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New Caring Connections program gives consumers advance-directive info

States find various ways to use program's resources

When thousands of Americans suddenly decided last March they needed to think about end-of-life issues because of the publicity paid to Terri Schiavo's hospice care and death, a new project called Caring Connections was readily available to provide them with the information they sought on advance directives.

The National Hospice and Palliative Care Organization (NHPCO) in Alexandria, VA, created Caring Connections in the fall of 2004 with funding from the Robert Wood Johnson Foundation (RWJF), says **Kathy Brandt**, MS, vice president of professional leadership and consumer and caregiver services for NHPCO.

Caring Connections is a continuation of RWJF grants directed at end-of-life care. The program is designed to increase community awareness and knowledge of hospice through capacity-building local projects, such as forming coalitions for end-of-life care issues, and national services, including websites, brochures, and other resources, Brandt says. **(See story about Caring Connections projects in Florida and elsewhere, p. 64.)**

One of the first projects under Caring Connections was the creation of a website (www.caringinfo.org) that provides free resources on advance care planning, caregiving, pain, hospice and palliative care, grief and loss, and financial issues. Visitors can obtain state-specific advance-directive documents and instructions.

The website had more than 90,000 hits between the end of March and the end of April, Brandt says.

Also, a help line available to people who have questions about end-of-life care had huge increases in call volume shortly before and for at least a month after Schiavo's death. From a typical 150 calls per day, the call volume peaked at 1,200 calls per day, continuing at a rate of more than 600 calls per day through April, Brandt says.

"People are looking for information about advance directives right

now, and we're sending it out to them free of charge," Brandt says. "The grant pays for it."

Caring Connections' work has assisted some hospices in expanding their outreach to minority communities, using new ideas and approaches for this work, says **Charlie Antoni**, RN, LCSW, manager for community outreach at Wuesthoff Brevard Hospice and Palliative Care in Viera, FL.

"I really feel this is the direction where we as hospices need to go, and it's where we've never been," Antoni says. "We've given lip service to being community partners, but now we've changed it to 'We're in your neighborhood, and we know we want your business, so we didn't send you a letter or flier; we sent me.'"

Through a website (www.endoflifecoalitions.org) intended for hospices and other end-of-life care providers, there are free resources detailing fundraising activities, outreach presentations, caregiver support guidance, sample press releases, fliers, town-hall meeting ideas, and other tools.

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"The tool kits have so many practical, usable units," says **Stacie Ogborn**, project operations manager for the Kansas Living Initiatives for End-of-Life Care (LIFE) project in Wichita, KS.

"If you want to use a poster on how to talk about end-of-life care, all you have to do is use their poster and drop a label on it," Ogborn says.

The $2.3 million RWJF grant is for one year, and NHPCO is in the process of requesting funding for another two years, Brandt notes.

"Part of what we were asked to do with the grant is to continue to advance the work the Robert Wood Johnson Foundation had previously funded, including the Rallying Points program and the End-of-Life Coalition," Brandt says.

Funding for those programs has ended, and Rallying Points was closed in January 2005, but through Caring Connections, the NHPCO and other organizations that had been involved in those initiatives plan to continue to use the coalitions and resources that were built as part of the earlier work, Brandt says.

"We're providing a lot of resources free of charge to consumers, and hospices can join our engagement campaign," Brandt says. "We've established a frequent flier rewards program, so the more activities hospices and coalitions do as part of the How you Live campaign, the more points they'll earn and exchange for marketplace gift cards to purchase resources for their outreach programs."

Caring Connections provides an excellent opportunity to reach deeper into communities around the country with hospice outreach and education, says **Myrna Peralta**, JD, MSW, president of Alta Consulting of Washington, DC. Peralta has been the coordinator for the National Resource Center on Diversity in End-of-Life Care in Washington, DC.

"Over the last several years, the investment by the RWJ Foundation has seeded a tremendous amount of activity out there, and Caring Connections has a real opportunity to build on what's already been done," Peralta notes. "My hope is Caring Connections can take the discussion of end-of-life care to the next external level, and that level for me has to do with policy-access issues and human-resource issues that I think get less attention but probably have a more profound long-term impact."

By the end of April, there were more than 400 partners signed up with the program, with organizations in 49 states, including more than 300 hospices and palliative care organizations. Other

partners include state and community coalitions and national groups, and they do not need to be NHPCO members in order to join, Brandt says.

The Kansas LIFE project had been involved in Rallying Points, which left a huge gap when it closed, Ogborn says.

"Rallying Points was a really good recruiting tool, a nice carrot to offer people who were considering putting together a coalition and starting an ad hoc group but didn't have anything they could sink their teeth into," she says.

Since most of the community-based coalitions were operating on zero-dollar budgets, the seed money from Rallying Points was very helpful, Ogborn notes.

