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What can hospice providers expect from Medicare deemed status surveys?

Joint Commission and CHAP officials give preview

About 1,000 hospices soon will be offered an opportunity to have their accreditation survey combined with a Medicare survey. The country's two largest accreditation organizations are expected to receive Medicare deemed status within the next two months. The question on everyone's mind now is: How will this change the survey process?

About 950 hospices are accredited by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) in Oakbrook Terrace, IL. For these hospices, the chief difference between an accreditation survey and a combined Joint Commission and Medicare survey is that the survey will be unannounced, says **Maryanne Popovich**, RN, MPH, executive director of the home care program.

Presently, Joint Commission surveys are announced. Since the Medicare survey would be combined with the regular survey, both would be unannounced. Agencies no longer would have the luxury of scheduling survey dates. Instead, they will have to apply for accreditation when they are prepared for a survey, Popovich says.

The Joint Commission expects to receive a decision on its deemed status application by the Baltimore-based Health Care Financing Administration (HCFA) in January.

Surveys will pose problems for hospices

If a hospice chooses to have a combined accreditation and Medicare survey, the Medicare survey would be conducted, followed by the Joint Commission survey Popovich says.

The Community Health Accreditation Program (CHAP) in New York City, should hear an answer on its hospice deemed status application by February, says **Kathleen Egan**, senior vice president of the organization which surveys about 50 hospices.

CHAP already holds unannounced surveys, which means that aspect will not change under Medicare surveys, Egan says.

However, CHAP-accredited hospices may not have been surveyed,

according to Medicare's Conditions of Participation (COPs) prior to 1997, Egan says. "We re-did the standards in 1997 and included COPs because we were preparing to apply for deemed status in 1998."

An extensive Medicare survey could be a big change for many hospices, because they have been low priorities in many states, Egan suggests. "The biggest problem is going to be within the hospice industry; there has not been regular standard-level HCFA surveys for the last six to seven years."

As a result, the hospice industry has not had the same benefit as other providers, such as home care agencies, and regular surveys where HCFA surveyors provide ongoing education, Egan adds.

Guidelines for survey preparation

Agencies that undergo a deemed status survey will know exactly what type of compliance measures are expected of them. This is important education, since the hospice industry may soon face the same kind of fraud and abuse scrutiny in recent years that has faced home care agencies under Operation Restore Trust, Egan says.

"Because of deemed status surveys, home care agencies learned when they were in compliance and not in compliance, they could correct things in an ongoing sort of way," Egan adds.

Hospices have a third accreditation alternative with the Accreditation Commission for Home Care (ACHC) in Raleigh, NC, which began accrediting hospices a year ago. However, the organization has not yet applied for deemed status, says **Tom Cesar**, president of the 13-year-old organization.

Whether a hospice prepares for a deemed status survey or a single accreditation survey, there are some basic steps to follow.

Popovich, Egan, and Cesar offer these guidelines for survey preparation:

1. Do your homework.

All three accreditation organizations have manuals that carefully spell out every requirement and expectation. Successful hospices have their staffs study them carefully — point by point. **(See advice from three hospices that passed their surveys, p. 3.)**

"We list the kinds of evidence that surveyors are going to be looking for to verify compliance," Cesar says of ACHC's manual. "Our standards are very explicit."

ACHC encourages agencies to copy its

standards manual and distribute it to allow staff to focus on different areas."That way, you have an ownership of the process; and two, if you cut up the pie and have more people working on it, they can be thorough," Cesar says.

The CHAP accreditation model looks at four areas:

- structure and function;
- quality;
- resources;
- viability in the long term.

CHAP surveyors will want answers to the following questions:

- What does the structure and function of an organization look like?
 - Is it set up to do the task or business of its hospice?
 - What does the governing body look like?
 - How are they set up financially?
 - What are the systems they utilize in terms of quality assurance?
 - What is the quality of the level of personnel they bring in to do the job, and do they have specific standards addressing that?
 - How do they set up their personnel department?
 - How do they track quality-of-care to clients and client satisfaction?
 - What kind of data are they collecting, tracking, and analyzing?
 - What outcomes measures have they been studying? "We expect to see at least two per program," Egan says. "We ask them to collect meaningful outcome data that has some applicability to their everyday practice; and that is an area that hospices struggle with the most."

