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Improve your hospice's end-of-life goals for care and planning

Short play is major educational tool

One of hospice staff's biggest challenges is helping patients and families set goals for end-of-life care.

For some patients, the hospice referral arrives so late that there is too little time for satisfying goal setting; for others, there are barriers that make it difficult for the patient and family to meet their goals in the time remaining.

There are different ways of documenting progress made toward these goals, an issue that will be a bigger priority when the Centers for Medicare and Medicaid Services (CMS) of Baltimore, MD, release new hospice Conditions of Participation (COPs), as is expected early next year.

"The new COPs will be a more demanding set of regulations, and they'll [likely] require we look at outcomes of care, which isn't something we've done in hospice to any great degree," says **Virginia Valentine**, MS, RN, CHPN, director of performance improvement for Family Hospice and Palliative Care of Pittsburgh, PA.

The assessment hospices do initially as part of the whole care planning process is crucial, Valentine says.

"You might have a patient experiencing a lot of pain, and it might be a barrier to their thinking about anything else, such as getting out to their grandson's ballgame," she says. "It might be a matter of relieving that pain and keeping it at a level that they deem is comfortable for them, and then they can go on and do the things they want to do in life."

The spiritual component is important, and there may be psychosocial issues to deal with, Valentine notes.

"We look at physical symptoms and social interactions within the family and their own network," she says.

One of the barriers or challenges of end-of-life care planning is provider involvement.

It's important that physicians realize what patients' goals are, and this might require education and training about end-of-life goals, says **Carol Schoneberg**, end-of-life educator and volunteer and bereavement program manager for Hospice of Southern Maine in Scarborough, ME. Schoneberg and Valentine have been featured speakers about establishing end-of-life goals of care at national hospice conferences.

Schoneberg and **Jill Bixby**, a palliative care coordinator at Maine General Hospital in Augusta, ME, developed a 30-minute play that is used to teach physicians, medical students, and others about end-of-life care planning.

Called BOATING for Before Offering Another Treatment Identify New Goals, the one-act play was written by Bixby in 2000, based on a dream she had, Schoneberg says.

"She was trying to find a way to break into palliative care and reach doctors and get them to shift their thinking around hospice and palliative care," Schoneberg says.

Schoneberg took a look at the play at Bixby's suggestion and then put music to it and added hospice elements. The women worked on it together and then began to perform it, along with several other cast members, at hospitals, national conferences, churches, and other public forums, including the Annual Assembly of American Academy of Hospice & Palliative Medicine, held Feb. 14-17, 2007, in Salt Lake City, UT.

"We've performed it maybe 50 to 75 times," Schoneberg says. "Our target audience is to get physicians to realize what the patient's goals are and what they want at the end of life."

The play includes a binder, so it doesn't require memorization, Schoneberg says.

"Its main character is Ramona, who is dying, and there's no speaking in her role," she adds. "With each new treatment, Ramona takes on pieces of scuba gear; when the doctor says, 'You have cancer,' she puts on a wet suit; then he offers another treatment, and she takes on pieces of scuba gear."

As Ramona grows more ill, she puts on a life vest and, eventually oxygen tanks, looking very burdened and miserable with her treatment, Schoneberg says.

"One character is a spirit whisperer, who says, 'You have a choice, you can tell them you don't want to do this anymore,'" Schoneberg says.

Ultimately, Ramona stops treatment and climbs into a boat at the center of the stage, and then she removes all of her equipment, one by one, until she is free of everything and her doctor finally understands, Schoneberg adds.

"The play educates the audience about comfort care and what it is, and it leads to wonderful dialogues and discussions," she says. "We've done the play any place somebody asks us to bring it, including the University of New England, where we performed the play for 125 first-year medical students, who were a major target audience."

The play's script and a CD of music to accompany it can be purchased by other hospices and end-of-life care organizations for educational purposes in their communities, Schoneberg notes.

The Hospice of Southern Maine also helps to improve the community's end-of-life care planning through its one-year-old Living Well Program, which is a volunteer-based, non-clinical case management service for people with a life-limiting illness.

It's an introduction to palliative care for people who may be involved with curative medical treatments and who may or may not be considering hospice care when the treatment ends.

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People who use the Living Well services typically are in their last year of life, often the last six months of life, Schoneberg says.

"They receive two social worker visits and one chaplain visit," Schoneberg says.

