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## New physicians' form may help resolve some issues with care at end of life

*Schiavo case turns spotlight on hospice care*

One positive aspect of the long public vigil and debate over what would happen to Terri Schiavo, who died in hospice care on March 31, 2005, after more than a decade of living in a persistent vegetative state, was that more people decided to complete living wills, according to media reports.

However, living wills, medical power of attorney, do-not-resuscitate (DNR) orders, and advance directives have limitations. Some health care providers say the ideal solution resides in a physician's order form developed in the 1990s by a multidisciplinary task force of the Center for Ethics in Health Care at Oregon Health & Science University in Portland.

The form, called Physician Orders for Life-Sustaining Treatment (POLST), is a simple way to let doctors and emergency responders know precisely which life-sustaining treatments a person desires.

"Living wills are not effective for many people because all they address is what you would want done if you were in a persistent vegetative state," says **Milton Zadina**, MD, of Columbus Family Practice Associates in Columbus, NE. Zadina spoke about the POLST at the Living a Good Life at the End-of-Life conference, held March 29-April 1, 2005, in Lincoln, NE. The conference was sponsored by the Nebraska Hospice and Palliative Care Association and other health care organizations.

"DNRs are not helpful when you have to make a decision about feeding tubes and ventilators," Zadina says. "But the POLST form goes into these in a little more detail and provides a good understanding about how aggressive a patient wants you to be."

Some health care providers fear that the public attention paid to the Schiavo case will continue to haunt the medical community, moving it backward toward the time when even dying patients routinely were put on feeding tubes and life-sustaining technology, regardless of what they might have wished.

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"I'm afraid they're going to extrapolate her case to people who are terminal, and they will begin to take us back to where we were 10-20 years ago when we had to put tubes in people to feed them when they were terminal from cancer and heart failure," says **Edward Vandenberg**, MD, CMD, an assistant professor of geriatrics at the University of Nebraska Medical Center in Omaha.

If public and political sentiment do lead to setbacks in end-of-life care, then the POLST form could be a powerful way to prevent the use of aggressive curative measures when these go against the patient's wishes.

As a family practice doctor who works in geriatrics and is the medical director at two nursing homes, Zadina often has been called to make emergency decisions about the care received by people in nursing homes when their regular physicians were unavailable.

"Sometimes things would come up based on

whether the person should be in the hospital or how aggressive their treatment should be, and I didn't have any information to guide me," Zadina says. "We couldn't find their medical power of attorney, and they'd have only a chart DNR order, but nothing else."

On several occasions, Zadina ordered care that was more aggressive than what the patient and family wanted because no one was able to communicate the patient's desires to him.

"So, I was interested in finding something that would help me know what the patient wanted," Zadina says.

He found his answer in Oregon Health & Science University's POLST form. The university encourages the form's use and adaptation, and has made information and a sample form available on its web site at [www.polst.org](http://www.polst.org).

"I looked at it, and it had all the information that would be really helpful and useful in making sure a patient's care was directed in the way the person would like it to be directed," Zadina adds.

Zadina had been working on bringing the POLST form to his community for a couple of years by the time Terri Schiavo's end-of-life care became a national and political issue.

"The Terri Schiavo story just happened to coincide while we were doing this," he says. "But if Terri Schiavo had had a POLST, there probably wouldn't be any question about what she wanted."

While anyone could use the POLST, the form is most helpful to elderly people and people with chronic illnesses, say Zadina and **Lisa Weber-Devoll**, CSW, BSW, a social worker with the Columbus Community Hospital and Hospice in Columbus, NE. Weber-Devoll also spoke about the POLST at the Living a Good Life at the End-of-Life conference.

People who are dying from cancer or another debilitating illness, people who have a serious chronic illness that repeatedly lands them in the hospital, and people who are in nursing homes are among those who would benefit most from the POLST, Weber-Devoll says.

"The POLST form is designed for people who have some kind of chronic illness or an illness that is expected to take their lives," she says.

The form answers some questions that other medical directives do not, including a question about receiving antibiotics, Weber-Devoll notes.

There are cases when people at the end stage of cancer or Parkinson's disease choose not to receive antibiotics for treatment of pneumonia because that would extend their lives, and they're

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### Editorial Questions

For questions or comments, call **Leslie Hamlin** at (404) 262-5416.

# POLST provides answers to medical questions

*Life-sustaining measures easily captured*

The Physician Orders for Life-Sustaining Treatment (POLST) form was developed over a four-year period by a multidisciplinary task force of the Center for Ethics in Health Care at Oregon Health & Science University in Portland.