2. Pay attention to your contracts.

Hospices need to attend to all of their contracts, including those with pharmaceutical organizations and home medical equipment organizations, Popovich advises. "Make sure those contracts specify who does what. This is very important."

Some agencies use contracts with general language that doesn't identify who performs which tasks or roles. For example, a contract with a medical equipment company might not specify who is supposed to deliver equipment to the patient's home and exactly what kind of equipment will be provided, Popovich explains.

Even if the hospice employees know the answers to these questions, it should be spelled out in the contract.

3. Complete all necessary staff competency evaluations.

Organizations should make sure their competency tests match employees' job descriptions, Popovich says. For example, a hospice shouldn't say that all RNs must be competency-assessed on venipuncture draws if they have some RNs who never do venipuncture draws.

"I might suggest that venipuncture draws should not be high on a list of competency assessments for hospice nurses," Popovich says. "In hospice, you might want to see an RN have good assessment skills in pain management; and if that's what you want, then you should be testing for them."

The point is, hospices should require competency testing for all staff, including volunteers, who provide direct patient care; and they should do this with a thoughtful approach that considers exactly what their skills should be, Popovich says.

4. Focus on infection control.

Infection control is a common problem area, and it probably always will be, Popovich says. "This is real basic in terms of whether something is supposed to be sterile; how do you make sure the sterility is maintained?"

Suppose a nurse is taking care of a patient's central line, and one of the tasks is to flush the central line. The needle must remain sterile. Yet, Joint Commission surveyors have seen nurses cause a break in sterility and keep on going. "I think there's a tendency in home care of thinking that the patient's germs are the patient's germs," Popovich says.

Dressing changes are another common problem

area. The dressing is supposed to remain sterile. When a nurse opens a new four-by-four package, he or she should open it in a way that keeps the package on the bottom so the sterile bandage does not touch the bed linens. "We've seen some nurses dump the dressing on linens and then put it on the wound," Popovich says. "We're seeing some real breaks in sterile technique, and I hope it's not because hospice nurses think these patients are dying anyway."

Popovich suggests hospices give nurses a refresher course on infection control before the surveys.

5. Do what your policies say.

Surveyors from all three organizations will carefully study each hospice's rules and standards. Then, they compare the standards to hospice staff's actions to make sure everyone is in compliance.

"Our surveyors are looking at an organization's policies and overlapping them with our standards," Cesar says. "Are they doing what they say they're doing; and are they incorporating our standards within their policies?" ■

Accreditation surveys are always challenging

Word of advice: Prepare, prepare, prepare

Accreditation surveys have always been tough. Now that two of the major accrediting organizations are expected to be given deemed status, these surveys will be more important and tougher than ever.

"Accreditation improves patient care and supports a standardization of care," says **Eric Storch**, LMHC, support services manager of Catholic Hospice in Miami Lakes, FL. The hospice's two offices serve two large counties in the Miami area. Storch is guiding Catholic Hospice in its preparation for an upcoming survey by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) in Oakbrook Terrace, IL. He also was involved in successfully preparing for accreditation at a previous hospice.

"Many third-party payers, managed care organizations, and insurers are looking to see if you've been accredited, because it's a nationally recognized standard of care," Storch adds.

If your organization has never been through an

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accreditation survey, or if you need fresh pointers for your next one, you might learn something from hospices that have successfully navigated the process.

Storch and other experts suggest hospices follow these guidelines in preparing for a survey:

1. Write a time line.

Catholic Hospice outlined goals for eight months of survey preparation, Storch says. The goals are clearly stated. One for September, for instance, simply says, "Meet and assign each chapter in (the) manual."

The Hospice of Marlboro County in Bennettsville, SC, used a time line to highlight realistic goals, says **Kevin Long**, executive director of the hospice, which serves rural northeastern South Carolina.

Time lines are a practical way to tie work goals with a survey deadline. And they make the preparation process more manageable, Long says.

Their efforts paid off. The hospice was accredited with commendation by the Accreditation Commission for Home Care (ACHC) in Raleigh, NC, notes **Tom Cesar**, ACHC president.

2. Form work groups.

Hospices should develop work groups that are broken down according to various chapters in the accreditation manual, Storch advises. For a Joint Commission survey, for example, there might be 11 work groups, including a work group that covers the ethics chapter and a work group for infection control. There could be four to eight people in each group, depending on the hospice's size.