Other services include a program of care that monitors patients, reports changes to physicians, provides emotional and spiritual support, assistance with reading, writing, meals, counseling, respite breaks for caregivers, and volunteer assistance as needed.

"What we have seen is people feel comfortable with the Living Well Program, and they are being educated about hospice and end-of-life services and palliative care," Schoneberg says. "Eventually, many of them sign on to their Medicare hospice benefits."

For some people at the end of their lives, this type of program fits in better with their goals then going straight to hospice care, she notes.

"We're doing everything we can to reach out to the people who may not be hospice appropriate, but have clearly-stated goals, or sometimes they may be hospice appropriate, but don't want to sign on," Schoneberg says.

The program is growing through word of mouth, and it's served about 25 patients in the past year, she says.

"Probably half of the patients came over to hospice care," Schoneberg says. "Ultimately, that's our goal to increase the hospice's length of stay and see patients sooner." ■

Improve staff turnover, LOS, and bottom line

Turnover went from 30 to 10 percent

Training hospice leaders to be effective managers may be one of the most effective ways to improve a hospice's staff turnover rate, as well as make a significant difference on the bottom line, according to the experience of one Florida hospice.

"We have made a major investment in leadership training, and the investment has had a tremendous return in terms of almost anything you can look at," says **Dale O. Knee**, MHCA, president and chief executive officer of Covenant Hospice in Pensacola, FL.

Six years ago, Covenant established the Covenant Hospice Leadership Academy, with a focus on training the hospice's current leaders and developing future leaders, Knee says.

Within months of starting the academy, the hospice had an up-tick in its growth, and that growth has continued over the years, Knee says.

"We have taken the employee turnover rate from what was typical in health care, 25 to 30 percent [annually], and have reduced it to less than 10 percent," Knee says.

This reduction alone has important implications for a hospice's financial well-being, since to replace a high-performing hospice nurse with three to four years of experience requires an investment of $75,000 to $100,000, Knee notes.

"So if you reduce the nursing turnover rate from 25 percent to 12 percent, then you have, frankly, put money in the bank," he adds.

Another outcome of the leadership training is an increase in the hospice's length of stay (LOS), Knee says.

The average LOS has improved about 20 percent from the low 50s to an average LOS of 70-plus days, Knee says.

"The median has stayed steady at 48 to 50 days LOS, but our volume increased, and we have more patients," Knee adds.

The higher LOS gives hospice staff more time to do what they are intended to do, and it has positive financial ramifications, Knee says.

All of the ways the hospice measures these changes show that it is directly correlated to the leadership program, Knee says.

A year and a half ago, Covenant officials decided to extend their leadership training to outside the hospice by forming an alliance with the Studer Group, a national healthcare leadership and management development group, in Gulf Breeze, FL. The two organizations formed the Studer Covenant Alliance, which provides training to health care organizations nationwide.

"We are taking the same type of tools and models of the Studer group and bringing that to hospices throughout the country and into the end-of-life sectors through partnerships and consulting agreements of one-to-two years long," Knee says.

"Secondly, we're putting together leadership development institutes, and will have one in Las Vegas, NV in September, 2007," Knee says.

"The proceeds we gain through the Studer partnership we put into furthering our mission in terms of other funded and unfunded programs, including our children's programs and some other things we do," he notes.

The leadership courses are for anyone who is identified as being a leader or supervisor in the organization.

"This is anyone in the organization who has hire and fire authority," Knee says. "In our case, there are about 65 people we consider to be in the leadership academy of the core group, and they are required, as a function of their employment, to participate in that."

The hospice holds leadership seminars each quarter for two full days.

"All the leaders in the organization come together from all the different offices and receive training and have a good time," Knee says. "We have a party the first night — maybe going bowling together or seeing a movie together, and the two days are filled with learning more about various aspects of leadership and how you can learn and develop additional skills."

The Covenant-Studer Alliance includes training services for home health, long-term care, and hospice care. Also, there are specialized consultation services and an institutional concentration on end-of-life care.

The hospice's training program received the 2005 Award of Excellence in Internal Staff Education from Florida Hospices and Palliative Care, as well as the 2004 Award of Excellence for Community Education by the National Hospice and Palliative Care Organization.

The leadership development training follows a model called evidence-based leadership, Knee notes.