The POLST has since been adapted for use in more than a dozen locales. An adaptation currently in use in Nebraska consists of a two-page form that contains these sections:

- **Resuscitation:** In the event the patient/resident has no pulse and/or is not breathing, the form provides a place to check that the patient either desires medical providers to resuscitate or do not resuscitate.

- **Medical interventions:** In the event the patient/resident has a pulse and is breathing, the patient may check any of these choices:

- Comfort measures only.
- Do not hospitalize if comfort measures fail.
- Hospitalize if comfort measures fail.
- Limited additional interventions, including all comfort measures and transfer to hospital, if indicated, and any cardiac monitoring and other interventions checked on the form; but there will be no endotracheal intubation or ventilation, cardioversion, or long-term life support measures given.

- Full treatment. This includes care above plus endotracheal intubation, ventilation, and cardioversion, if indicated.

- **Antibiotics:** The patient/resident may decide to receive antibiotics or to receive no antibiotics.

- **Artificially administered fluids and nutrition:** The patient/resident may check any of these choices:

- no feeding tube;
- defined trial period of feeding tube;
- long-term feeding tube;
- no IV fluids;
- defined trial period of IV fluids.

The form also indicates whether the patient/resident is competent, incompetent, or with someone else who has the authority to consent on his or her behalf, and whether there is appropriate documentation attached, including guardianship papers or power of attorney with health care clause.

The POLST also contains a section where changes can be noted after the form is reviewed, which is stated to occur in the event of one of the following:

- the patient/resident is transferred from one care setting or care level to another;
- there is a substantial change in patient/resident health status, either improvement or deterioration;
- the patient/resident treatment preferences change;
- the following specific event occurs:
- after \_\_\_ days of the authority or the last review of this form. ■

ready to die, Weber-Devoll says.

In the Columbus community, which has a little more than 20,000 people, Zadina and Weber-Devoll have convinced local hospitals, nursing homes, physicians, and other providers to encourage patients to complete the form and keep it in the front of the patients' charts. For people who are living at home, the forms could be kept on the refrigerator, where emergency medical responders would easily be able to find it, Zadina says.

"We hope that at least 45 percent of the people in nursing homes will have a POLST in place within a year or two," Zadina says.

"In our community, we have a number of trained counselors or POLST preparers, besides

the physicians," Weber-Devoll says. "We have trained social workers and other individuals in the hospital, and the next training session will include people in doctors' offices and a dialysis center."

The two-page form takes about 30 minutes to complete. Although it's short, patients will need time to ask questions and hear about potential scenarios regarding the use of life-sustaining equipment, Zadina says.

"We go through each section of the POLST form and discuss, for example, what CPR is and what happens to a patient who undergoes CPR, and what are the benefits and burdens," he adds.

Counselors will present statistics on the success of various procedures, Zadina notes.

“When we talk to patients about CPR, we might tell them, ‘You have to code 29 80-year-olds to get one long-term success,’” he says.

Columbus providers have received permission from the Oregon group that created the POLST to adapt it for use locally, Weber-Devoll says. (See **story about what POLST contains, p. 51.**)

“Nebraska had done an end-of-life survey report where they interviewed a number of individuals and came up with what people know about hospice and advance directives, and that motivated us to follow through with this program,” Weber-Devoll explains. “We investigated how the form pertained to Nebraska’s laws, and we changed some of the wording.”

What high-profile cases like Schiavo’s fail to show is how individuals and families weigh the burdens and benefits of life-sustaining treatment, Zadina says.

“There are certain situations where there’s good evidence that a feeding tube isn’t a helpful intervention,” Zadina says. “One example is advanced dementia, where there’s evidence that doing hand-feeding and encouragement can do just as well as a feeding tube for people at the end of Alzheimer’s disease.”

Also, the use of POLST provides counselors, nurses, and doctors with an opportunity to teach patients and their families about aspects of end-of-life care in a way that they would never understand from watching television reports about Schiavo’s deaths.

“Dehydration is one of the most humane deaths; it’s not painful,” Weber-Devoll says. “Just removing a feeding tube doesn’t mean you are withholding food and fluids; you’re still offering them if the person can take them by mouth.”

Weber-Devoll says her job with the POLST is to advocate for patients that they have the right to make decisions for themselves.

“Everyone has the right to decide what type of life-sustaining medical interventions they prefer. It is all based on what the person views as their own quality of life,” Weber-Devoll says. “There are many factors that influence how a person views their quality of life—personal values, religious foundation, and progressive medical services.”

The POLST provides people a very clear way to describe their desires, she notes.

“By not communicating—both verbally and in writing—these wishes, it could mean leaving these decisions up to family, physicians, or even the legal system,” Weber-Devoll says. ■

## Consider how caregiving affects hospice families

*New burden at stressful time causes problems*

One of the major challenges of providing hospice care is working with caregivers who typically have received no training in the role.