Each group should have a team leader who is usually someone in a management position who coordinates the group's work, Storch says.

Each work group looks at each standard in a chapter. They compare the standard to what the hospice has been doing in terms of compliance.

For small chapters, the work group could cover the standards jointly at group meetings. The group may want to divide standards and have members handle them individually when dealing with larger chapters, Storch says.

When groups find standards that are not covered in their hospice's current policies and procedures, they may suggest the hospice revises or writes new policies.

"It's important that all the leaders of the different work groups meet on a regular basis to discuss what's going on," Storch says.

Some changes that affect one work group's

chapter may also affect another chapter. They will need to work jointly on changes.

Work groups could hold meetings every two weeks to start and, during the middle of the preparation process, they could meet once every month. Toward the end, they might again meet every two weeks. "I think it's important to not have a lot of meetings because part of the process is to demonstrate quality care, so we can never lose focus of the fact that patients come first," Storch says. "Limit meetings to no more than an hour to an hour and a half."

3. Address key areas of concern.

Infection control is an area that needs a lot of attention, says **Ruth Gent**, MPH, vice president of patient/family services for Hospice and Home Care by the Sea in Boca Raton, FL. The agency was accredited with commendation by the Joint Commission, and Gent worked with another Florida hospice that was also successfully accredited. Gent and Storch spoke about how to prepare for Joint Commission accreditation in October 1998 at the Washington, DC-based National Association of Home Care (NAHC) conference in Atlanta.

"Infection control is a big area, and it's a problematic area. No matter how well you think you're prepared, someone can inadvertently slip up and not wash their hands at the right time," Gent says.

Staff competencies also pose problems, she adds. "Make sure you do evaluations and competencies in performing particular tasks that are associated with each job."

4. Make needed changes.

The Hospice of Marlboro County had not done a great deal with quality assurance projects before the accreditation process, Long says. "We always felt we had a good product; we did various things, but we never had any vehicles to record and track and monitor. That goes back to the fact that we are a small and young organization," Long says.

However, the accreditation process forces hospices to improve quality assurance processes and assess, revise, and improve all forms and documentation, he adds.

5. Ask for help.

Several months into the preparation process, the Hospice of Marlboro County asked ACHC for help. A surveyor visited them to answer questions

and to help get the hospice get back on track, Long says. "We were starting to spin our wheels, and decided to get someone in here to give us some examples and illustrations so we could determine exactly what it was they were looking for," Long explains.

The best way to find out what a hospice needs to change is to check the accreditation organization's manual, Storch suggests.

What's in a hospice's policy book should reflect standards found in the accreditation organization's manual. Some agencies have even structured their policy and procedure manuals based on Joint Commission chapters. "I don't think that's necessary," Storch adds. "The most important thing during the survey is that you need to be able to find that information easily."

6. Prepare staff for surveyor interviews.

Surveyors typically set up formal interviews with hospice employees. Agencies should make sure all employees are able to recite policies and procedures that relate to their jobs.

Employees also need to be aware that even during casual encounters with surveyors, they may be evaluated.

"The Joint Commission surveyors that I have been involved with have been very adept at informal interviewing," Gent says. "They engage you in a conversation; and in the conversation, they're definitely looking for certain answers but you wouldn't know it."

For instance, a surveyor may pass a nurse in the hallway and stop to ask what the nurse does and then say, "I see you have an alarm system in this hallway, do you ever have fire drills here? What do you do during a drill?" Gent says.

"The surveyors are amazingly quick and astute," he adds. "They could take a policy and procedure

book, for instance, and in a short period of time they would find what they were looking for even when they were unfamiliar with the agency."

Long says he was surprised to find that surveyors are almost never off duty during the survey process.

Once, an ACHC surveyor checked the hospice's off-hours response to patients by calling one evening and pretending to be a client. The surveyor asked to have the nurse call her back because there was a problem.

"It was a matter of minutes when the surveyor received the call back from the nurse, and she was very impressed with that," Long says. "But it really caught me off guard because I thought I had pretty well identified everything the surveyor would do. ■

Can your hospice extend care to kids?