While the Caring Communities initiative provides no seed money for individual coalitions, it does reinforce the work that already has been done by giving coalitions further purpose and ideas, she says.

"I've sent out notification to our 31 Caring Communities, encouraging them to join as a partner," Ogborn says. "For our coalitions, it gives them another feather in their caps to be part of something nationally."

Likewise, Caring Connections was begun at the ideal time for hospices and end-of-life care coalitions in Nebraska because the state already had strong collaborations in place and was ready for the next step of community outreach, says **Jonathan Krutz**, MBA, executive director of the Nebraska Hospice and Palliative Care Association and the Nebraska Coalition for Compassionate Care in Lincoln.

"We've built some strong relationships," Krutz says. "And now we want to bring those people to the tables and say, 'We know what Nebraskans are thinking about end-of-life issues, and we have a program that can raise awareness about things like advance care planning and hospice, and we'd like to work with you to get this across the state.'"

One initiative the Nebraska groups will implement under Caring Connections is to fund an education and outreach position for at least one year, Krutz says.

The educator will work with hospice professionals to educate staff at assisted living facilities, area agencies on aging, Medicaid and Medicare carriers, and other organizations about end-of-life care, he explains.

"Part of the campaign is to look at how we can get communities and our citizens to think ahead about the kind of situations they may face, so they're not caught by surprise or making decisions in a crisis or finding themselves in a situation they don't want to be in, which, sadly, often is what happens," Krutz says.

According to a survey conducted two years ago, about one-third of Nebraskans have living wills, and many of those same people have health care power of attorney. The state groups plan to conduct another survey to see if that percentage has risen because of the Schiavo case, Krutz says.

The state of Nebraska ran out of its books about advance directives this year and then finally put the information on line. A separate website at www.respectmywishes.org had more than 200,000 downloads for its advance directives information, Krutz says.

Making decisions before a crisis occurs

While public interest still is high, it's important for hospice coalitions to encourage the public to talk about their end-of-life care wishes with their loved ones so if a situation arises in which they can't make decisions for themselves, their families will know what they desire, Krutz says.

"Caring Connections gives us the tools to get out in the community in ways we have not done before," he adds. "It gives us a common theme and a set of materials that fit that theme, and a dozen brochures and booklets we can use at different events, including stock PowerPoint presentations, fundraising suggestions, op-ed pieces, and press releases."

One of the major goals of Caring Connections is to enhance consumer capacity building to recognize demand, Brandt says.

"We know consumers need this information, and they need to make informed choices and make them in a timely manner," Brandt says.

"Far too many people are reacting to things that happen to them in the midst of a crisis when they get a diagnosis," she adds. "They get treatment, and then the family doctor says, 'I think that's all I can do,' and two weeks later the patient is dead, and the family doesn't know why they didn't get hospice care sooner."

Through the program's outreach suggestions and tools, hospices can build relationships with the community and increase the public's knowledge about hospice work, which eventually will lead to increases in early hospice referrals.

"That's the payback to hospice, but it's not necessarily the reason we got into this initiative," Brandt says. ■

Program leads to innovative outreach and education

Diversity is main focus of some initiatives

Wuesthoff Brevard Hospice and Palliative Care in Viera, FL, handed out 3,000 living wills and gave nearly 30 community presentations during the first six months after implementing the Caring Connections consumer engagement program.

"This is all what we consider to be friendship building and relationship building," says **Charlie Antoni**, RN, LCSW, manager for community outreach for Wuesthoff Brevard Hospice and Palliative Care.

"We're building all these different relationships based on needs, such as for AIDS awareness, advance directives, and health fairs," Antoni says. "Our feeling is when you are in need, you go to those you know best, so if we're a good partner and collaborator in the community, we're the ones they'll look to when they need hospice and palliative care."

Caring Connections, sponsored by the National Hospice and Palliative Care Organization of Alexandria, VA, began last fall as guidance for hospices and other organizations working to increase public awareness about end-of-life issues.

The program provides resources and encouragement for hospices to reach out to diverse communities and populations that traditionally underutilize hospice care due to poverty, racism, and other obstacles, Antoni says.

Antoni has worked with a wide variety of diverse communities, including African Americans, Hispanics, gays and lesbians, fundamentalist Christians and Catholics, and veterans.

"This is where having 'real' relationship building vs. traditional marketing pays its greatest benefits to the community, as well as to the hospice agency," Antoni says. "It starts with identifying key stakeholders and then meeting the people behind the identified stakeholder."

Antoni and other experts describe some of Caring Connections' outreach programs:

• **Friendship breakfasts:** Establishing trust takes time and personal relationships, and Wuesthoff Brevard Hospice has made inroads at developing trust within the African American community by holding breakfast meetings with community leaders, Antoni says.

