Experts' Roundtable

In each issue of *ALC*, we will ask a panel of experts to comment on a pressing issue of the day. Watch for this roundtable, and let us know if you have any suggestions regarding experts you would like to hear from or questions you would like to see addressed.

What affect do you think the Terri Schiavo case has had or will have on assisted living facilities?

Dan Haimowitz, *MD, CMD*
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This case really has had ramifications on the local level—both positive and negative—in private homes, ALFs, and skilled nursing facilities. The positive side is that any education to the public about the need for advance directives/living wills/durable powers of attorney for health care is beneficial. This is important because, generally, the public doesn't understand the issues involved or doesn't want to talk about them.

The negative is the implication that if there is any sort of disagreement about a resident's wishes, these matters will end up going to court. I've had at least one person tell me that his wife had a living will, but he wasn't going to honor it because he didn't want all of the publicity and trouble that he saw with the Schiavo case. Another negative that came out of this case was the proliferation of misinformation, including claims of starvation/malnutrition being agonizing and painful. That is contrary to basic hospice teaching and simply not true.

ALFs generally do not assume any responsibility for or take an active part in assisting residents or physicians in collaborating on advance health care directives. This follows directly from the fact that these facilities aren't "health care facilities," per se. Rather, they are consumer-driven. The majority of facilities in which I have patients have no process in place at all for asking about advance directives or documenting their presence. Nor do they have any way of honoring wishes for patients who have an advance directive in place. Obviously, the Patient Self-Determination Act doesn't apply to ALFs in my state.

There is much that facilities can do to address this issue. First, they need to understand the state-specific regulations concerning cardiopulmonary resuscitation (CPR) in assisted living. Then they can develop a process to educate and help residents make viable choices and make some forms readily available for these individuals to peruse and complete. It also is important to make advance directive education part of the admission process and to have a means of following up with residents—especially if there is a change in their status or a new, serious medical diagnosis.

Facility leaders can make it a point to become politically active on this issue and educate legislators about the realities of how serious it is and how it affects residents. They also can work with physicians—especially if the facility is wise enough to have a medical director. Finally, having some appropriate reader-friendly articles available for residents and staff also would be helpful. If facilities need guidance, they can look to nursing homes and adapt some of the policies they have implemented over the years.

If there is any good to come out of the Schiavo case, I hope it is that residents will be more aware that they should try to express their choice of what they would or would not like to have done to them. They also need to know their options, should they become unable to express their wishes at any point. I also hope that they realize they should not be afraid or intimidated because of all the negative publicity this issue has received in recent months.

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I hope that the impact of the Schiavo case will be increased interest and willingness on the part of people of all ages to talk about advance care planning long before they—or their loved ones—experience a serious illness. From our recent experience, this interest certainly appears to be there. Requests for our "Five Wishes" document [see page 37] have increased significantly in the last month alone. We also have received thousands of phone calls. And these requests and calls are coming from people of all ages—including young people in their 20s and 30s. This is significant because the impression previously was that advance planning was just for those individuals who are sick and old. People saw how young Terri was, and they realized the same thing could happen to them.

The overarching message we are hearing from the thousands of callers is: "We don't want the same thing to happen in our family." They want to remove any uncertainty. They say that they have talked to their wives or husbands about their preferences and wishes, but now they want to have this information in writing in a legally binding document.

I hope that all of this indicates a societal change and a move toward advance care planning being seen as a conversation families should have together—and long before a health crisis or major life change.

Health care providers, including those in assisted living, don't want to play the role of referee. So it behooves them to promote information, education, communication, and follow-up that promotes advance care planning on the part of their residents and family members. While the forms can't answer all questions or solve all problems, they do take a big chunk out of the uncertainty; and this is tremendously important.

In assisted living facilities and other settings, there needs to be a focus on advance care planning beyond the formality of checking a box in a to-do list. Most facilities offer advance directives to new residents. In many cases, this is just an item in a welcome packet or a line on the admission form completed by a nurse that says something like, "Yes, I asked the patient if he/she had an advance directive."

These activities are all well and good, but we need to do more. Facilities should have a comprehensive approach to advance care planning. They should make sure that they have access to a form that is easy to use and understand. They also need to ensure follow-up—going back to residents and family members from time to time to see if those who don't have advance directives now want them or if those who have them want to update them.