“They don’t plan for caregiving, and most of the time the caregiving comes at the most stressful time in their lives,” says **Jeanette Denson**, director of Custer Care Center in Broken Bow, NE.

“They’re not prepared ahead of time, so that puts a strain on the caregiver,” she says.

Understanding how the stress of suddenly becoming a caregiver can affect a hospice family is a key aspect of hospice care, but it entails knowing some of the common types of caregivers and what their particular challenges might be, Denson notes.

Denson provides these tips for dealing with various caregivers:

- **Daughters/sons:** Generational differences often are the source of conflict in families in which a parent is dying and is being assisted by a daughter or son, Denson says.

### **Modern waste vs. Depression-era thrift**

“They’re required to go in and help with their parent, but they don’t do things the same way the parent does,” she explains. “I see my generation as more of the throw-away generation than the generation before us, and that causes some struggle in families.”

For example, the hospice patient might be from the Depression-era generation in which nothing is thrown away or wasted, while the child tends to throw out used plastic bags rather than washing them out, Denson says.

The role of hospice is to teach caregivers that they’ll need to make some allowances for how the patient expects things to be done in the household, she says.

“If saving plastic bags is the thing that makes the person you’re taking care of happy, and if it’s a big thing to that person, then you may have to do that for the person,” Denson says.

Some battles are not worth fighting, and it’s important for hospice staff to teach caregivers this principle, she notes.

For example, if the hospice patient refuses to walk with a walker and wants to use a cane instead, then even though the caregiver is correct in assuming this is less safe, it's better to let the patient do as he or she pleases, Denson says.

"Each person has to be validated from where he or she is," she adds. "I think the hospice nurse has to look at where each person is at that point, acknowledge that both are right, and try to help the other one understand where they are."

Sometimes traditional power structures within family relationships are altered because of the caregiving situation. The parent who formerly always made the decisions now is forced into a more passive role, and the adult child is thrust into an unfamiliar decision-making role, Denson says.

### ***How do you handle role reversal?***

"It puts bigger stress on the child," Denson says. "I know this from personal experience. I was trying to take care of my mother, and she has always been the one to tell us what she was going to do and how she was going to do it."

This role had continued long past Denson's childhood, and it led to problems when her mother needed her help later in life, she says.

"A mother might say, 'I would like you to come over because I just need a little help right now,'" Denson says. "And this reminds us how when we were growing up we felt like we had to do too much work for our mother, although now we're normally not helping her out very much."

While the roles now are different, they still could bring back old feelings, and these can surface during hospice care, Denson adds.

"The hospice staff can see the dynamics of the family and talk about how it was before with them," she suggests.

Adult children who are caregivers typically have families and jobs of their own to handle in addition to the care of the dying parent, so hospice staff can help caregivers out by finding volunteers to assist them, Denson says.

• **Pre-Baby Boom husband:** Men of this generation might have been accustomed to the wife doing all of the caregiving in the marriage, so the role of caregiver can be a shock and an uncomfortable change.

"You need to find out what things the man has done before as far as helping the wife," Denson says. "Does he know how she did certain tasks?"

Also, hospice staff might need to help the wife understand that just because she has always done things a certain way, they don't always have to be done that way, especially now that her husband has taken over the household chores, Denson says.

"Men seem to find easier ways of doing things, maybe finding a shorter route to accomplishing a task," she says. "And I think hospice nurses have to help them deal with how the task is being done."

The most important thing is that the hospice patient is being cared for, and the details are not as important, Denson notes.

"If the bed's not changed every week, it's not going to matter," she says.

Likewise, the wife who is a patient will need to learn that she has to give up her longtime role as caregiver and allow her husband to take over the role, Denson adds.

"That's difficult, because we as women seem to be martyrs, and it can only be done the way we do it and by us," Denson says. "In the [older] generation, women would be more willing to do things regardless of whether it caused them pain and suffering."

### ***Looking beyond traditional relationships***

• **Pre-Baby Boom wife:** Financial issues are one of the biggest burdens experienced by women of this generation who become caregivers of a dying husband, Denson says.

"The women often are not used to handling financial issues," she says.

Other issues include driving, because often the wife has not done much driving, and taking care of household tasks such as taking the trash out, Denson says.

Sometimes hospice staff might help find solutions to these situations by finding the caregiver another family member or a volunteer who can take care of the tasks that don't come as easily to her, such as cleaning gutters, Denson says.

"We have to look beyond the traditional relationships," she says. "In that generation, they didn't always ask other people to do things for them and they took care of it themselves, so we need to show them it's okay to ask for help."