At one recent meeting, about 50 people — including local pastors, community leaders, and ordinary citizens — attended a breakfast at which there was a panel presentation about hospice concepts, Antoni says.

A keynote speaker talked about palliative care and the hospice experience. After the talk, the attendees formed two workgroups, divided geographically, that continued to meet monthly to identify the community's need for education and awareness about hospice and palliative care, Antoni explains.

One workgroup had a member who belonged to a local college sorority, and the woman said her sorority had an international day of service for which AIDS was their focus. Another workgroup member said his ministry would be interested in doing a program on AIDS and African Americans, so the two organizations joined with a local AIDS service organization, received publicity from a local black newspaper and community college, and held a Wednesday night program on AIDS at a local church after the church service. The AIDS program was attended by 250 people, Antoni recalls.

• **Community health fairs:** Wuesthoff Brevard Hospice has worked with a local church to hold a health fair featuring the typical blood-pressure screening and diabetic screening booths, as well as a hospice booth, with volunteers available to help people fill out living wills and health care surrogate forms, Antoni says.

The fair also featured information on housing, low-income assisted living facilities, and a range of materials about hospice work and hospice myths, Antoni adds.

"We will grow presentations out of this, and this goes back to our philosophy of having relationships that are real," Antoni says. "We'll be recognized in the community as a presence and permanence, and we don't just come out once; we're there on a regular basis to support the community and build relationships."

• **Spanish-language resources:** Alta Consulting and the National Resource Center on Diversity in End-of-Life Care of Washington, DC, provide a Spanish-language resource for end-of-life care issues, says **Myrna Peralta**, JD, MSW, president of Alta Consulting and coordinator for the resource center.

"The publication is a resource telling where to go for what and under what conditions, including Web pages, telephone numbers, and national resources," Peralta says.

"Part of the challenge is that the Latino community is not aware of the extent of materials available for end-of-life care, so we put together this publication listing a compendium of resources," she adds.

The resources are available at www.nrcd.com.

• **Town hall meetings:** In Nebraska, end-of-life groups have held a town hall meeting on caregivers that was attended by 130 people and recorded by a public television station that will broadcast an hour-long program on the subject, says **Jonathan Krutz**, MBA, executive director of Nebraska Hospice and Palliative Care Association and the Nebraska Coalition for Compassionate Care in Lincoln.

People who serve as caregivers to family members joined medical professionals, university experts, and others to discuss caregiving issues in light of the demographic trends that have led to predictions that there will be a greater need for caregivers in the future, Krutz says.

"We need to think about what we can do for our families to support the dying, because family caregiving is a key component of hospice," he says.

• **Quality consultants:** In Kansas, end-of-life care professionals sponsored an educational program on pain management for physicians, nurses, and other health care providers, says **Stacie Ogborn**, project operations manager for the Kansas Living Initiatives for End of Life Care project in Wichita, KS.

"We were able to host training for about 1,200 different professionals in our state," Ogborn says.

Although this program took place under a program that preceded Caring Connections, called Rallying Points, its mission will continue as resources become available, Ogborn says.

Rallying Points provided funding to pay for the consultants, and so far there is no similar pool of money available through Caring Connections, Ogborn notes.

"But I don't think you stop educating because you don't have the money to do it," Ogborn says. "We're still going to try to make that happen, and the organizations are just going to have to come up with creative ways to bring pain management education to their communities."

• **Advance directives:** Wuesthoff Brevard Hospice created a package on advance care for large corporate employers, Antoni says.

"We offered to come to their location during the work day and put on short presentations on advance directives," Antoni says. "We've done some of that work in churches, too, and we had one church ask for 630 living wills and health care surrogate forms."

One church has planned a church-wide day of decision, and the hospice will support that effort, Antoni notes.

"We have been at the county government building and community college and three large space-industry employers," Antoni says. "So we're building good partnerships with our corporate neighbors as well, and we're filling a tremendous need."

NAACP sought hospice as partner

When the National Association for the Advancement of Colored People decided to send advance directives to its local branches to engage those communities in discussions of end-of-life care, they came to the hospice as a natural partner to help them with the effort, Antoni says.

"I'd like hospice administrators to understand if you build real relationships rather than just marketing relationships, then when there's a real need, you'll be the go-to person for them to seek as a partner," Antoni adds.

• **Publicity from alternative media:** From Wuesthoff Brevard Hospice's Caring Connections work, hospice directors have discovered that it is easier and more effective to seek publicity from alternative, community media sources rather than to simply try to get articles in an area's dominant daily paper, Antoni says.

The hospice has worked with a local Spanish-language newspaper and a newspaper read by the African American community, and the hospice has encouraged the hospital to advertise in these publications, buying both consumer and employment ads, Antoni says.