"You start with the foundation and put the whole leadership evaluation process into place, including very objective ways to hold people accountable," Knee explains. "First, you do an evaluation of all leaders and then identify what needs to be done in terms of leadership development, and that means creating a process to develop the skills they need."

Leaders learn how to select employees for hire, how to use key words at key times, and how to write thank-you notes to employees — even sending these to their homes. This process of recognizing employees' positive behaviors is called "rounding," he says.

The entire leadership training and organizational development process can be broken into these categories:

- **Evaluation:** finding out where the organization is and what's needed for improvement, including holding staff accountable;
- **Development:** coming up with a plan to help staff learn necessary skills;
- **Alignment:** bringing the organization into focus in terms of what's important, and identifying key leadership behaviors that are desired;
- **Breakthrough:** changing things and breaking through old practices to form standardization of improved practices and behaviors;
- **Acceleration:** improving the organization continually, creating fertile ground for staff to seek new ways to make the organization better, Knee explains.

"Acceleration is where the organization takes off," Knee says. "You see dramatic increases in growth and better ways of doing things efficiently, including doing all the things you've always wanted to do and could never understand why we couldn't get there and sustain changes."

Training sessions provide tools and concepts for improving leadership skills. For example, one segment focuses on how to identify and handle the high, middle, and low performers within the organization, Knee says. **(See story on handling high, middle, and low performers, p. 77.)**

Leadership trainers show participants how to identify the high, middle, and low performers, as well as answering these questions:

How do you move low performers up to a higher category or remove them from the organization? "We give people specific skills in dealing with that," Knee says.

- What are interviewing techniques to determine whether someone will be a high, middle, or low performer?
- How do you start a conversation with a low performer?

"We know that a good percentage of a supervisor's time is taken up with having to deal with low performing issues," Knee notes. "I've seen estimates of 60 to 65 percent of a person's time dealing with personnel matters is dealing with low performers."

So the leadership program teaches leaders how to eliminate the time they spend on low performers, freeing them to spend more time boosting the performance of middle and high performers, Knee says.

"The other aspect to this is that high performers tend to lose respect for supervisors who tolerate low performers," Knee says. "So we identify high, middle, and low performers, and we continually praise and constantly re-hire high performers — on a monthly basis."

A quick answer to what constitutes as high, middle, or low performer is this analogy, Knee says:

"If you have a group of people in an office, and you let it be known that you will buy pizza a week from Wednesday, and then you come in with pizza, the high performers will stand up and cheer; the low performer will say, 'Have you got pepperoni?'" Knee says.

"The high performers are the ones who will do not only their jobs, but are looking for more work, and they'll give 110 percent to an organization," Knee says. "They're always looking for challenges."

When a supervisor gives a high performer a performance review, the last thing on the high performer's mind is making more money, Knee says.

"The first thing a high performer wants is more responsibility, asking themselves, 'How can I help the organization?'" he says. "The low performers are the ones who are always complaining, and they're the last ones interested in being a member of a team — they're the ones for whom you always have to look over their shoulder, and they're the ones who never get their documentation done either correctly or on time."

Through effective leadership training, not only will the organization be improved, but there will be greater retention of leaders because leaders want to feel they're being trained and supported, Knee notes.

"I'm a former hospital administrator, and I think it's very typical in hospices and all of health care that we tend to promote people into leadership positions because they were good clinicians," Knee says. "That's okay, but when you do that you also have an obligation to help that outstanding clinician who has leadership potential to become a great leader."

There's another benefit to providing leadership training and enforcing the management skills that are taught.

"In every community, the word gets around," Knee says. "We have more and more people apply to us, and when we ask why they chose Covenant Hospice, we've heard increasingly in the last year and a half that they've heard about the leadership academy and they've heard that we don't tolerate low performers."

This reputation brings more high performers to the door, and an organization can become an employer of choice in health care, Knee adds. ■

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Program teaches zero tolerance for poor performers

Teaches strategies for dealing with troublemakers

Hospice leaders know very well who are their high, middle, and low performers, but they may not take the time to identify employees this way or deal with the conflicts posed by the low

performers, and this can lead to systemic and long-term problems in the organization.

According to the training techniques of a Florida leadership training program, there are some very specific ways managers can improve the entire hospice's performance, partly through dealing with low performers and boosting the morale of middle and high performers.