• **Parents of adult patients:** This is one of the more difficult caregiving roles, because it's easy for parents to fall back into the pattern of treating the adult child as though he or she is a child again, Denson says.

"Are they allowing them to do things that are functionally possible?" Denson says. "There needs to be some acknowledgement of independence and making decisions."

In these cases, the hospice nurse might be able to help the parent caregiver know that there are some things the patient can continue to do on his or her own and that the parent doesn't have to do everything for the patient, she adds.

• **Sibling caregivers:** When siblings are caregivers to each other or sharing the role for a parent, there are rivalries and other issues that might arise, Denson notes.

Sometimes it's difficult for siblings to decide who will handle which aspects of the caregiving, she says.

"One person is here, and somebody else lives miles away, but when that person comes back to visit, he might say, 'We should do it this way,'" Denson explains. "And that ruins how everybody is feeling and how they view the experience."

Another common scenario is when the long-distance sibling feels left out of the care decisions, Denson says.

Hospice staff could help smooth out these problems by helping the siblings decide on particular roles for everyone so no one feels left out, she suggests.

For instance, perhaps the long-distance sibling could agree to call the patient on Sunday nights, which would allow the sibling who lives nearby to take that evening off, Denson says.

"When hospice staff acknowledge everyone, whether they live a long ways off or not, then it helps," she says. "The family will say, 'It was so nice that I could talk with the hospice nurse, and the hospice staff kept me informed.'"

Along with siblings, hospice families need to acknowledge the potential for grandchildren to participate in caregiving, Denson notes.

"I just listened to a lady who was talking about how important it was that the grandchildren understand death and what's going to happen before and after," Denson says.

Perhaps one of the best ways hospice staff could help caregivers is by showing them the joys of caregiving for a dying family member, she says.

"People think about caregiving as a burden, but there are lots of rewards to caregiving," Denson says. "All of a sudden you're going to be spending quality time with people you may not have spent time with in a while, and you'll hear new family stories."

Caregivers, whether they are spouses, children, or parents, will learn new things about the family member who's dying, and they might be able to engage in new activities with the person, Denson says.

For example, if the hospice patient is able to get out for a ride, that's a good opportunity to have a talk and do something spontaneous, she says.

In one hospice family, the father was always the domineering, macho sort of man who never showed his softer side, Denson recalls.

When the man was dying in hospice care, he and his caregiver wife began to bird-watch, something he'd never done before, she says.

"When he died, she said she wanted everyone to know he had been a tough guy, but he also was a bird-watcher," Denson adds. "At the end of his life they did things they hadn't done before." ■

## Nursing home patients can benefit from hospice care

*Expert offers ways to improve hospice access*

As increasing numbers of older Americans spend their last days in a nursing home, it's important for nursing home staff, as well as hospice providers, to identify nursing home patients who might qualify for a hospice placement, an end-of-life care expert says.

Hospices often cite examples of how nursing home patients are referred to hospice care too late in their dying process to receive the most benefit from what hospice and palliative care can offer.

"The issue is how well are we caring for individuals dying in nursing homes," says **Edward Vandenberg, MD, CMD**, an assistant professor of geriatrics at the University of Nebraska Medical Center in Omaha. Vandenberg spoke about identifying terminal patients among the nursing home population at the Living a Good Life at the End of Life conference, held March-April 1, 2005, in Lincoln, NE. The conference was sponsored by the Nebraska Hospice and Palliative Care Association and other health care organizations.

"It becomes very important when so many people may plan their last few days there to know how to improve that quality of care," Vandenberg says.

Quality improvement studies in nursing homes have identified various ways to enhance care, but one item that stands out is teaching staff how to identify the patient who is going to die despite the best curative efforts, Vandenberg notes.

“Those individuals sometimes have experienced undue suffering from repetitive curative attempts,” he explains.

“An example is the person who has end-stage Alzheimer’s disease who gets repetitive pneumonia, going to the hospital to receive all treatments,” Vandenberg says. “Then in another month the person goes through the same sequence again.”

One of the ways quality of life could be improved for this individual is for someone to identify this person as someone who would benefit more from a palliative approach than from aggressive curative care, he adds.

### ***Seek opinions of experienced staff***

A first step toward identifying patients for whom it’s time for a hospice referral or a shift to palliative care is to solicit the gut feelings of experienced staff, Vandenberg says.

“Never expect the newly trained individual to tackle this,” Vandenberg says. “But the experienced nursing home employee will have this gut feeling from a collection of tangible and objectified elements and intangible, non-objectified elements.”

For instance, experienced staff can be assisted in trusting their intuition about patients by suggesting they ask themselves this question: “Will I be surprised if this person dies during the next six months?” Vandenberg says.