PA hospices makes this a priority

Hospice officials have long found themselves caught in a dilemma when it comes to treating terminally-ill children.

Children's families and physicians traditionally are not willing to give up on curative treatment until the child is within days of death. By the time hospice is referred the case, it's too late for an agency to provide many of its supportive services to the family and patient.

"Most of the children we're referred live [less than] a week, and one recent referral was for a child who died 45 minutes after we received the initial call for an evaluation," says **JoAnne Reifsnyder**, MSN, RN, director of supportive care division for the Visiting Nurse Association (VNA) of Greater Philadelphia. VNA, which was founded in 1886, serves southeastern Pennsylvania, southern New Jersey, and northern Delaware.

Problems associated with handling pediatric patients underscore a bigger hospice concern, Reifsnyder says. "Right now, the hospice industry is facing some real challenges in the type of care we provide," she explains. "The industry has a declining length of stay, which is troublesome, because it means patients who were eligible for much longer service instead received a couple of days of care or a couple of weeks of care from a hospice team."

SOURCES

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Reifsnyder refers to a 1986 study that reveals how more than half of the terminally ill children studied received curative therapy right up until their death.¹

“That’s a very important consideration because generally, that is not the case with adults,” she says. “Once death is anticipated for adults within a week or two, therapies frequently are stopped.”

The VNA of Greater Philadelphia has a supportive care division to address this problem for both adults and children. The division includes both a home care program as well as a Medicare-certified hospice, and they operate under different conditions of participation for federal funding. The supportive care program is for patients who may not yet be medically or emotionally ready to receive hospice care, Reifsnyder says.

“It’s a way of providing their home care through our specialty team of nurses, social workers, and other clinicians,” she says. Reifsnyder gave a lecture about the program’s focus on improving end-of-life care for children at the recent National Association for Home Care (NAHC) conference in Atlanta.

The program has had limited success with children since it began in August 1997. Twelve children have benefited from the program, and all but one died.

Although the services are designed for families who may still be seeking cures, many parents have a natural bias against anything having to do with the word “hospice,” Reifsnyder says. “They hear the ‘H’ word and think, ‘My child’s not ready for that,’ or the physician says, ‘I don’t want to bring this up with them now.’”

Still, Reifsnyder says she believes the program is a much-needed service for these families; eventually more people will seek it out, because it offers so many benefits in the forms of support services. For example, a child enrolled in the program celebrated some major milestones of his brief life with hospice professionals. When he lost his first tooth, hospice workers were there to help the family celebrate and be happy about this developmental milestone. “That was a life moment, not a death moment,” Reifsnyder says.

The program gives hospice professionals extra time with the terminally ill children. “We get into celebrating the day-to-day triumphs and focus less on preparing for the disaster,” she says.

Reifsnyder explains how the program works by answering these questions:

- **How do you find terminally ill children?**

“That’s our ongoing challenge. What we’ve

begun to do is move away from traditional settings, such as acute care settings,” Reifsnyder says.

Physicians and other traditional gatekeepers might say the program sounds terrific, but they continue to refer children at very late stages of their disease. The agency has begun to reach out to community agencies and schools that provide support to chronically ill children. The program is looking for children who may have more than six months to live, but not expected to live past childhood.

“Once we identify children who need care, then we’ll go to their doctors and say, ‘Here’s a program we have for children, and you don’t have to sign that they have a life expectancy of less than six months,’” Reifsnyder says.

The agency also markets the program to the public through public service announcements and information distributed through United Way.

- **Where do you find funding?**

Foundations have helped fund the program’s start-up and special projects and supplies. Some children have received Medicaid funding, which covers the program as a home care and not a hospice service. The children can become eligible for hospice services once their families abandon curative treatment and their life expectancy is less than six months.

Also, commercial payers have paid some of the services.

Still, the program’s services often are not covered by governmental or commercial payers, so the VNA has picked up some of the cost. “What we’re trying to do is reach beyond this handful of children who meet the strict hospice eligibility criteria; it’s not that I have all the answers, but we’re asking the questions,” Reifsnyder says.

- **What kinds of benefits does the program offer?**

The program gives nurses, counselors, and other hospice therapists an opportunity to meet with terminally ill children and their families months before they die. This allows enough time for building trust and rapport, which are essential to bereavement counseling, Reifsnyder says.

