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Hospices face a unique challenge in helping adolescents deal with grief

Programs pivotal in helping teens get back on track

A little more than a year ago, **Marilyn Hansmann's** then-16-year-old daughter was a typical teen-ager surrounded by the trappings of adolescence — school, friends, boys, and nurturing parents. Months later, she and her rural Minnesota family learned her 74-year-old father had pancreatic cancer, which had spread to his bladder and one remaining kidney.

The prognosis was grim. Unwilling to undergo chemotherapy treatment, radiation, or surgery, Hansmann's husband chose hospice. He was given just a few weeks to live but still remains in hospice care more than a year after his terminal diagnosis.

In the past year, the family has endured episodes where Marilyn's husband was near death, punctuated by periods of recovery, only to be followed by yet another decline.

Now 17, Hansmann's daughter struggles to cope with her father's terminal illness. The once outgoing teen-ager has grown distant, her grades have dropped precipitously, she frequently engages in verbal and emotional warfare with her mother, and she refuses to talk about her father's illness. There even have been threats of suicide.

"Dad's dying doesn't affect me," she told Marilyn and would-be counselors.

"It was as if something switched off in my daughter," Hansmann, 51, recalls. "She became distant. Or one minute she would be arguing with me, the next minute she would hang on me like she did when she was a little girl."

While there is no good time to lose a loved one, losing someone close to you during adolescence is perhaps the most difficult time in one's life to experience grief. Adolescence represents a crossroads where childhood and adulthood intersect. It is a distinctly different stage of life than preadolescence and adulthood. Teen-agers use this period to determine a

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direction in life, strive for independence, and build intimate relationships that provide them with a sense of belonging.

But it hasn't been until recently that grief experts have acknowledged how the dynamics of adolescence translates into a grief and bereavement process that is unique to those of younger children and adults. For years, grieving adolescents were counseled using a broad brush that placed them in the same category as children and older adolescents, and they were often treated like adults.

Caught in a funding pinch

The story of Hansmann's 17-year-old daughter underscores what is at stake and the importance for hospices to ensure their programs do not let the needs of teen-agers fall between the cracks. In some cases, hospices pinched by disappearing profit margins find children's bereavement programs expendable.

"Because it is so difficult to get teen-agers to attend bereavement programs, it's tempting to cut out children's bereavement programs," says **Mary Kelly Perschy, MS**, the author of *Helping Teens Work Through Grief*, and a bereavement consultant based in Laurel, MD.

According to the Hospice Foundation of America, based in Washington, DC, there is too much at stake for hospice to write off programs aimed at teen-agers. Because teen-agers are in a pivotal developmental stage, the introduction of a crisis, such as the death of a parent or sibling, threatens to stunt critical development tasks.

In short, teen-agers who have not properly dealt with their grief will manifest the effects during adulthood.

One of differences between children and adolescents is that adolescents have an abstract understanding of death, but unlike adults, they have not fully developed the coping skills needed to process the death of a loved one. This can result in the following:

- **Shock, disbelief, and denial:** Although a teen-ager can intellectually understand, the death of a parent — for example — can seem unreal. In order to function, a teen-ager may try to carry on normally as if nothing has happened. Teen-agers, in particular, may show little signs of grieving in the beginning.

- **Guilt:** Most people who grieve experience some level of guilt. Guilt takes on a new wrinkle with teens because arguing with parents and

rebellion are part of their development process, says **Jean McCaw, MA, ATR-BC**, child and adolescent grief coordinator for Point of Hope Grief Counseling in Falls Church, VA.

- **Anger:** Death can bring about feelings of abandonment, followed by feelings of anger. This can manifest itself in a bereaved teen-ager "acting out," says Perschy. The anger can translate into nonproductive and destructive behavior such as fighting, drug use, and sexual activity.

- **Unusual happenings:** It is not at all uncommon for a bereaved teen-ager to hear the voice of the deceased or feel as though they see that person passing by or in a crowd. These occurrences can be frightening unless there is someone around to let them know that this is a natural part of the grieving process.

- **Thoughts of suicide:** It is not uncommon for a teen-ager to have thoughts of suicide as a way of escaping pain or joining their loved one. It is important that these thoughts can be shared in a safe environment without the fear of judgment or panic from the person who is listening. Wanting to escape the pain is a normal response.

- **Sexual activity:** The need to be close to someone, both physically and emotionally, can be very strong at this time, and sexual activity also can serve as a distraction from pain.

- **Drugs/alcohol:** It is a natural response to want the pain to go away; unfortunately, some teens turn to drugs and alcohol to numb their pain. Bereaved teens are at high risk for involving themselves in self-destructive behavior. While these drugs may temporarily numb the pain, they very clearly prolong and complicate the grieving process.

"Kids who fare well are those who deal with their experience," says McCaw. "They have to talk about. If they don't deal with it as teen-agers, grief will resurface and become more complicated as adults."

Reaching reluctant teens

One of the greatest challenges is getting bereaved teens to participate in counseling. But if hospices structure their bereavement programs to reflect the unique nature of adolescent grief, the chances of reaching reluctant teens are increased.

So, what should bereavement programs include if they are to meet the needs of not only children and adults, but of adolescents, as well?

McCaw believes art therapy is a key component to drawing teens out where they can communicate

Eight myths about childhood grief

Helping children cope with the loss of a loved one can be difficult, but the process can be made problematic if approached with some common misconceptions. The Hospice Foundation of America identifies the following eight myths about children and loss:

1. Children do not grieve. While the child's age, development, and experiences affect the grieving process, children of all ages grieve.