Once hospice managers learn how to improve responses to employees' positive and negative behaviors, then they'll start to get more reinforcement and honesty out of their staff, says **Dale O. Knee**, MHCA, president and chief executive officer of Covenant Hospice in Pensacola, FL. Covenant has an alliance with the Studer Group of Gulf Breeze, FL, to provide managerial training through a leadership academy.

"Once people know you're sincere, and you have an honest relationship with them, then they'll sincerely want to know what they can do for you," Knee says.

The leadership training program provides various tools, examples, and strategies for improving end-of-life organizations from the top down. But here are Knee's examples of how an organization can solve the ever present problem of improving low performers while not driving out high and middle performers:

1. Have a conversation with the low performer.

For example, a manager should set an appointment with the low performer, call the person in and have him or her sit down, dispensing with all pleasantries, Knee says.

"You can say, 'Thank you very much for coming to this appointment on time. I have some things I want to discuss with you,'" Knee says.

Then the manager should immediately tell the person about the behaviors that have identified the person as a low performer, including a bad attitude, if applicable, Knee says.

"Say how you expect that behavior to be corrected, and tell them very specifically that you expect this behavior to be corrected quickly," Knee advises. "Tell them you will meet with them on a weekly basis, and you would expect to see significant improvement immediately, or you will then have to take more definitive action."

The manager should also tell the employee that he or she will document this conversation and will continue to document further meetings so there will be a clear record of understanding what the expectations are, Knee adds.

"One of the techniques would be to not allow the employee to redirect the conversation or to point fingers at someone else, or direct the conversation back to you," Knee says. "They might say, 'You haven't spent enough time with me, or whatever.'"

If the employee tries to redirect the conversation, then the manager should say, "Look John or Jane, we're not here to talk about someone else today, we're here to talk about you," Knee says.

If the low performer goes away from the office thinking the manager is serious and that there will be some consequences, then it won't take long for word to get around, and the manager must follow through, Knee says.

2. Follow-up on low performer meeting.

"That's the next key ingredient: you must absolutely follow-through," Knee says. "It can't be a vacant threat; it has to be kept, and the staff will learn that someone is being scrutinized, and they'll expect some action to be taken."

Low performance needs to be corrected quickly, and it cannot be allowed to continue for months or years, Knee says.

"You don't call someone in and say, 'You got to change your attitude, and the next time I do an annual performance review, there will be consequences,'" Knee explains. "If I'm having a low performer conversation with someone I tell them that they must make the change the minute they walk out of my office."

And why shouldn't this be expected of employees? he asks.

"Why should we be at the mercy of low performers?" Knee says. "The organization should not be held hostage to low performers, and there's no reason for it."

Monitoring the low performer will take some time and effort.

For instance, if the employee's problem has been documented, then the manager might need to enlist help from other staff to review the employee's medical records and document problems, Knee says.

"If it's an attitudinal problem, then you have to observe the employee," Knee says. "That period of evaluation takes an investment on your part, and the pay-off is that you either improve the person and move them up to a middle performer category, or you rid the organization of the low performer."

The leadership training includes instruction on what is an appropriate disciplinary action and what isn't; a hospice manager who is uncomfort-

able that there may be side issues, such as claims of discrimination, can contact a labor attorney used by the hospice, Knee says.

"One thing we don't do, and I think it would be a vital mistake, is to be afraid of doing anything," Knee says.

"We give leaders the tools and resources to help them deal with low performers, so they shouldn't be like deer staring in the headlights, thinking their hospice will be sued," Knee says. "We don't run scared of a potential lawsuit just because we're afraid of it."

When Knee explains these leadership concepts at seminars and conferences, he often hears from leaders that they can't take this kind of action because their human resources department wouldn't let them do it.

"If I hear a leader at a hospice organization say that their human resources department won't let them do it, and I'm consulting with the hospice, then I'll have a frank conversation with the CEO, and say, 'Before you can do anything else, you need to take a hard look at the HR department,'" Knee says. "The HR department should be a service department, and through improved personnel administration, you improve the entire organization."

In about 20 to 25 percent of cases, the low performing employee will quit, which is good because those likely would be the most difficult ones to deal with, Knee says.

3. Continue to monitor if employee improves.

Leaders are taught to set 90-day goals for all employees, and the more general goals, omitting specific names, are shared on an Intranet site so everyone can see them, Knee says.

One of these goals is for the front-line supervisor to continue monitoring the low performer.