You cannot give residents or family members the impression that they must have an advance directive for admission, but you can offer information and guidance. Of course, any conversation staff has with residents should be documented, and residents' advance directives should be included in the medical chart. It also is important to make sure that the document is portable and goes with residents if they are transferred to hospitals or other settings.

We often hear from health care providers that they are reluctant to bring up advance care planning because they want to be there as a voice of hope for patients and not someone who makes them think or talk about death. To help these practitioners become more comfortable with this process, we suggest that they complete their own advance directive. It is surprising how many health care providers for whom we do presentations don't have an advance directive of their own. As we talk with these people about the process, we see the lights go on; and they realize how important this is.

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The Terri Schiavo case has called attention to how we die. It has made it easier for health care providers to talk about advance directives and for families to talk to each other about their wishes and preferences. Suddenly, more people are interested in completing advance directive documents. That is a positive trend.

At the same time, the Schiavo case has generated a great deal of confusion about what is required for individuals to have their wishes honored and to be able to live the end of their lives and die the way that they want. Because of the media portrayal of this case, alarmingly, many people came away with the impression that Terri Schiavo was "killed." Many intelligent, well-meaning people now equate the removal of a PEG tube with euthanasia. This is unfortunate.

Just this week I had a conversation with an elderly patient and her family who referred to "the killing of that woman in Florida." It troubles me that they now consider the thoughtful discontinuation of artificial nutrition and hydration—something we have done openly and within ethical guidelines for years in American hospitals and in hospice programs—as "killing." As a physician, I have dedicated my life to the preservation and celebration of life. But to be truly life-affirming, I have to embrace all aspects of life, including its end.

In general, our culture hasn't grasped that we all die of something. An illness-related loss of appetite or inability to eat is the predominant way in which all mammals die. This is true for people as well. Nature has provided us with a gentle way to pass from this life. If we declare that such ageless ways of dying are unacceptable, we must also ask: What are wholesome ways for someone we love who is seriously ill and has lost all consciousness or who has profound dementia to die? If everyone needs a feeding tube, must we also treat all infections? Must everyone have CPR before they die? Of course not. It is not euthanasia to selectively choose medical treatments that enable someone with a progressive illness to orchestrate a gentle end to this life.

As a culture, we need to grow up the rest of the way. We must acknowledge that people die, then explore what socially acceptable, morally wholesome ways there are to die well.

What does the Schiavo case mean for assisted living facilities? I suggest that ALFs conduct thorough conversations with residents and family members at least once a year. Such conversations are important for shared decision-making. They can also enable families to express their confusion and grief about the illness and impending death of someone they love or their own death. When there are potential conflicts, the guidance of an experienced clinician can help them work through these tensions and come to agreement or at least respect each other's good intentions.

As professionals, we must provide residents and families with anticipatory guidance, helping them navigate difficult discussions and decisions. Our challenge and opportunity are to care well for whole persons and families. If we do the right things in terms of care, a byproduct will be that the legal peril facilities often feel will greatly diminish.

By clarifying people's values related to care and how they would want to die, the quality of care would rise and, paradoxically, the costs of care actually would fall. Instead of doing whatever we can, we need to do what is right.

Lori Diaello
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When the Schiavo case was in the news, I heard a lot of sympathetic discussion about allowing people to die when it is their time—pretty much in tune with her husband's decision. I didn't see anything happen at administration level in my facilities. However, this issue has affected me from a personal standpoint. Many of my friends and acquaintances have asked me how they could complete advance directives, and I have helped them in any way I could.

I didn't think the Schiavo case would have any widespread or global impact—at least not until recently when I visited one local assisted living facility. This Alzheimer's disease facility had been aggressive about putting necessary language in advance directives so that they are very clear about how to manage residents at the end of life and to ensure that residents' wishes are respected. A few weeks prior to my visit, a resident had died in the facility. This individual was very ill; the cause of death was likely a cardiac arrest and—because he had a Do-Not-Resuscitate order in place—he was allowed to die a natural and peaceful death. The facility, as well as the resident's family, was satisfied that the right things had been done for this individual. Now, suddenly, state surveyors were there, threatening the facility with a moratorium because the facility did not call 911 or try to revive the resident. After the facts of the case were closely examined, no legal or regulatory action was taken; but it concerned everyone greatly.