“And if I wouldn’t be surprised, then the next question is, ‘Am I doing everything I can to keep this person comfortable, or is that comfort being pushed aside in favor of more painful curative treatment that wouldn’t work anyway?’” he adds.

The next step is to examine goals and care plans at quarterly care conferences with patients and their families, Vandenberg says.

If a patient is repeatedly hospitalized, this might be a time to discuss a change in care with the family. Also, staff might wish to discuss family members’ comments or impressions about the patient, because often a first clue that a nursing home patient is dying will come from a family member who asks, “Do you think he’s dying?” Vandenberg suggests.

“Some things an experienced staff person might notice is if a person is going back and forth to the hospital with repetitive aspiration pneumonia, and each time the person is coming back worse,” Vandenberg says. “Or maybe the person has pressure ulcers you can’t heal despite your best attempts, or maybe the person is losing weight or has lost the ability to do activities of daily living.”

A third step is for a physician to use a terminal prognosis tool to confirm staff and physician impressions about a patient’s prognosis, Vandenberg says.

There are good prognosis tools available that were developed based on evidence-based procedure studies, including tools for predicting prognosis in chronic obstructive pulmonary disease patients, cancer patients, and dementia patients, Vandenberg says.

“If nursing home staff feel a patient is reaching that point of futility, but they need affirmation of their hunch, then they can use these tools, looking at a variety of parameters that the tool asks them to check and see if their hunch is right,” he says. “There may be a few staff members at the care planning meeting who say, ‘I wonder if we’re doing anything good for old Bill and his dementia,’ and then they can use the tool.”

Most important, health care providers need to be alert to changes that might be a sign that a nursing home patient has reached the stage where a hospice referral or a switch to palliative care is needed, instead of aggressive curative care, Vandenberg says.

“The goal is to improve the quality of their end-of-life care in these facilities,” he adds. ■

## **Newborn home care can improve outcomes**

*Provide well-trained staff, resources for moms*

A newborn is most at risk for jaundice and dehydration during the first 10 days of life, and these conditions mean increased risk for hospitalization and emergency department (ED) visits. Unless, as demonstrated by a Pennsylvania State University Children’s Hospital study, the mother and newborn are discharged with orders for a home visit within two days.<sup>1</sup>

"I was not surprised at the improved health outcomes for babies who received home health visits within 48 hours of discharge," says **Ian M. Paul**, MD, assistant professor of pediatrics at Pennsylvania State University Children's Hospital in Hershey and co-author of the study.

"I was surprised, however, at the cost-effectiveness of home health visits when you compared the costs of hospitalization or emergency department visits for the group that did not receive home health visits to the costs of the group that received home health visits," he says.

Paul's study shows 5.5% of newborns who did not receive home health visits required either a hospitalization or a visit to the ED in the first 10 days of life. Only 0.6% of newborns who received a home health visit required additional hospital services, he points out.

Payers that cover a home health visit within two days of discharge can save as much as \$181.82 for every child who does not require additional hospital services, he says. "These home health visits pay for themselves and produce much better outcomes for the newborn," Paul adds.

Home health visits are not just necessary for at-risk babies, he says. "Any new parents can benefit from a home health nurse visiting the home to reinforce education about the care of the newborn, offer breast-feeding support and tips, and evaluate the home for safety issues related to a young child," Paul explains.

"Home health nurses can answer questions the mother may have about postpartum care and can make sure that parents understand when the infant needs to see a pediatrician for well-visit checkups and immunizations," he adds.

The nurses at the Visiting Nurse Association (VNA) in Camp Hill, PA, always have visited new moms and infants, but there wasn't a specific program for the service, says **Nancy Alleman**, RN, DPNP, CSN, maternal child health coordinator for the agency. "Some of the nurses said the work made them nervous because they didn't always have the training to answer questions related to breast-feeding or newborn care," she continues.

In addition to Alleman, who is a pediatric nurse practitioner, the agency now has three other RNs who are experienced pediatric and prenatal nurses. "In addition to caring for the new moms and infants, we are all available by telephone for other agency nurses who may encounter a question related to infant or postpartum care or breast-feeding," she says.

The VNA Maternal Child Health Project accepts a wide range of newborns and their mothers, Alleman notes. "We care for preemies, babies with gastric tubes, babies who are failing to thrive, and uncomplicated, healthy newborns," she says. If insurance does not cover the home visit or visits, Alleman has United Way funding to underwrite the project, she adds.

"Nutrition and sleep position are two areas in which nurses answer the most questions from new parents, and breast-feeding counseling is also important," Alleman explains.

