a home care employee or agency to a patient or the patient's family. To protect the consumer

Kathleen O'Brien, senior vice president of programs and community services with the Alzheimer's Association, suggests that providers talk about advance directives at the time of preadmission, again at family orientation, and any time there is a change in status. "You want to re-open this discussion every time there is a change in status, because you might decide you want to treat glaucoma today, but four years from now when your relative develops breast cancer, you may decide that this person is not going to go through radiation and chemotherapy," she says.

If the resident has a living will that names somebody to make decisions, and also has a power of attorney, Goldsmith cautions that providers should ensure that the same person is named on both documents. "What happens a lot is that Mom does not want to choose between two children, so she names one on one docu-

ment and the other on the other document. When a decision needs to be made, the facility doesn't know whom to turn to.

"Make sure the documents are consistent, or get them corrected at that stage when you are still able to," says Goldsmith.

When residents are admitted without advance directives and without capacity to make their own health care decisions, a proxy decision maker will need to be selected. "The biggest problem I see is that providers don't know who is out there" as a potential decision maker, she says. "If the choice comes down to brothers and sisters and one sister visits frequently, the facility may assume that she should be the decision maker. Facilities should explore who else is out there. This sister may not be the best person to make decisions; it just may be that she has a lot of free time on her hands."

Cautions Tuch, "This process is

more than just filling out an advance directive checklist. It is a process of ongoing communication and development of a real advance care plan that talks about the values and goals of the resident, and over time that dialogue continues."

### Substituted Judgment

Once a surrogate or proxy decision maker has been selected and the need for surrogate decision making kicks in, the surrogate's job becomes one of determining what the resident would want done in that situation. "For the most part, most states require decisions to be made on a substituted judgment," that is, doing what the person would choose had they been able to make the decision, Tuch says.

O'Brien adds, "The [surrogate must] make decisions as the person would make them. You must approach the situation on what they want, rather than what you want."

These decisions can be fraught with ►



## Sheila McMackin

and the home care industry at large, legitimate recommendations involve proper research into home care agency options.

An ethical home care agency follows three strict guidelines: It undertakes a professional criminal history search on all of its employees, it researches previous work history, and it manages and supervises all work done in the home. If a home care provider has not been screened, consumers are putting themselves and their financial welfare at risk.

### Finding Appropriate Caregivers

According to Hager, the challenge to finding a reputable home care employee is being able to conduct appropriate background screenings and manage the person in the home. Before recommending an agency or independent home care provider, consider the following questions:

Does the agency employing the home care provider supervise the care being provided?

- Does the agency employing the home care provider have specific clients?
- Does it know its rights and responsibilities and communicate them effectively?
- Does it issue appropriate screenings and provide proper training to employees?
- Does it supervise the care being provided?

The same attention must be given to the independent home care provider as well. An irresponsible, negligent home care employee can negatively affect the entire home care industry and health care institution that recommended his or her services.

For more information on how to find a reputable home care agency, contact NPDA at [www.private-duty-homecare.org](http://www.private-duty-homecare.org) or (317) 844-7105.

*Sheila McMackin is president of NPDA, Indianapolis.*

emotion, and facilities must be available to help family members deal with the emotions involved. Cynthia Pearse, a licensed clinical social worker and long term care consultant in Palm Harbor, Fla., says, "I had to make the decision to withhold nutrition from my own mother. Sometimes it is very difficult to do what you know the other person would want.

"Even so, it is the role of a surrogate or a proxy to put aside their own feelings and make decisions they know the person would want. My mother was very clear that she did not want her life prolonged, and I'm very savvy, but when it comes down to applying it to someone you love, it becomes a very painful process."

In the event that a proxy does not know what the resident would have wanted, most states allow decisions to be made in the best interest of the resident, says Pearse. The best interest standard could be applied even in cases where a living will had been executed, but was not specific to a given situation, such as an elderly resident with Alzheimer's disease and several comorbidities who falls and breaks a hip.

However, in five states—California, Delaware, Michigan, Mississippi, and New York—statutes say that the state has a compelling interest to use extraordinary measures to keep a person alive if a proxy does not have clear, convincing evidence of what the resident would have wanted.