Clearly, the Schiavo case has caused some positive changes as well as some negative backlash. However, I think ultimately it will result in a shift to more caution on the part of providers, more detailed documentation regarding end-of-life care and resident choices in medical records, and facilities hesitating to follow any end-of-life instructions unless they are in writing. This shift hasn't happened yet, but I think it is coming.

I know that I will be working to ensure that my patients are more specific in their advance directives and that they address issues such as feeding tubes, hospitalization, and resuscitation. I am emphasizing to them the need to include some of this language in writing. Before, we often did this verbally—but this doesn't seem to be sufficient anymore.

We're starting to see some action on the legislative front as well. In the Florida legislature, a bill was proposed (and failed) stating that unless an individual specifies in a living will that he or she doesn't want a feeding tube, one would be inserted by default. Despite the bill's failure, hospices in the state are concerned that what they are doing—however ethical, appropriate, and conscientious—isn't enough.

Assisted living facilities need to be prepared to talk about end-of-life issues more openly with their residents and family members. In one facility I visited, the activities director actually initiated a discussion on this from newspaper coverage of the Schaivo controversy. While I was only in the room briefly, it seemed as though residents were very interested. The discussion seemed more spirited than usual.

It is up to all of us who care for assisted living facility residents to help ensure that they have an opportunity to express their preferences and that these wishes are honored at the end of life. We need to reach out and raise awareness of the issue with all practitioners and institutions where our senior patients receive care. This includes hospitals and emergency services, where clinicians may not always discuss end-of-life options with the resident or family members.

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This case has brought out strong opinions in people, but there really isn't any right or wrong answer. However, the interest it has generated is positive, because it reminds all of us about the importance of this issue and what we can do to avoid similar situations in ALFs.

In terms of impact, I think the Schiavo case has made people think about what they would do in a similar situation. There is a realization among both health care providers and the public that end-of-life decision-making issues are extremely complex and that these need to be addressed before an accident or serious illness.

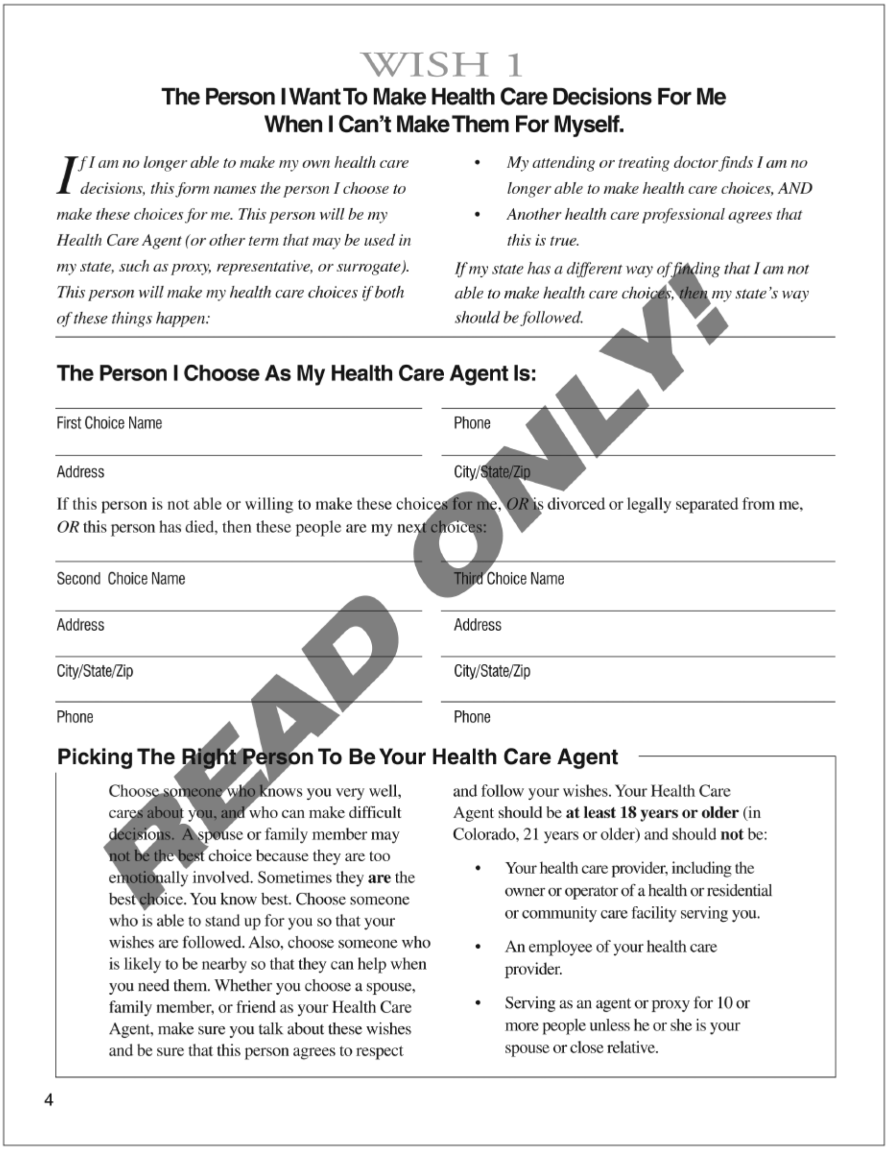
We can't forget the key issue about this case—Terri Schiavo had no written advance directive in the form of a living will or durable power of attorney. This should serve as a serious reminder that it really is essential for our residents to have both of these documents in place. Designating a person as durable power of attorney for health care provides a real person health care providers can talk to in ambiguous medical situations.