"It has to be a full circle of involvement, from recruiting employees and getting kids interested in these careers to putting revenue in small community newspapers, all of which furthers your presence and furthers you relationship with that community," Antoni explains.

And this relationship will pay off with free publicity. For instance, when a national speaker about end-of-life care presented a column about advance care to the local daily and the community newspaper, the daily passed it up, but the community paper ran it, Antoni adds.

• **Summit presentation:** Wuesthoff Brevard Hospice also has plans to hold a sit-down summit with the local Veterans Affairs hospital and a local

veterans service organization, Antoni says.

The VA approach to health care doesn't always fit in easily with the seamless transition of care the hospice and hospital might have, so that causes confusion and perhaps presents an obstacle to hospice referrals from the VA, Antoni notes.

"So in the interest of trying to get on the same page, we are holding a summit meeting, " Antoni says. "We hope that once we sit down with VA officials, we can talk about how we can partner and collaborate to gain a better understanding of what we need to do as providers."

Hospice officials will discuss how hospice works in the community, VA officials will discuss how the VA can work with hospice, and both sides will answer questions from attendees, he adds. ■

Pain medication providers face legal scrutiny

Here's what you need to know to avoid trouble

Federal regulators and civil litigators are forcing palliative care clinicians to be more vigilant with documentation and more cautious with pain medication prescriptions, a pain management expert says.

The U.S. Drug Enforcement Administration (DEA) has given medical providers mixed messages in recent years with regard to pain medication prescriptions, says **Robert Twillman**, PhD, pain management program director for the University of Kansas Hospital in Kansas City, KS.

When Asa Hutchinson was head of the DEA before Karen P. Tandy replaced him as DEA administrator in mid-2003, he reached out to pain management groups and talked about the issue of balance. Hutchinson said the DEA would make sure drugs are available to the people who need them but would simultaneously watch out for people who are diverting and abusing, Twillman says.

But now there's an indication that the DEA is cracking down on prescriptions for oxycodone (OxyContin), despite the fact that most of the illegally sold oxycodone is obtained through illegal activities, such as pharmacy robberies, and not from legal prescriptions, Twillman says.

"They're cracking down on doctors, and it's hard to understand why they are," Twillman says.

Also, the DEA recently reversed its policy of letting physicians prescribe three months of a Schedule 2 narcotic at one time. Now physicians have to write a new prescription every month, and some doctors have responded by requiring the patient to return to their office each month, which can be a hardship for many patients, Twillman says.

Physician does time on murder charge

"We have patients who might have to come 100 miles for the appointment," he says.

Three prominent court cases also have drawn new boundaries with regard to pain management, Twillman says.

Two of the cases were civil cases that were settled in favor of the plaintiffs, and the third was a criminal case in Kansas, which resulted in a physician spending two and a half years in prison for attempted murder, Twillman says.

"We're starting to see a fair number of criminal cases against physicians for what they're doing in pain management," he says.

In the case of the physician who was convicted of attempted murder for the way he managed a patient's pain, the chief lesson involves documentation, Twillman notes.

"The biggest issue that caused the problem in that case was inadequate documentation," he says. "If he had documented what he had done appropriately, it wouldn't have been an issue."

Twillman describes the three cases and how they are affecting pain management for end-of-life patients:

• **North Carolina cancer patient:** As detailed in a landmark civil suit, Henry James, a 75-year-old man with metastatic prostate cancer, had received pain control treatment in the hospital with a high dose of morphine, Twillman says.

"He was discharged to a long-term care institution, and while there, his initial orders for morphine were cut drastically," Twillman says. "Then one of the nurses decided he probably shouldn't have all that morphine because, in the nursing director's opinion, he was addicted to morphine."

The nurse reduced his pain medication from the hospital's level of 150 mg of morphine every few hours to 7.5 mg of morphine in that same period of time, adding in a mild analgesic. This resulted in the patient receiving inadequate pain treatment, Twillman notes.

When the elderly man was discharged, his family brought suit for substandard care, winning the suit in 1990. The nursing director admitted withholding the pain medication and said she had never seen anyone on such high doses, Twillman says.

The jury awarded $15 million to the plaintiffs, and the insurance carrier for the nursing home later settled the case in lieu of appeal for an undisclosed amount.[1]

This case marked one boundary for pain management, basically saying that health care professionals could be held responsible in civil court for not treating a patient's pain aggressively enough, Twillman says.

• **California man with metastatic lung cancer:** In this case, an 85-year-old man with lung cancer was admitted to the hospital with pain, and the treating physician, Wing Chin, MD, decided to give him meperidine (Demerol), Twillman says.

Generally, meperidine is not a good option for elderly patients because of a potential for convulsions, particularly among weaker and older patients, he explains.