In Florida, a similar statute—the clear and convincing evidence standard—is required of proxy decision makers to offer or withhold treatment. In one case, says Tuch, somebody cut out an article about "some disaster in end-of-life care, and wrote on top, 'I never want this to happen to me.' That turned out to be clear and convincing evidence."

### Family Communication

For Beverly's Ludington, communication with the resident and the resident's family is essential to ensure

smooth decision making. "We really want to recognize every resident's wishes, and to do that, the process involves every family member. We need to have a good working relationship with the family so they can tell us what the resident's wishes are."

In many cases, several siblings or adult children may step forward, each having his or her own ideas for "what



**'My mother was very clear that she did not want her life prolonged, and I'm very savvy, but when it comes down to applying it to someone you love, it becomes a very painful process.'**

mother would have wanted," says Goldsmith. What's important, she says, is "when you get into decision making by committee, you need to make sure that your committee is made up of everyone you need."

Decision making by committee is fraught with potential hazards, says Cathy Massaro, director of social services with Bon Secours Maria Manor Nursing and Rehabilitation Center, in St. Petersburg, Fla. "Family disagreements among children happen whether there is an advance directive or not.

Families can have internal issues, and it can be an incredible nightmare trying to provide care," she says.

Massaro says providers must be available to offer lots of mediation and supportive care to the family as they try to make decisions. In the end, she says, the final decision must be that of the surrogate. "Out of courtesy and dignity, you try to work with the family, try to set boundaries and guidelines, and try to have communication among all the players. But when there is definite disagreement, you have to go with whomever is signed on the advance directive."

"Families must realize that staff need to work with one decision maker," says Grubman. "Often, facilities have three or four family members calling to make requests about their loved one, and facilities need to be sensitive to this and address it at admission." She suggests telling the family, "I know this is going to be an issue, since you all care about your loved one, but we need a plan for this." If the family needs help working through issues, a social worker or ombudsman can help.

### When Families Disagree

O'Brien says that in her experience, when family members disagree, it is usually based on "emotion and usually based on what they would desire and not what the person with dementia would desire."

At Beverly facilities, a corporate nurse attorney is called in when family members cannot agree on a plan of care. "Our job is to be very good listeners and to bring as much information to them as possible," says Ludington.

Another winning strategy, providers say, is to involve the physician. "The physician is the voice of reason and the expert on the medical condition of the resident," says Ludington.

Adds McMahon, "You may have a resident who says, 'I am going to eat cake, and I don't care what any of you say,' and in some instances, depending

on the risk to the resident, we might advocate for that resident, and involving the doctor helps. In the end, we are required to abide by the decision maker, but the physician is important, because people will usually listen to the physician.”

If there is no advance directive and the family cannot resolve its issues, the next step may be for a guardian to be appointed. “Unfortunately, these types of circumstances happen all the time,” says David Doukas, MD, the William Ray Moore endowed chair in medicine and the humanities and professor of family and geriatric medicine, Institute for Bioethics, Public Policy, and Law at the University of Louisville Health Sciences Center.

“If one family member wants to use a feeding tube and another does not, more than likely a guardian would be appointed.”

### **Family Covenants**

To avoid such situations, Doukas has developed the “family covenant” for surrogate and end-of-life care planning. A family covenant is an approach that begins with an acknowledgment that residents’ family members have “valid and important interests” in the way their loved ones are cared for and should be heard as part of the decision-making process.

In practical terms, a family covenant would involve convening all stakeholders, which could include family members as well as close friends, and discussing their reflected values of the resident. “Its purpose is to try to get a multiperspective view of the reflected values of a patient who can no longer talk to us,” Doukas says.

In the end, say providers, open communication is the key to avoiding conflict during crises. “We get into trouble

when we’re confronted with a crisis and we have not had that communication, so as providers, we are not sure whether the living will fits the criteria of the circumstance, and we have screaming family members who cannot agree on the course of action,” says Tuch. ■

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### **For More Information**

- For additional information on advance directives and living wills, contact the Alzheimer’s Association at (800) 272-3900 or visit [www.Alz.org](http://www.Alz.org).
- For downloadable, state-specific living wills and medical powers of attorney, visit [www.PartnershipforCaring.org](http://www.PartnershipforCaring.org) or call (800) 989-9455.