For example, suppose a registered nurse is the leader of the team, and she has on the team an LPN who has serious documentation and timing issues. The low performer conversation has been held, and the LPN's performance has improved vastly within the first two weeks to a month, Knee says.

Then, the leader needs to continue to sample the employee's documentation and medical reports to make certain the person doesn't fall back into being a low performer, Knee explains.

"If the person does fall back then that's grounds for termination, and the employee would need to be told that up front," he says.

"If I had a low performer who corrected his or her behavior within 30 days, then I'd call him or her in and have a good conversation," Knee says. "I'd say, 'You've done a good job, and I hope you understand now what you need to do to keep your documentation up. Documentation is critical in health care, and I hope you know that I don't expect you to fall back, and I don't expect to have another low performer conversation with you because, at that point, I'd have to seriously question your dedication to our organization.'"

Low performers are survivors, who know what to do to get by in an organization, Knee notes.

"They've outlived several supervisors, so they know they can play the yo-yo game and think, 'I can clean up my act until they're not looking, and then I can fall back,'" Knee says. "So you have to let it be known that there will be no falling back."

4. Be direct when firing an employee.

"Assuming you have the documentation you need, you call in the employee, and the conversation should be short," Knee says. "You basically say, 'As you know, I've had conversations with you, and I've put you on corrective behavior, and we've attempted to correct what's lacking, but since there has been no improvement in these areas, we're terminating your employment with us."

That's the end of the conversation, Knee says.

"Obviously you don't want them going away feeling terribly put-upon, but keep in mind that they're low performers, and they have not been doing the organization any good," Knee says.

5. Reinforce middle performers.

Middle performers should be called into the supervisor's office periodically and on an individual basis, Knee advises.

"I'd say, 'Thank you, John, for coming in today. How's your family doing?' etc., etc.," Knee says. "And I'd have a list of things in mind that are written down."

For instance, the manager will praise the middle performer for his or her good work, saying, perhaps, "I'm extremely pleased with the feedback I'm getting from patients about you," Knee suggests.

"Then you transition into an area where you are becoming the employee's mentor and coach in helping him or her improve," he says. "I might say, 'There is one thing that I would like to talk with you about where there is more room for improvement: I've noticed that occasionally your documentation is a little bit late; John, I'd really

like you to work on that, and if you do, then it would be wonderful for you and wonderful for the team.'"

Then the supervisor can suggest the employee meet with someone else to learn how to improve his or her skills.

"The key thing is to ask John, 'What can I do for you? Do you have all the tools you need to do your job?'" Knee says.

"John might say, 'I have X number of patients, and I'm doing documentation and sometimes I'm working on my kitchen table doing it. Is there any way our team could get laptops?'" Knee says. "So you make the employee part of the solution, and have him go away feeling that he's been complimented, and you're interested in his career and helping him improve."

If a manager does all of this well, then the employee is re-recruited.

The key is 100 percent honesty, Knee says.

If the employee's solution cannot be done because of the organization's budget, then the manager should say that it's a great idea and the managers will look very hard at how they can do this, but since it would be a challenge to find money in the budget for it, then the key is for the staff to promote hospice each day and bring in more patients, Knee says.

"You can say, 'If we increase the size of our organization, then we'll have more money to make other investments, and you can be a part of that solution,'" Knee says. "Don't make promises you can't keep, but get them to be part of the solution, which is critical because an organization's efficiency and effectiveness occurs at the middle level."

The high performers are the thinkers, innovators, and people way out there with big ideas," Knee says. "But the efficiency, effectiveness, and productivity occur within the middle performer levels, and that's where you want to encourage it."

6. Motivate high performers.

"High performers must be challenged, and they constantly want to feel they are achieving," Knee says. "They want to take on more responsibility, and so it behooves a high performer supervisor to frankly take advantage of that and recognize that they have someone who is a high performer and who has a high capacity for producing a lot of work."

A high performer conversation with a manager might go like this: "You say, 'I want to know not only what I can do to help you, but what would you like to do, Judi?'" Knee suggests. "Do you know something we're involved in that you'd like to be involved in, and what would excite you?"

With a high performer, it's a more personal conversation and the manager is really getting to know them, Knee says.

"You want them to know that they are really a major contributing factor in the success of the organization," Knee says. "You do anything you can to promote them, and, once again, it's a constant rehiring process."