The patient was in the hospital for six days, and each day nurses documented a pain level of between seven and 10 on a 10-point scale.

At the civil trial in 2001, the nurses said they gave the man meperidine whenever he reported a lot of pain, but they failed to document when they gave him the doses and whether the medication was effective in alleviating his pain, Twillman explains.

"The doctor says, 'I like to walk into the room and ask how the patient is doing, and if the patient says, 'I'm okay,' then that means there's good pain control, and we don't have to do anything,'" Twillman says.

The man left the hospital, receiving prescriptions for pain medication, but not for morphine as his family had requested.

The man's family called a hospice and received an order for morphine for him from a different doctor, and the man died three days later in good pain control, Twillman says.

After his death, the patient's family filed a claim of elder abuse. The family won a claim against the physician, while the hospital settled with them. The jury assessed $1.5 million in damages, Twillman recalls.

Since this case, California legislators passed a law requiring every physician to take 12 hours of education in pain management in palliative care, he notes.

"One of the really important functions hospices serve is educating physicians in general about pain management and palliative care," Twillman says. "When educating doctors, you can use these cases to raise the level of concern, saying, 'We think we do a good job of taking care of pain, and we want you to do that also, and it's important to protect yourself from liability.'"

• **Kansas small-town doctor:** On the other side of the boundary for pain management treatment, L. Stan Naramore, DO, a Kansas physician, was tried and convicted in 1996 of attempted murder and second-degree murder. He was sentenced to concurrent terms of five to 20 years in prison.[2]

The conviction was overturned by the Court of Appeals of the State of Kansas in 1998. The court wrote in its decision, "We find that no rational jury could find criminal intent and guilt beyond a reasonable doubt based on the record here."

One of the convictions stemmed from Naramore's pain management treatment of a 78-year-old woman who had metastatic breast cancer, Twillman says.

Doctor's personality causes problems

As the only doctor of a small community in a rural area, Naramore was well known but not well liked, Twillman notes.

"He was a little moody, blunt, and didn't have the best bedside manner," Twillman says. "He drove his Cadillac around Main Street and didn't quite fit in with the locals."

Ruth Leach, who had suffered from cancer for years, was admitted to the hospital in May 1992. Her condition continued to worsen, resulting in Leach's children meeting with Naramore in the hospital's chapel to discuss her condition. The family asked for more pain medication for her, despite the doctor's explanation that further pain medication could slow her respiration and result in her death.

"In the course of talking to the family, the doctor did some things that were a little unusual," Twillman says. "He was trying to be a nice guy and he read poetry to them, and they were a little uncomfortable with what was going on."

When Naramore concluded the family meeting by saying he would give Leach more medication, the family became fearful that he was going to try to kill her, Twillman says.

According to court documents, the woman's son thought her respiration slowed to a low level after Naramore gave her a 4 mg shot of Versed

followed by a 100 micromilligram shot of Fentanyl. The family thought she was near death, and Naramore asked everyone to hold hands while he recited Robert Frost's poem "Into the Woods."

After that, Leach's son told Naramore that he thought he had given her too much medication and he would rather have his mother lie there suffering for 10 more days than have the doctor do anything to speed up her death.

When the son made it clear he'd hold Naramore responsible for her death if the doctor continued to treat her, Naramore withdrew from the case and the family transported her to another hospital, where she was given morphine injections and died a couple of days later.

After this case, Naramore treated an 81-year-old man who was a severe diabetic with a history of heart disease. The man had been sent to the emergency room after being found passed out in a convenience store, and Naramore treated him with emergency procedures including artificial ventilation, pulse and blood pressure monitoring, administration of drugs, and cardioversion.

Naramore diagnosed the man as having had a stroke and being brain-dead, and he recommended removing life support. The man's family agreed, but then the patient made movements that caused them to think he would regain consciousness. Nonetheless, the patient's movements soon stopped, and another physician agreed that he was dead, so life support was removed.

After this case, Naramore was arrested for the attempted murder of Leach and the murder of the man who died after the stroke.

It's likely that Naramore did not receive a fair trial because it was held in the community where he already was disliked, Twillman says.

"He served two and a half years in prison, and four years after the charges were filed, the appeals court unanimously reversed the verdicts based on insufficient evidence," Twillman says.

While Naramore regained his medical license, the criminal convictions and years spent battling for his freedom and livelihood took their toll, Twillman adds.

The lesson to take from Naramore's case is that he had failed to document which drugs he prescribed and how much of the medications he administered, and he didn't provide good follow-up in terms of vital signs after he gave the medications, Twillman says.

"The whole thing was a mess; nobody was writing anything down," he says. "If he'd written down how much he gave, and if they'd assessed the patient, they would see that there wasn't anything wrong with her breathing."