Typically, one or two home health visits are made to infants who are not at risk for other medical conditions, she says.

### **Educate referral sources**

Marketing the program involves visits to obstetricians, family practitioners, and hospital social workers to make sure they understand the qualifications of the VNA staff and the benefits to the patients, Alleman notes.

In addition to reducing the need for hospital and ED visits, as demonstrated in Paul's study, pediatricians benefit from the visits because new parents make fewer calls to the pediatricians' offices with questions, she says.

A new-mom-and-baby program proved so successful for HealthTouch, a private-duty home health agency in Wakefield, RI, that there was a waiting list before the program officially began.

"We knew there was a need for doulas in the area because one of the local hospitals had identified the need through their telephone hotline for new mothers," says **Candace Sharkey**, RN, MS, executive director of the agency. (*Editor's note: A "doula," as defined by Klaus, Kennell, and Klaus, is "a woman experienced in childbirth who provides continuous physical, emotional, and informational support to the mother before, during, and just after childbirth."*<sup>1</sup>)

The hospital developed a course to train doulas, but the local health department would not recognize them as health care providers, she adds. "We chose 10 certified nursing assistants [CNAs] for the new-mom-and-baby program and sent them to the 30-hour doula training course developed by the hospital," Sharkey says. "They learned how to care for a newborn, how to recognize symptoms of postpartum depression, how to address sibling rivalry, and how to care for premature babies and multiple babies," she says.

The CNAs also learn how to offer support to a breast-feeding mother and answer general

questions, but they are not lactation consultants, she says. If a mother needs a referral to a lactation consultant, the CNAs have a list of resources for this and other issues, she adds.

While the agency doesn't require motherhood as a prerequisite for training as a doula, most CNAs in the program are mothers, and that gives them a special perspective on their patients' situations, Sharkey says. "They remember how tired they were when they had a newborn and how overwhelming newborns can be." In addition to the information doulas can provide, their main benefit is the calm reassurance they offer new mothers, she notes.

It is important to provide extra support for CNAs, Sharkey adds. "Be sure that they have a nurse to call for advice if they notice signs of jaundice, lack of weight gain, or other symptoms that might indicate a problem," she says.

That gives the agency a chance to step in with education or a recommendation that the infant be seen by a physician before he or she becomes too ill, Sharkey explains. "For example, in one home with twins, the CNA discovered that the mother was feeding cereal to the 1-week-olds so they might sleep through the night," she continues. "The CNA called an RN, who visited the mother to further educate her about nutrition and proper feeding for infants."

If you are considering a new-mom-and-baby program for your agency, be sure to plan well, Sharkey suggests. Staffing is tricky because this is not a program that generates a steady stream of patients on an ongoing basis, she explains. "You have to be flexible and have staff members who are willing to work with a variety of patients when you don't have any new moms and babies," she says. "This is also not a program that generates a lot of revenue. It does, however, create a positive image for your agency, and that new mom may have an aging parent who will need home health."

A new-mom-and-baby program is like any other specialty program, Sharkey says. "If you plan well and provide a good service, referral sources will keep you in mind for a wide range of home health referrals."

## Reference

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# Careful planning required for new mom and baby

*First, make sure the need is there*

Before you jump into a new-mom-and-baby program, be sure there is a market for it, suggests **Candace Sharkey**, RN, MS, executive director of HealthTouch in Wakefield, RI. "We did extensive market research before we implemented our program to make sure there was a need for doulas," Sharkey says. "We knew birth projections for our area, competitors' programs, types of reimbursement available, and the types of services new moms would want," she explains.

## Overnight care proves popular with new moms

Even with her market research, Sharkey says she was surprised by a few things after the program got off the ground. "We knew new moms would want light housekeeping, help with the babies, help with errands, and help with siblings," she says. "What we did not expect was the number of moms who wanted overnight care so that they could get some sleep. In fact, this is the most requested service. We also have no typical length of stay. Some new mothers keep the doulas for only three or four days; others continue the service for as long as three to four months.

"We average two to three patients at a time on the service, so we do have to float the doula-trained certified nursing assistants [CNAs] in and out of other home care services," Sharkey explains. "The challenge is to avoid disruption of long-term continuity with traditional home care patients. We don't assign a doula-trained CNA to a long-term patient; instead, we try to keep them assigned to a shorter-term patient so that we don't compromise continuity when the CNA is needed for the new-mom-and-baby program."

Although her agency charges \$25 per hour for the doulas — slightly more than a standard CNA charge — the program generates more goodwill than significant revenue, she admits. "Because this is a service that insurance generally doesn't cover, we do appeal to a certain income level," Sharkey adds. "We find that many times, the mother or other family member of the new mom will pay for the service as their way of helping, especially if they don't live nearby," she explains. ■

# Expert: To ease end of life, embrace death

*Culture plays big role in palliative medicine*

Medicine knows too little about the process of dying. This was among the conclusions reached by a National Institutes of Health (NIH) consensus panel on end-of-life care convened in December 2004.