Usually when people are called into the supervisor's office they wonder what they've done wrong now. So with high performers, the manager should give the person a call or drop off a note and say, "Sometime this week, please drop by and see me," Knee says.

"I say, 'I just wanted to take this opportunity to ask how you are doing,'" he adds. "Or, I'll go to their office and knock on the door, go in, and say, 'I just wanted to stop by and say how much I appreciate you.'"

Leaders should constantly reinforce their appreciation of the high performers, and this has the added benefit of the staff witnessing this appreciation, which might motivate some of the middle performers to move into the high performer category, Knee adds.

"I don't want to say we're the most wonderful and all-knowing hospice, but this is a journey that we continue to be on, and no organization ever reaches the end of it," Knee says. "For all of the great things going on, we still have issues and things we need to deal with, but we deal with them in a different, more effective manner than we did five years ago." ■

Addressing incontinence: Outcomes improve 24%

Education, better assessments help agency, patients

With "improvement in urinary incontinence" identified as one of the pay-for-performance measures for the upcoming Centers for Medicare & Medicaid Services' demonstration project, it is essential that hospice managers take a closer look at how they identify and treat incontinence.

"Incontinence is an important issue for home health patients because it can lead to other problems," says **Theresa Gates**, PT, director of rehabilitation services at Home Care Advantage in Jacksonville, FL. Incontinence can lead to skin integrity issues and can be a cause of falls in the home, she explains. Proper assessment of incontinence and identification of the type of incontinence the patient is experiencing is necessary to provide the right treatment, she adds.

"A lot of patients don't want to talk about incontinence," says **Diane Tiberg**, RN, CHCE, director of nurses at Keweenaw Home Nursing and Hospice in Calumet, MI. "We even have staff members who are not comfortable asking patients about incontinence or did not know how to ask without embarrassing the patient," she says.

In 2002, when Tiberg's agency first addressed incontinence, the agency's rate of "improvement in incontinence" jumped to 62.3% from 37.7% in 2001. "The national reference in 2002 was 52.4% so we were not only able to improve our own rate, but we reached a level above the national average," says Tiberg. The rates have continued to stay above the national reference rate but they have fluctuated between 64% and 54%, she says. "Some of the change is due to new staff and a need to re-educate existing staff to remind everyone that although we're focused on other performance improvement areas, incontinence is still important," she adds.

The first step to improving success with incontinence was a comprehensive education program, says Tiberg. "We invited an urologist to talk about how to recognize symptoms of incontinence, how to assess the cause of incontinence, and different techniques to treat incontinence," she says. An assessment card with questions to ask and clues to notice in the home helped nurses better identify the patient's incontinence at the start of care, she says.

"One of the reasons for a low improvement rate for incontinence is recognition of the problem later in the patient's care rather than earlier," points out Tiberg. When patients' incontinence is identified after care has started or at or near discharge, the agency has no time to improve the patient's condition, she says. "If nurses identify the problem early, we can document more accurately and we have time to address the issue," she adds.

Because incontinence is almost never the primary reason for a patient's admission, patients don't think it is important because they don't realize that incontinence can lead to other problems related to skin integrity and falls, says Gates. "When a patient is going to the bathroom four or five times every night, there is a real risk for falls," she explains. "We need to address incontinence to make sure that we improve outcomes in all categories," she adds.

Word questions carefully

When asking patients about incontinence, it is best not to use the word "incontinence," suggests Gates. "Many patients don't understand the word or they don't want to admit to another medical condition," she says. When asking a patient about incontinence, Gates suggests asking, "Are there any times when you can't make it to the bathroom in time?" This question is not threatening and it is specific and simple to answer, she says. If you get a positive response to this question, you can continue with other specific questions about accidents during the night, accidents during the day, and more details about what the patient is doing when the accidents occur, she adds.

Even if the patient does not admit to a problem, nurses need to be aware of any signs, says Tiberg. Odor, a package of pads in the bathroom, or the patient's defensive reaction to questions related to incontinence are all reasons to follow up with other questions, she says. Point out that many of your patients have told you about problems and that usually it is very simple to find ways to address the problem, she adds.

There are two types of incontinence, says Gates. "Urge incontinence can be treated with a variety of urge-suppression techniques and exercises to strengthen pelvic floor muscles," she points out. "We can also teach the patient to be proactive and use a voiding schedule so that the patient can urinate before the urge is so strong that it cannot be controlled."