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Special-needs patients need care during disasters

FL agency pays employees who assist at shelters

While Floridians are relieved to be over the 2004 hurricane season and able to focus on the ongoing cleanup, other parts of the country have been dealing with snow and ice storms and flooding that disrupt transportation and the ability of people, including home health agency staff members, to perform daily duties as normal. One benefit of the unusual hurricane activity in Florida is the visible reminder to all home health agencies to make sure their emergency preparedness plans cover opportunities to help during an emergency.

In Stuart, FL, the Visiting Nurse Association (VNA) of Florida not only prepares its own patients for evacuation and care during an emergency, but the agency also actively participates in the special-needs shelter operated by the county in which the agency is located.

"We have provided staffing for the special-needs shelter for 15 years," says **Elizabeth Simmons**, RN, BSN, director of professional services for the VNA. "We believe that it is part of our service to the community to make sure the county has enough help to provide the shelter," she explains.

VNA employees volunteer to work at the shelter based upon their own family situations, Simmons explains. The employees who volunteer are paid for their time by VNA. Other shelter staff members are county health department workers who are required to work, she says.

During Hurricane Frances, Simmons and a social worker from VNA volunteered to work at the shelter. "It was a terrific experience, and I'm proud that my agency participates in a community project like the shelter," she says. Every community should have plans for a special-needs shelter, Simmons suggests. No matter who is involved in the setup and management of the shelter, there are lessons that can be learned from the Stuart shelter, she says:

• Staff appropriately.

"We worked continuously for five days, taking shifts to rest at night," Simmons explains. "We worked in teams of two nurses and two lifeguards/emergency medical technicians." Be prepared for patients with physical limitations, she continues. "The lifeguards were a big help because they were able to help with lifting patients, and we had some immobile patients in the shelter," she adds. The health department also had a physician at the shelter throughout the storm.

• Designate one organization as shelter manager.

Although VNA of Florida has made a commitment to provide staff for the shelter, staff members also understand that the shelter manager is designated by the county health department and that during the emergency, VNA staff members at the shelter report to the shelter manager, says Simmons. "The health department has the resources and the personnel necessary to set up the shelters, but volunteer nurses and staff members are important additions to the health department staff," she says. While the shelter is successful because of a team approach, it is important that one person be in charge, adds Simmons.

• Make sure patients know what to bring.

The shelter in Stuart housed almost 300 patients for the five-day period.

"Patients are instructed to bring three days of food, water, and medication as well as their own caregiver, but some patients were dropped off with nothing," she notes. Hurricane Frances was unusual because the storm stalled over the east coast of Florida, and the shelter was occupied for five days rather than the typical three.

"Luckily, the shelter was located in an elementary school, so shelter employees were able to improvise with food in the cafeteria, and other shelter residents shared what they had when the storm stalled and would not leave the area," says Simmons.

• Clearly define who can be accepted by the shelter.

Home health agencies in the area registered patients for the special-needs shelter if the patient had no way to evacuate the area or no family member with whom he or she could safely stay, she points out.

Criteria should be determined ahead of time

"To qualify for the shelter, a patient either needed electricity, which is provided by generator in the shelter, or had a special care issue, such as a Foley catheter or wound care," she says. Although some dialysis patients were at the shelter, they could not be dialyzed, Simmons adds.

"We did refuse one tracheotomy patient who needed to be suctioned every hour because we did not have the staff to assign to one patient. He was sent to the local hospital," she explains.

• Be prepared for oxygen patients.

"Over 60 of our shelter patients were using oxygen," Simmons adds. While nurses are familiar with the use of oxygen tanks, they were all grateful to staff members from a local durable medical equipment company who volunteered to stay at the shelter to help with the oxygen equipment, she says.

"I don't think they got more than a few hours of sleep throughout the entire five days. They even brought extra tubing, equipment, and tanks that they used for all oxygen patients — not just their own patients," Simmons explains. "They were able to handle problems with tanks, nebulizers, and concentrators that we would not have known how to correct," she adds.

After the hurricane had passed through the area, VNA nurses who could drive into Stuart came to the shelter to relieve nurses who had been there for the five days, Simmons notes.

"VNA nurses made visits to our patients who were at the shelter, and they also gave those of us who had been working during the emergency a chance to check on our homes and get some rest," she says.

At the agency office, laptops powered by a generator enabled staff members to check schedules and find patient information. "Because power had been out for so long in areas where our nurses live, we had a number of power strips set up to enable staff members to charge their cell phones and PDAs," Simmons continues.

Nurses made phone calls to check on patients still in their homes. "Many of our patients needed

us to deliver water, ice, and other essential items more than anything else," she says.