ALFs need to educate both residents and families about these issues. This needs to include a discussion of hospice care and clarification of many misconceptions about end-of-life care. One of the major misconceptions we need to address is that withholding food or fluids causes individuals to suffer. Many studies show that people who are not taking food or drink are not suffering; and, in fact, we do a good job of keeping these people comfortable. Another misunderstanding surrounds the issue of resuscitation. People often see patients on television shows or in movies who are resuscitated and get back on their feet in no time. In fact, there are many negative consequences of resuscitation in elderly patients, particularly those with several comorbidities. Additionally, the outcomes of resuscitation statistically are not very good for this population. Many die shortly after being resuscitated, and very few regain much in terms of function or quality of life. We need to make sure that residents and family members have all of the facts so that they can make informed decisions.

As practitioners, we need to help create a culture of openness about conversations regarding death and dying. Advance care planning needs to be an ongoing activity. Just because residents or family members don't want to talk about this issue at first doesn't mean that they won't be ready to discuss it later. We need to enable them to have the conversations when they are comfortable.

A complicating issue in the Schiavo case was that there was so much disagreement among her family members. As resident advocates, we need to be consensus-builders. We need to be communicators. This should be a natural role for all of us. ALC

Below is a sample page from "5 Wishes," a type of advance directive document that can be used by assisted living residents. Order copies of this document at *www.agingwithdignity.org/5wishes.html*. State-specific forms can be found at local hospitals or via state links at *www.uslivingwillregistry.com/forms.shtm.*



WISH 1

The Person I Want To Make Health Care Decisions For Me When I Can't Make Them For Myself.

If I am no longer able to make my own health care decisions, this form names the person I choose to make these choices for me. This person will be my Health Care Agent (or other term that may be used in my state, such as proxy, representative, or surrogate). This person will make my health care choices if both of these things happen:

- *My attending or treating doctor finds I am no longer able to make health care choices, AND*
- *Another health care professional agrees that this is true.*

If my state has a different way of finding that I am not able to make health care choices, then my state's way should be followed.

The Person I Choose As My Health Care Agent Is:

First Choice Name
Phone
Address
City/State/Zip

If this person is not able or willing to make these choices for me, *OR* is divorced or legally separated from me, *OR* this person has died, then these people are my next choices:

Second Choice Name
Address
City/State/Zip
Phone

Third Choice Name
Address
City/State/Zip
Phone

Picking The Right Person To Be Your Health Care Agent

Choose someone who knows you very well, cares about you, and who can make difficult decisions. A spouse or family member may not be the best choice because they are too emotionally involved. Sometimes they **are** the best choice. You know best. Choose someone who is able to stand up for you so that your wishes are followed. Also, choose someone who is likely to be nearby so that they can help when you need them. Whether you choose a spouse, family member, or friend as your Health Care Agent, make sure you talk about these wishes and be sure that this person agrees to respect and follow your wishes. Your Health Care Agent should be **at least 18 years or older** (in Colorado, 21 years or older) and should **not** be:

- Your health care provider, including the owner or operator of a health or residential or community care facility serving you.
- An employee of your health care provider.
- Serving as an agent or proxy for 10 or more people unless he or she is your spouse or close relative.

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