Stress incontinence requires more assessment to determine the trigger, says Gates. "Does the patient lose control when sitting down or standing from a sitting position, or is the loss of control related to coughing or laughing?" she asks. Once you've identified the cause, you can teach patients to use their pelvic floor muscles to prevent accidents, she says.

Gates' agency has a group of physical and occupational therapists who have undergone extra training to address incontinence. In addition to the

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advanced clinical training for rehabilitation staff, agency nurses received four hours of general education to help identify incontinence upon admission or early in the patient's care and to distinguish between stress and urge incontinence, says Gates.

In addition to teaching Kegel exercises to patients to strengthen their pelvic floor muscles, Gates' therapists use behavior modification techniques that include biofeedback, electrical stimulation, and voiding schedules to help patients learn to control their incontinence. "Because fluid intake can affect a patient's ability to control their bladder, we have patients keep a three-day diary to measure their fluid intake, their voiding schedule, and the occurrence of leaks," she says.

After reviewing the diary, the therapist will suggest changes in behavior, she explains. "For example, a patient who is going to the bathroom frequently during the night might routinely drink a 24-ounce Pepsi at 8 p.m. every night." Eliminating drinks that stimulate the bladder, reducing amounts of fluid taken just before bedtime, and changing the time that larger amounts of fluid are drunk can reduce the number of trips to the bathroom, she adds.

The multidisciplinary approach with nurses identifying incontinence and therapists offering different treatments geared toward the patient's needs has resulted in some wonderful outcomes, says Gates. "We have some patients who have gone from using five pads per day to only one per day, and we have patients who would have 10 leaks per day improving to one leak per day," she says.

Even if your nurses and therapists accurately diagnose incontinence, your efforts won't be successful unless the patient wants to address the issue, warns Gates. She explains, "Even though you know you can help, some patients are quite comfortable wearing pads and they don't consider their incontinence a quality-of-life issue. In these cases, you let them know you can help when they are ready and you respect their decision." ■

Hospice as continuation of care, not just end of the road

Open access could help patients avoid 'terrible choice'

Hospice evolved from the need to provide medical and social support to terminally ill patients in the last weeks of their lives. But while the benefits hospice can provide have expanded, the perception that hospice is where patients go to die has, until recently, stayed the same.

According to **Richard Payne,** MD, director of the Duke Institute on Care at the End of Life at Duke University Divinity School in Durham, NC, patients at end of life who might benefit from what hospice has to offer — medical, social, and spiritual support — have been faced with what has come to be known as the "terrible choice:" To qualify for Medicare hospice benefits, most patients have had to resign themselves to giving up advanced medical treatments such as chemotherapy and dialysis.

But that's changing, as evidenced by a movement toward "open-access" hospice programs that allow patients to continue the treatments that, while not life-saving, can make the quality of the end of life much better.

"We're not talking about people like Elizabeth Edwards or Tony Snow, who have incurable conditions but who aren't likely to die in six months," says Payne, referring to the wife of presidential candidate John Edwards and the White House spokesman, both of whom recently have had recurrences of cancer.

"But what hospice can do is provide open access to people who are likely to die in six months but who can be made more comfortable through palliative chemotherapy or radiation, antiretroviral drugs — treatment that is not going to cure them, but will make the last weeks or months of their lives much more comfortable," he explains.

'Terrible choice' forced by money

Medicare's rules on hospice care do not require that hospice programs deny patients advanced medical care. But at a benefit of $130 per day for such care, the ability for a hospice program that's not backed by a larger institution to offer that kind of care to its dying patients is not likely.

To qualify for hospice benefits, a patient must be diagnosed with a condition that is likely to result in death in six months or less. For many patients and their doctors, that requirement in and of itself is enough to delay entering hospice.

"Physicians in their training are taught to cure," points out **Roseanne Berry**, RN, chief compliance officer for VistaCare, an Arizona-based national hospice provider. "There is much more education going on now in end of life [in medical schools], but some doctors have had little or no training in how to help their patients die."

The challenge for hospice providers, Berry says, is to help patients and physicians see hospice not as the end of the road in treatment, but as another layer in the continuum of care — a natural continuation of the care the patient has had up to the point where hospice becomes a consideration.

"We're getting there, but we still have about one-third of hospice patients die within a week of admission, and while we're glad to provide that care, it certainly doesn't give us the chance to provide the best care we could for those patients," Berry adds.