“Events surrounding end of life are poorly understood, leaving many Americans to struggle through this life event,” the panel of experts on death and palliative care wrote in a preliminary report.<sup>1</sup>

“Ambiguity surrounding the definition of end of life hinders the development of science, delivery of care, and communications between patients and providers,” the panel noted.

For medicine to better address death, the culture at large needs to “embrace death,” says **Barbara Koenig**, RN, PhD, senior research scholar and executive director of the Center for Biomedical Ethics at Stanford University in Palo Alto, CA.

## ***Understanding when end of life occurs***

The NIH consensus panel wrote that medicine and researchers should abandon some long-held ideas about the end of life — including the notion that there is a clearly defined end to life.

“There are individuals for whom identification of end of life is relatively clear; however, data support that this is relatively uncommon,” the consensus panel wrote.

And although our culture demands that a time of death be noted officially, NIH experts are of the opinion that data demonstrate “it is not possible to accurately predict an individual’s time of death.”

Koenig says our ways of looking at death — the most absolute medical condition that all humans share — makes little sense when compared to how we view other medical care.

“For most people, death is a complex thing, and they have a hard time embracing their death,” she says. “You have to embrace the idea of your death. It’s a counterintuitive thing, but it affects all of us.”

Although death is inevitable, Koenig says, many aspects of dying are left to choice, rather than to good palliative or end-of-life care.

“For example, if you fall down in the street with a heart attack, the system takes over,” she explains. “You don’t have to invent the idea of an ambulance to come take you to the hospital. We have a set of shared assumptions on how to take care of that. But there is no comparable default system in place for the huge problem of end-of-life care. We need a system where the defaults are to provide good palliative or end-of-life care.”

The NIH panel report states that cultural issues and consistent delivery of care to all populations should be major topics addressed in upcoming research.

Koenig says her own studies of end-of-life and palliative care in ethnically diverse communities led her to conclude that while care is doled out inequitably in some cases, minority populations often act as harbingers of problems that will affect the entire population.

“When we look at diverse communities, we could see the failure of these things, such as advance directives, first in these communities,” she notes.

“But then as I worked more with it, it became apparent that, while you could see some of the tension in those communities earlier, the problem was actually with the system of bioethics innovations that we’ve developed,” Koenig explains. “They are problems for the entire population, but they just show up in these smaller populations sooner.”

## ***Calls for more research funding***

At the conclusion of its meeting, the NIH consensus panel called for increased funding from public and private sectors for research into end-of-life and palliative care.

“All people will die,” the authors of the NIH report wrote. “Most deaths are not sudden. Most persons will experience death also as caregivers or family.”

And while there is a growing body of research, the NIH acknowledged, more is needed in the areas of cultural and ethnic attitudes toward the end of life, death in children, protracted end of life in cases of organ failure and cancer, and patient, caregiver, and health care system influences on end-of-life care.

Koenig says she sees an unhealthy discrepancy between funding for diseases and funding for the outcome that everyone reaches eventually.

“There’s 100% mortality for all of the diseases

that NIH combats, and each of those diseases has large budgets, but none of the agencies have devoted much time, attention, and resources to the fact that a lot of people die in these conditions," she explains.

Koenig points out that while NIH does not conduct research directly, it does have the responsibility of setting research agendas, and she welcomes the attention to the end of life.

"We need to start with our culture of biomedicine that leads us to ignore the reality of death," she says. "Denying the reality of death is not a natural feature; it's a cultural feature."

## Reference

1. National Institutes of Health. "State of the Science Conference Statement — Improving End-of-Life Care." Dec. 6-8, 2004. Web: [www.consensus.nih.gov](http://www.consensus.nih.gov). ■

# Report shows insurance 'cracks' in diabetes care

*Diabetics find it hard to get and keep insurance*

During a program at the Washington, DC, office of the Kaiser Family Foundation, the Alexandria, VA-based American Diabetes Association (ADA), in conjunction with the Georgetown University Health Policy Institute, unveiled a study delineating how health insurance fails many Americans with diabetes.

The 14-month study of 851 people from across the United States identified a host of components in the health insurance system that can prevent diabetics from properly managing the disease.

The report, *Falling Through the Cracks: Stories of How Health Insurance Can Fail People with Diabetes*, was funded by the Commonwealth Fund, the Robert Wood Johnson Foundation, and the W.K. Kellogg Foundation.