“You need to establish a trusting foundation or relationship as the basis of this ongoing care,” she explains. “If you’re only seeing kids or adults in the last two or three weeks of their lives, it’s going to be very difficult to establish this kind of bond you need to provide ongoing care.”

The VNA has a maternal and child health division with many services for chronically ill children. This division existed before the supportive care division. The pediatric services are

SOURCE

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available to more families as part of the agency's end-of-life program for children.

The agency brought in new staff and cross-trained existing hospice staff who had experience working with children. Also, the agency trained some of the pediatric staff to become comfortable with end-of-life care for children.

"Then, we tapped into additional therapists on a contract basis, including art therapy, play therapy, and those types of things," Reifsnnyder says. The program also offers nursing services, social work care, speech therapy, and chaplains.

The program also may help a family buy equipment that is needed to help the child attend school. These are the types of things that hospice normally would not provide.

"This agency has a commitment to this program, and I know there are children who could use this kind of help and aren't getting it," Reifsnnyder says, adding that its services will continue whether or not funding covers everything. "This agency existed in 1886 before Medicare and before anybody thought of third party payment for home care," she says. "The care was provided then and somehow it worked."

Reference

1. Lauer, ME, Mulhern RK, Hoffmann RG, Carmitta, BM. Utilization of hospice/home care in pediatric oncology. *Cancer Nursing*. 1986; 9(3):102-107. ■

Teen volunteer program wins clients' hearts

And teen garners national honors, too

The Hospice of the Florida Suncoast in Largo, FL, has always used teen-age volunteers, but there was no formal program to recruit and find special jobs for them.

"We had always had a lot of young people," says **Mary Labyak**, MSW, president and chief executive officer of the hospice, which sees 1,250

patients a day in the St. Petersburg-area on Florida's western coastline.

"At Christmastime, we always did caroling at many patients' homes, and everybody brings their families," Labyak says. "We'd notice how much patients enjoyed having children come in."

Then, in 1994, the hospice applied for and received an intergenerational grant through the Juvenile Welfare Board in Pinellas County, FL.

The grant's focus was to bridge the generational gap by giving young people a chance to know older people. This is especially important in Florida where many children don't see their grandparents on a regular basis, and many retirees live far away from their grandchildren, says **Sandra Mahood**, BA, intergenerational volunteer program specialist.

The program has worked quite well. The first grant of \$25,000 paid for training students to work in a hospice home to provide support and companionship to residents. The next year, the program was expanded to include nursing home patients. Now, the students visit patients' homes.

More than 350 high school students have trained to become hospice volunteers, and the teenagers have won national awards and received praise from clients and their families. For example, the Hospice Teen Council at Palm Harbor (FL) University High School, which has about 80 teen hospice volunteers, was selected in October 1998 to receive a President's Service Award that is co-sponsored by Washington, DC-based Points of Light Foundation and the Corporation for National Service.

Also, 18-year-old volunteer **Brenda Corace** was the national teen-age recipient of the Volunteers Are the Foundation of Hospice Award, sponsored by the National Hospice Foundation in Washington, DC, which was awarded in Dallas in November 1998. Corace is president of the Hospice Teen Volunteer Organization at Palm Harbor University High School.

The Hospice of the Florida Suncoast's intergenerational program easily could be duplicated by other hospices that are willing to devote some resources for the project. Here are Mahood's and Labyak's tips for getting started:

- **Recruit dedicated teens.**

The students should be at least high school, at least freshmen and between the ages of 14 and 18.

The Hospice of the Florida Suncoast focuses its recruitment efforts at several area high schools with magnet programs. Magnet schools often attract an area's most talented and brightest students.

Here's how teens help

Teen volunteers for The Hospice of the Florida Suncoast in Largo, FL, assist in the following programs:

- Nursing home volunteers
- Hospice house
- Home team volunteers
- Teen mentors for children's program
- "Life, Camera, Action!" video project
- Computer support
- Clerical support
- Research assistance
- Collating and mailing assistance
- Reception
- Gift-wrap volunteers
- Trees of Love volunteers
- Golf and tennis tournament volunteers
- Fashion show volunteers
- Regatta volunteers
- Thrift shop sales assistance
- Thrift shop window display
- Thrift shop donation drives
- Hospice teen council
- Hospice teen speaker's bureau
- Intergenerational advisory committee ■

"Those magnet programs require 300 hours of service in the community," Mahood says. Plus, many of those students are interested in pursuing careers in medicine, so hospice work is a natural draw for them.