The state of Florida requires home health agencies to develop an individual emergency plan for each patient with the input of the patient and the patient's family. The purpose is to make sure patients and their caregivers know what the patient will do and where the patient will go in the case of an evacuation order or the threat of a hurricane, Simmons explains.

"Patients are usually reluctant to talk about emergency plans when there is no threat of an emergency, but I think our experience with multiple hurricanes in one season will make it easier for us to discuss plans in the future," she adds. ■

Use technology to improve your patients' health

Telehealth boosts outcomes, retention, efficiency

(Editor's note: The Association of Telehealth Service Providers defines telehealth — also known as telemedicine — as follows: "Telemedicine is the use of electronic communication and information technologies to provide health care when distance separates the medical professional from the patient. It also includes educational and administrative uses of these technologies in the support of health care, such as distance learning and administrative videoconferencing. . . . Telemedicine typically involves physicians using interactive video and/or store-and-forward consultations to treat patients.")

Home health managers constantly are looking for ways to improve efficiency without compromising patient care. At the same time, they want to improve retention of good nurses so they are not always in a hire-and-train mode. A recent study conducted by the Pennsylvania Homecare Association in Lemoyne and Penn State University in University Park shows the use of telehealth can increase efficiency as well as improve retention of nurses. **(For more information on the study, see box, p. 71.)**

The data show agencies using telehealth have an average RN-to-patient ratio of 1 to 15, while non-telehealth agencies have a ratio of 1 to 11. Thirty-four Pennsylvania home health agencies are participating in the study. Twenty-three agencies use telehealth, and 11 agencies do not.

"We decided to participate in the study when it began three years ago because we saw an opportunity to improve patient outcomes," says **Kim Kranz**, RN, MSN, vice president of operations for Home Nursing Agency in Altoona, PA. "We did not have telehealth prior to the study. We have seen improved outcomes because the information that we now receive daily through the telehealth system enables us to make decisions to intervene in a more timely manner," she explains.

Not only has Kranz's agency seen a decrease in the number of rehospitalizations of congestive heart failure (CHF) patients, but she and her staff have noticed additional benefits.

"Our relationship with our patients' physicians has improved because we can call them with hard data about changes in their patients' condition," Kranz explains. "Physicians like data, and when we can provide readings from several days in a row to show trends, they are more responsive," she adds.

Kranz also expects telehealth to help when recruiting new nurses. "When younger nurses are ready to leave the hospital and look at home health as an option, they see telehealth as an important tool," she explains. Unlike current home health nurses who may not be familiar or comfortable with new technology, younger nurses have grown up with technology, Kranz continues. "These nurses are techno-savvy, and they expect to have this technology available," she adds.

Even with existing staff, the use of telehealth is a plus, says **Linda E. Bettinazzi**, RN, BSN, president and chief executive officer of Visiting Nurse Association (VNA) of Indiana County in Indiana, PA. "Our nurses are proud that our agency is progressive and looks for ways to help them do their jobs and better care for patients," she says. "Our retention rates are high anyway, but telehealth is one more way to improve job satisfaction," Bettinazzi adds.

VNA of Indiana County has offered a telehealth service since 1999 and currently has 83 monitors that serve 90 patients. Some of their monitors can handle multiple patients who use an electronic card with their personal health information to access the monitor and send information. "This is very helpful in an assisted-living facility where you can place the monitor in one central easy-to-reach location, as opposed to providing multiple units in one location, Bettinazzi says.

"When we first began researching the technology, the video component was not very good, so

we opted for a monitoring unit that collects vital signs through a unit in the patient's home that sends the information via a phone line to a central station in the home health agency's office," she explains. "We can also program specific questions for the patient to answer, such as, 'How do you feel today?'"

The patient's case manager reviews the data each day, Bettinazzi says. These data aren't used to replace nursing visits; instead, they are used to determine when the patient most needs a visit. "The nurse can visit the patient if there are readings that indicate a problem," she says.

This differs from the traditional system of scheduling a visit to a specific patient on Tuesday and Thursday of each week, Bettinazzi notes. "It is more effective because the patient might be fine on Tuesday but might have a crisis on Wednesday."

Bettinazzi's agency has a dedicated group of four nurses to handle all 90 telehealth patients. "Their caseload is higher than non-telehealth nurses' caseload, but they are not visiting their patients as many times," she points out. "We've found that our CHF patients on the telehealth service receive an average of 10 visits, as compared to CHF patients on traditional service, who receive an average of 17 visits," she says. "Our telehealth patients are also rehospitalized fewer times."

At this time, the four telehealth nurses are responsible for both the installation and removal of the telehealth equipment, Bettinazzi says. "I have suggested that we could train someone else to handle these tasks to free the nurses' time to be with patients, but the nurses want to continue the installation," she says. "They believe it is an important teaching opportunity, as they get to know the patients and their family members." Bettinazzi is considering setting up an employee to handle the removal of the equipment upon discharge, she explains.