Common problems highlighted by the report form a long list:

- insurance policies that do not cover basic diabetes needs;
- high-risk pools with pre-existing condition exclusions;
- health insurance premium surcharges for

diabetes that drive premiums above affordability;

- underwriting practices designating diabetes as uninsurable;
- Medicaid rules that make many low-income people ineligible;
- complex processes and procedures that drive many to give up seeking coverage altogether.

**Karen Pollitz**, project director at the Georgetown University Health Policy Institute, says the study identifies a range of instances making it harder for those with diabetes to get and keep health insurance, calling this "a profound irony, given [that] the purpose of health insurance is to protect people when they are sick." Among these problem situations were job loss, family status change, and safety net plans that don't work because what they offer is incomplete.

## Undercoverage and uncontrolled diabetes

She notes that people with stable coverage also had problems with being underinsured, which caused them to lack coverage for blood glucose test strips and prescriptions or to have high deductibles.

"The people we talked to needed coverage that was available, affordable, and adequate, and two out of three just didn't work," Pollitz says. "Many people had trouble managing their diabetes, got sicker, or went into debt as a result. The implications of these coverage problems for public health, costs to Medicare and Medicaid, and the impact on the entire health system due to uncontrolled diabetes are enormous," she says.

According to **R. Stewart Perry**, chairman for the advocacy committee of the ADA, the report shows that a "patchwork health care system that just doesn't fit together" puts people with diabetes "at serious risk."

"Most of the policy solutions currently being considered by our state and federal policy-makers do little to fix the problems identified by the report," he explains. "It is time for policy-makers to seriously rethink the flawed health insurance solutions up for debate that harm as opposed to benefit people with diabetes."

The ADA says as many as one in 10 Americans live with diabetes, and with a disease growth rate of 8% per year, one in three will have the disease by 2050. In 2002, 1 in 10 health care dollars and 1 in 4 Medicare dollars was spent for diabetes care. The cost of diabetes in 2002 in the United States was estimated to be \$132 billion. ■

# Report studies sources of Medicare spending boost

*Minority of enrollees consume most resources*

Recent increases in Medicaid spending have been due largely to rapid increases in the enrollment of low-income families, according to a recent report released by the Kaiser Family Foundation and published in the journal *Health Affairs*.

The findings may be unusually pertinent at this time as Congress begins to debate the proposed White House budget for the 2006 fiscal year and as Mike Leavitt, the new Department of Health and Human Services secretary, lays out plans for Medicaid reform.

The report, which was sponsored by the Kaiser foundation's Commission on Medicaid and the Uninsured, found that Medicaid spending increased in fiscal year 2003 to \$276 billion, up a significant one-third from 2000.

From 2000 to 2003, Medicaid spending grew at an average of 10.2% annually, the report says. However, state Medicaid cost-containment actions — ranging from curbing provider payment rates to reducing benefits — and a slowing of enrollment growth did serve to moderate Medicaid growth spending in 2003.

## **Private insurance costs grow faster**

**Diane Rowland**, executive director of the Kaiser Commission on Medicaid and the Uninsured, says the real problems are rising health care costs and the inability of states to pay the bill, rather than out-of-control Medicaid spending.

"We know states are struggling with Medicaid spending and the pressure it puts on other state priorities, but this study shows that Medicaid costs actually grew at a slower rate than private insurance costs," she explains.

Comparing Medicaid's purchase of acute-care services to private insurance costs shows the program's cost increases are lower than those of private insurance. The average growth rate of per-enrollee Medicaid costs for acute care from 2000 to 2003 was 6.9%, which is lower than the 9% increase in per-enrollee costs of the privately insured, and substantially lower than the growth in employer-sponsored insurance premiums (12.6%), the report says.

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Although Medicaid purchases health care services in the marketplace for 75% of its beneficiaries, the bulk of Medicaid spending — roughly 70% — finances health and long-term care for the 25% of beneficiaries who are elderly or individuals with disabilities. Federal and state governments share joint responsibility for funding the program, according to the report.

During the period of time studied, 68% of the growth in Medicaid spending was attributable to acute care, and 30% was spent on long-term care due to the faster growth in enrollment of children and nondisabled adults in the program.

At that time, 90% of Medicaid's total enrollment growth (8.4 million) was from families, with only 10% of growth from the elderly and individuals with disabilities.

Although families dominated Medicaid enrollment growth from fiscal year 2000 through 2003, they only accounted for 44% of Medicaid spending growth. The elderly and individuals with disabilities accounted for 56% of spending growth.

The report also notes that, even though the elderly and the disabled are a minority of the Medicaid population, they are responsible for the majority of program costs due to their intensive use of services. ■