Besides Palm Harbor University High School, the hospice has worked with Boca Ciega (FL) High School, like Palm Harbor, has a medical magnet program.

The intergenerational volunteer program, however, is open to other area high school students, and volunteers have come from about every private and public high school in Pinellas County, Mahood adds.

Labyak says she was pleasantly surprised at how polite and mature the students have been. "It's been a wonderful program; it has grown far beyond any expectations I've had."

However, after a couple of years of recruiting high school students, it became clear to hospice officials that the hospice marketing materials needed to be made more appealing to youths. The hospice obtained more grant money to start an intergenerational marketing project.

"Rather than have our marketing department do some new marketing material, we wanted to involve young people," Mahood says. "We wanted to see how they would like to reach out to other young people to tell them about hospice."

Several senior adult volunteers met with the teens, and together they created a campaign called Hospice Teen Volunteers. The students designed a campaign logo of "HTV" that resembles the popular Music Television Video (MTV) logo.

The students worked with a graphic artist to design a brochure, and made an HTV video. Teens wrote the video script and scheduled people to appear on camera.

Teens were also trained to be speakers, and formed a Teen Speakers Bureau. Now, they speak to community youth groups.

"It creates an awareness of hospice, and it challenges kids to get involved in their community," Mahood says. "We've had a tremendous response from this campaign, and recruited 75 students since the implementation of the marketing grant."

• Provide meaningful training and work.

Students attend 24 hours of hospice training over an eight-week period. They go through the same application and screening process as adult volunteers. They must fulfill the following requirements:

1. Provide four references;
2. Take a tuberculosis test;
3. Complete all training requirements;
4. Accept a placement in an approved teen volunteer program. (See box, left, for complete list of programs in which teens participate.)

One advantage to having many students attending area magnet schools is that the hospice trainers can go to the schools and offer after-school training, Mahood says.

Students also may enroll in Saturday classes, or attend ongoing training classes at different sites throughout the county.

• Support their skills, ideas, contribution.

As the project evolved, the teens began to take on more and newer roles as volunteers. They even have applied for and received a grant from an agency that funds projects that are designed and implemented by youths. "They do their own budget and present the idea to a panel of judges," Mahood explains.

The teens, including Corace, received about \$650 to start the hospice's "Life, Camera, Action!" video program. Students visit hospice patients at the patients' request, bringing a video camera, tripod, and tape. Then, the students videotape the

patients, giving them a chance to review their life memories or to say farewell to loved ones, Mahood says. (See story on videotape program, below.)

The intergenerational program has taught the students about life and death, as well as helped

hospice patients and families.

“The wisdom of these young people is phenomenal; the outcome is, we’ll raise the next generation of adults who find these topics less taboo and less

(Continued on page 10)

Video project preserves patients’ life histories

Teens give families lasting memories

Teen volunteers for The Hospice of the Florida Suncoast in Largo, FL, decided to combine their collective high-tech skills with service by providing free videotaped memories to hospice patients.

The students obtained \$650 in local grant funding in January 1998, several months after they wrote a grant proposal and researched video camera prices, says **Brenda Corace**, an 18-year-old senior at Palm Harbor University High School in Palm Harbor, FL. “Hospice counselors trained us and gave sample questions to ask patients; they gave us advice on how to approach the patient.”

About 15 students, including Corace, have conducted taped interviews as part of their “Life, Camera, Action!” program.

Hospice counselors play an important role in offering the project to patients, and are present when teens do the interviews. They provide emotional support for both patients and the teens. Each time there’s a life review, there are two students with a camera and a counselor present. “The counselor is key, because the counselor knows that patient and the family,” says **Sandra Mahood**, BA, intergenerational volunteer program specialist.

The students also edit the videotapes according to the patient’s wishes. If patients begin to lose focus of what to say, the teens gently direct them, by asking “What is your favorite childhood memory?” or “How did you meet your spouse?”

The patient may share memories, a personal history, or leave an important legacy for children or grandchildren, Mahood says.