At VNA of Wyoming Valley in Edwardsville, PA, home health aides install and remove the equipment, says **Nancy P. Barnard**, RN, BSN, MHA, director of home health at the agency, an affiliate of Wyoming Valley Health Care System. "The nurse is in the home immediately after — or at least on the same day as — the installation to teach the patients, but we've found that using the aides to install the equipment shortens the nurse's visit and makes better use of the nurse's time," she says.

One of the unexpected challenges with managing telehealth equipment is tracking all of the equipment and accessories, Barnard notes. "You always remember to pick up the monitoring unit and items such as the blood pressure cuff, but little things like ground wires and telephone jacks often got left behind when we first started," she says. "We now have a checklist that lists all of the

Telehealth can affect staff retention, job satisfaction

The three-year study conducted by the Pennsylvania Homecare Association and Penn State University is designed to evaluate how telehealth affects not only patient care but also home health's ability to continue providing care during the nursing shortage. In addition to looking at agency workloads, this study assessed home health nurses' attitudes towards their jobs and their response to telehealth. A total of 1,241 surveys were distributed to home health agencies participating in the study, with a total of 629 surveys returned. Respondents were asked to score their responses on a scale of 1 (low) to 5 (high).

Results included:

- Job satisfaction was high, with an average score of 4.18.
- Nurses' involvement in telehealth activities is low, with an average score of 1.9. The majority of nurses report they perform telehealth activities less than once per week. This can be attributed to the fact that many agencies use a small core group of nurses to perform telehealth activities.
- The average score for perceived usefulness of telehealth is 3.57. The longer the home health agency has been using telehealth, the more useful the nurses perceive it to be.
- Overall, nurses indicate organizational support for telehealth is in the midrange, with an average score of 3.76.

Study coordinators also looked at the relationship between telehealth and nurse retention rates. A measurement of the annual turnover rate for each of the 34 participating home health agencies was taken.

Data show the following:

- Voluntary turnover rates for RNs in this sample of home health decreased from 17% in the first year of the study to 13.4% in the second year.
- The lowest turnover rates were found in home health agencies that have implemented telehealth, estimated at 11%, as compared to 19% for agencies without telehealth.

Source: Pennsylvania Homecare Association, Lemoyne, PA.

items used to install the equipment, and the aide uses that checklist to make sure all of the items are picked up at discharge," Barnard adds. "You can design your checklist to be taped to the monitor so that you don't have to search for the list when it's time for the aide to remove the equipment," she suggests.

All of the nurses in Barnard's agency work with telehealth patients. "We have an LPN who monitors the daily readings at the central station," she says.

The LPN checks with the scheduler to see if a patient whose readings are abnormal is scheduled for a visit that day, and together they will rearrange the schedule to make sure the patient is seen. "We also talk with the patients by telephone to see how they are feeling and to see if their vital sign reading might have been affected by diet, medication, or other activity," she says. The combination of telehealth and telephone contact with patients enables Barnard's nurses to see patients when they most need to be seen, she explains.

Therapists find data helpful

Most agencies are targeting patients with certain diagnoses — such as CHF, diabetes, prenatal, coronary artery disease, or stroke — for telehealth, but the technology can be helpful for non-nursing cases as well, Barnard notes. "We may discharge a stroke patient from our nursing service before the therapy services are complete, but we don't immediately pull the monitor from the home," she says. "We found that our therapists were very interested in the data that showed a patient's vital signs when at rest, immediately before therapy, and immediately after therapy," Barnard says. "We started leaving the monitors in the home when therapists expressed disappointment that we were taking them as soon as the patient was discharged from nursing care," she adds.

One recommendation that Bettinazzi has for managers implementing a telehealth program is to have standing orders for interventional activities in place. "There are things our nurses can do in the home to prevent a trip to the hospital, but some of our physicians are hesitant to allow us to intervene at home when we call to tell them their patients are experiencing difficulties," she says. "They tend to send the patients to the hospital." If, at the start of a telehealth service, you can set up some standing orders specific to CHF or other conditions, it will further decrease visits to the emergency department and rehospitalization, she says.

"As nurses age and we have to care for patients with fewer nurses due to the nursing shortage, it becomes more important to have data from telehealth to determine which patients need to be seen on each day," Bettinazzi says. By making sure a nurse's time will be used effectively, you can provide quality care without overextending your staff and risking staff burnout, she adds.

Kranz contends telehealth is an important tool for home health. "With the emphasis on reducing rehospitalizations and improving home health outcomes, and the pay-for-performance approach to home health reimbursement that is around the corner, telehealth is not going to be just a nice addition to our services; it is going to be essential to our agency's success," she says. ■