In 2005, only about a third of the 2.4 million people who died in the United States were in hospice care, Payne says, perhaps half as many as could have benefited from hospice programs.

He says Medicare policy makers argued that by giving patients a choice of staying in traditional health care or opting into hospice care that would allow the government to save money and still give patients what they need to die comfortably.

"But where do you draw the line?" asks Payne, addressing advances in medicine that blur the line between palliative and curative care. "How do you decide if something is given with palliative intent vs. curative intent?"

Larger hospices can offer more in the way of palliative care because they can spread their costs over a larger population, he points out.

"If you have 1,000 patients and 900 are getting relatively low-intensity therapies that cost less than $130 a day, you can spread around the remainder to provide higher-cost care to the other 100 patients who need it," he says.

As the baby boom generation and its parents age, they are demanding more choices than just a place to die comfortably, Berry says, so hospice services are changing to meet that demand.

"I bet you have seen more changes in this area in the last two years than you've seen in the 10 years prior to that," she suggests. "But you have to have those conversations. We're great at planning parties, planning vacations, planning everything but the end of our lives; but having those conversations lets us say, 'If you're eligible for hospice care, if your doctor has certified that you are, then let's remove the barriers and look at hospice as another part of your treatment.'"

The question that remains, Payne says, is how to afford it. While Medicaid is saving money by paying only $130 per day in benefits, for many patients the costs skyrocket because of expensive trips to the emergency department or hospital admissions that could be avoided with advanced care provided within the hospice setting, experts say.

"It's a good thing to do to offer patients these options, and it does diminish the psychological barrier of the terrible choice," says Payne. "If there is a way to provide the care they need in hospice — team-oriented, physical, psychosocial, and spiritual well-being — and provide some medically oriented therapies with palliative intent, it makes a lot of sense medically, and it's a reasonable health policy."

Open access means providing these types of therapies, Payne continues. A hospice does not get paid any differently when advance treatment is provided, so open access can mean providing more care at a financial loss. And if Medicare determines that the treatment is curative, not palliative in intent, it could withhold funds for that patient completely.

Removing obstacles and fear

Patients who might be eligible for hospice

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often are kept away by fear and lack of understanding, Berry and Payne agree.

"We want to remove the obstacles. We tell patients you don't have to have a caregiver in your home. You don't have to have a [do not resuscitate] order, you don't have to have advance directives to come into hospice," explains Berry. "Medicare allows hospices to have their own philosophies, so we do what we can to remove as many of the obstacles as we can, get them into hospice, and then work with them to plan how they want their end of life to be."

Payne says the psychological barrier of looking at hospice as a place to go to die is one of the biggest obstacles.

By not choosing hospice, or by choosing it only in the last days of life, Berry says, many people are giving up a valuable system of care and support.

"Most of our services are provided in the patient's own home," she points out, often with providers the patient has come to know and trust.

"One big concern among patients at the end of life is abandonment. They don't want to be abandoned by their primary care or oncology provider," she says. "In hospice, we can tell them that we will work with their providers, and we are just another layer of care and another set of providers who are here to enhance the care their doctors say they should have."

Payne advocates educating patients and their health care providers and support systems (family, clergy) about hospice, so that the decision to choose hospice is made ahead of time as a part of continued care, not as a last resort.

"The No. 1 complaint I hear from patients is, 'Why didn't we get this sooner?'" says **Ronald J. Crossno**, MD, medical director for VistaCare Hospice in Temple, TX. "Thirty-five percent of eligible U.S. patients receive hospice care. Twenty-five percent of these patients get hospice care for less than seven days [before they die].

"An earlier referral means the patient can still go see the grandchildren and it improves the transition. If you're hurting or in pain, you can't deal with the other issues relative to dying."

Berry says that patients who enter hospice shouldn't think they have to give up hope.

"But you have to have the prognosis [of death likely in six months], and those prognoses are very hard for physicians because they want to be optimistic," she explains.

Palliative care physicians can be a good resource if a patient — or his or her physician — is having a difficult time concluding that hospice is an option.

"Palliative care specialists deal with all of the issues that terminally ill patients face. The specialist makes arrangements and goes beyond the social worker," Crossno explains. He says 25% of U.S. hospitals had palliative care specialists in 2005, but expects that number to jump by 2010. ■