“One 39-year-old man, who is terminal and has a three-year-old son, said he wanted to do the video to leave it for his son,” Mahood says. “When the boy grows up, he’ll see what his dad

looked like, and hear his dad’s special messages.”

Students have done about 25 videos so far, and each story is different. Corace was impressed by a grandmother in her late 50s who was dying of cancer in a hospice residence home. The woman wanted the video for her grandchildren in Washington, DC, whom she had only met once.

The woman wanted to tell her grandchildren about her family history. She based her video around the theme of flowers, Corace says. “She said that as she moved from place to place, she remembered flowers every place she went.”

The hospice will expand the project by offering patients other types of life review options, Mahood says. The expanded project will be funded by a Florida Learn and Serve grant, which is sponsored by the Florida Commission on Community Service in Tallahassee.

“Some people don’t like to be on camera, so we’ll offer other ways to do it,” she says. “We’ll work toward a grant that provides audio tapes or a memory book, which is a photo album that students will put together with the patient, or a journal to give to the patient’s family and friends.”

Corace says the video program has been especially gratifying to the students because the work appears to mean so much to the hospice families. “We’ve gotten so much response from families after a patient has passed away, and they tell us how much it means to them.” ■

SOURCES

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difficult to talk about,” Labyak says.

“When they’re 50, 70, or 90 years old, they’ll see death much more differently than all of us, and maybe they’ll embrace the gift of their lives,” she adds.

Corace recalls how her first hospice project was to be a mentor to a 12-year-old boy who had a life-threatening disease and was waiting for a transplant. She and another teen volunteer befriended him, taking him fishing, to movies, and breakfast. They also helped him with homework.

“He was down in the dumps and was having peer pressure at school. His mother wanted us to be positive role models for him,” Corace recalls.

The boy eventually moved, and the students never saw him again, Corace adds. “Before he moved, he told us he wanted to know if there was a hospice where he was moving so he could volunteer and help people like we did.” ■

Group gives support to cancer survivors

Agency reinforces hospice concept

Hospital-based MedCentral Home Care/Hospice in Mansfield, OH, formed a cancer support group for people surviving with cancer — for a very personal reason.

Faith Proietti, MA, MDiv, chaplain, had a mastectomy in 1995. After the surgery and chemotherapy treatment, she looked around for a support group. The hospital didn’t have one, and its oncology nurses were too busy to start one. Proietti decided to start one as part of hospice work.

Emotional support and education

“One reason I started it and brought it under the hospice umbrella is [that] I realized a lot of people I befriended in my treatment had died,” Proietti says. “I thought if I could educate people

about their cancer, and if they weren’t going to make it, then at least I could make them more aware of hospice.”

In the nearly three years since Proietti started the group, it has succeeded both as an emotional support group for cancer survivors, and as a means to educate the dying about hospice.

Between 15 to 25 men and women attend the monthly meetings. Sometimes spouses, children, and other loved ones also attend. Since the meetings are held in the hospital chapel, members sometimes attend in wheelchairs with IVs attached.

The group introduces cancer survivors to hospice in a natural way. It’s brought up whenever a member dies or Proietti introduces herself to new members. And the word spreads to the members’ friends and acquaintances. For instance, Proietti says, a group member might mention hospice as an option to a friend in the oncology ward when it appears that the friend is running out of treatment options.

Often spouses of cancer survivors attend the hospice’s grief support group after their loved one dies. Members often call Proietti for advice or support because they know she is a hospice chaplain.

“I think their attitudes do change about hospice the more they hear about it,” Proietti says. “I want them to talk with other people who are terminally ill even if they are not.”

A focus on living, not dying

Each meeting has a theme. For the anger theme, Proietti had everyone bring pillows that they could punch. Another month might be about humor, in which everyone tells a funny story. At Christmas, the group holds a potluck party. The group also holds a fundraising auction each year to raise money to support members who need help or to buy flowers when members die.

The group features speakers four times a year, and one always involves death, dying, and hospice. Other speakers may include a dietitian, nurse practitioner, and an oncologist. Each speaker helps the cancer survivors learn a little

COMING IN FUTURE MONTHS

■ Focus on cultural diversity issues

■ A palliative care update

■ Compliance still is key word in 1999

■ Hospice stamp will soon roll out

■ What is the real role of spirituality in hospice?

SOURCE

Faith Proietti, MA, MDiv, Chaplain, MedCentral Home Care/Hospice, 335 Glessner Ave., Mansfield, OH 44903.
Telephone: (419) 526-8443.

bit more about their disease and treatment, enabling them to make better-informed decisions.

Although some members die, including 15 last year, the group focuses on how to live life fully. Members sang holiday carols in December for patients in the hospital's oncology ward. Members visit each other's homes if someone needs that kind of support, and keep in touch with each other between meetings. "We're an active group that tries to do more for the community and for each other," Proietti says.

Typically, a support group meeting begins with Proietti introducing herself to new members. Everyone sits in a circle. Then she holds a roll call where members talk for three minutes about themselves, their cancer, their families, or whatever they choose to discuss. They may choose not to speak as well.

These introductions usually open up discussions about how someone dealt with a particular treatment. The introductions also enable members to become more comfortable with the fact that they have the "Big C" word in their lives, Proietti says.

If it's a lecture meeting, the speaker talks for the first 40 minutes to an hour. Then Proietti asks the group if anyone has any questions or problems they'd like to share with the others.

This gives members an opportunity to express their fears and to ask for information that might help them make a decision about chemotherapy or surgery. "Then we have a group discussion as a result of that," she says.

'What do you want to do?'

Proietti recounts one meeting that typifies the synthesis between this support group for the surviving and its ties to hospice. One of the group's members, a woman in her 20s, called Proietti three days before a meeting. The woman had been attending for six months and was now dying and wanted Proietti's advice. Proietti visited her at her home that day, telling her, "You have to make a decision; what do you want to do?"

The young woman asked her about hospice, and Proietti recommended that she decide quickly. The woman permitted Proietti to call her

physician and ask for a referral.

A few days later, the woman came to the support group and made the announcement that she had joined hospice.

"Everyone looked at each other, and we realized as a group that she had come to say goodbye," Proietti recalls.

It stunned the other cancer survivors, and they didn't know what to say. Proietti asked each member, sitting in a circle, to thank their young companion and tell her what she has meant to them.

"Then I asked her to come into the middle of the circle, and we all gathered together and prayed that God would give her strength on her journey," Proietti says. "There wasn't a dry eye among us, but it was a moment of transition and pure spirituality and connection."

Proietti says she believes the group's outpouring of support and prayers gave the woman the strength she needed to go home. She died a week later.

"That's what we provide for each person who has come to the group: strength, courage, and whatever it takes to walk that journey," she says. ■

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Editorial Questions

For questions or comments, call **Park Morgan** at (404) 262-5460.

NEWS BRIEFS

Stamp delayed again

The U.S. Postal Service has postponed its release date for the hospice care postage stamp, which industry leaders hope will provide an unprecedented opportunity for raising public awareness about hospice care. The stamp, announced last fall at the National Hospice Organization (NHO) annual meeting in Atlanta, was set to be released on Nov. 5, 1998, and costs 32 cents.

However, since postal rates are increasing in January, the Postal Service now plans to delay issuance of the hospice stamp until after Jan. 10, 1999, when a one cent rate increase goes into effect. This would give the stamp a longer shelf life. NHO is continuing to coordinate plans to maximize public exposure for the stamp, which will be released at the offices of the Hospice of the Florida Suncoast, Largo, the world's largest community-based hospice. ▼

NIH grants available

The National Institutes of Health (NIH) in Bethesda, MD, have announced the availability of research grants in the clinical management of symptoms and syndromes associated with life-limiting illness, such as pain, dyspnea, delirium, cachexia, nausea, fatigue, and depression. Other priorities for this research initiative include studies on the combinations and interactions of these symptoms in specific populations, development of instruments sensitive to the distress associated with end-of-life symptoms, and ethical issues in end-of-life research.

The new program, "Management of Symptoms at the End of Life," is part of a U.S. Public Health Service-led effort called "Healthy People 2000," aimed at setting national health research priorities and encouraging integrative, multi-disciplinary research. Applications may be obtained from the Division of Extramural Research and Information Resources, NIH, 6701 Rockledge Drive, MSC 7910, Bethesda, MD 20892, (301) 435-0714, E-mail: ASKNIH@od.nih.gov. Request the program by name and number, PA-98-019. ■

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