2. The death of a loved one is the major loss children and adolescents experience. Young people experience a wide variety of losses. These include loss of pets, separations caused by divorce or relocations, loss of friends and relationships, as well as losses due to illness or death.

3. Children should be shielded from loss. It would be impossible to protect children from loss. Instead, adults can teach children ways of adapting to loss by including young people in the grieving process.

4. Children should not go to funerals; children should always attend funerals. It's important to allow young people to make their own choice. They should decide how they wish

to participate in funerals or other services. It is the role of adults to provide information, options, and support.

5. Children get over loss quickly. No one gets over a significant loss. Children, like adults, will learn to live with the loss. They may revisit that loss at different points in their lives and experience grief again.

6. Children are permanently scarred by loss. While a loss is a difficult thing to overcome, children are resilient. Given solid support and strong consistent care, children can cope with a significant loss.

7. Talking with children and adolescents is the most effective approach to dealing with loss. Different approaches are helpful to young people. It's important to talk openly with children and adolescents, but it is also helpful to let young people use creative approaches. Play, art, dance, music, and rituals are all valuable modes of expression that can allow them to say what words cannot.

8. Helping children and adolescents deal with loss is a family responsibility. Other people and organizations can share this responsibility. Hospice, schools, and faith communities can all offer necessary support. In times of significant loss, it's important to remember that the ability of family members to help one another can be limited. ■

openly about their feelings. "It's less threatening, and a lot can be told through artwork." (See related story on art therapy on p. 138.)

Aside from art therapy, there are some basic approaches to adolescents, according to McCaw:

- **Meet them where they are.** This is a lesson that is true for all ages. For teen-agers, hospice counselors need to be aware to the developmental dynamics at play and respect their wishes to talk or not talk.

- **Encourage them to grieve in their own way.** As part of the need for independence, they should be allowed to express grief individually, rather than they way others would expect them to. Hospice counselors also need to encourage parents to affirm their children's right to grieve differently.

- **Normalize their feelings.** In a time when they are trying to fit in or gain a sense of belonging, feelings of grief separate them from their peers.

Programs should reinforce that what they are feeling is a normal response to a crisis situation.

- **Acknowledge their right not to talk.** For counseling to be effective, the grieving teen needs to be a willing participant. If the teen-ager is unwilling to talk, he or she should be given permission not to have to talk, but ask the teen-ager why he or she doesn't want to talk or start a dialogue by discussing reasons for avoidance.

- **Use group counseling.** Group counseling allows grief-stricken teen-agers to see that they are not the only ones going through the same situation and that the feelings and emotions they are experiencing are normal.

Group counseling can help teen-agers:

- legitimize their feelings. Rather than feeling as if they are "going crazy," group discussion will show that they are normal feelings;

- see that they are not the only ones with those types of feelings;

- realize that someone else cares what they are going through;
- realize that their feelings do matter;
- see that there are ways to express their feelings in ways that can help them cope.

Experts point out that group counseling can be hard to implement because it is difficult for teen-agers to attend. Hospices should engage patients and their families in discussion and education about bereavement options, including adolescent group counseling to promote the program before the time comes to persuade teen-agers to participate.

- **Use family-based programs.** Often, the ability of a teen-ager to cope with the death of a loved one partly is dependent on parents or the surviving parent. Not only does the parent need to manage their own grief, but also they need to understand the behavior of their children. The hospice counselor needs to become a liaison between the parent and teen-ager and teach both sides how to communicate.

Partner with schools

The hallmark of a good bereavement program is its ability to marshal community resources to help those in need. The same holds true for

adolescent-specific programs. One community resource in particular should be considered mandatory for adolescent programs: schools.

Networking with school counselors allows hospices to build a relationship with local schools. The trust built over time allows both hospice and school officials to confidently rely on each other when a student is in crisis. Hospice counselors should encourage teens they are counseling to talk with their school counselor. “If they are having a particularly bad day, it’s good to have someone there they can talk to,” says McCaw.

Partnering with schools can also provide an opportunity to provide “death education” to students. By having an open dialogue with students about death, it can prepare them for coping with future loss.

Other community organizations, such as churches, synagogues, and youth groups can also be valuable resources.

In fact, the 17-year-old Hansmann finally agreed to meet with an outside counseling service. While Marilyn wants to know what her daughter and counselor have discussed, she recognizes her daughter’s right to privacy. “I figure if she wants to talk to me about it, she can,” the mother says. “I can see the ‘old’ her coming out. She isn’t as angry as she was.” ■

PBS series shines light on end-of-life issues

Hospices seek to capitalize on new awareness

It was clearly the single most dramatic public focus on issues of death and dying in recent memory. For four consecutive nights, from Sept. 10-13, Bill Moyers hosted a series on PBS, “On Our Own Terms,” which was seen by 19 million viewers.

Highlighted by unusually frank and open discussions, the series embarked on a four-part dialogue:

- **Program 1. Living with Dying:** the ways in which patients and caregivers are trying to overcome the American culture’s denial of death.

- **Program 2. A Different Kind of Care:** a report on the evolution of palliative care and its emphasis on patients’ psychological, emotional, and spiritual well-being.

- **Program 3. A Death of One’s Own:** an

exploration of the choices surrounding dying, including physician-assisted suicide, terminal sedation, the withdrawal of nutrients and hydration, and the implications for families, institutions, and communities.

- **Program 4. A Time to Change:** profiles of crusading individuals who offer palliative care to the working poor and the uninsured.

Building on the impact

Recognizing that public awareness would be raised dramatically by the series, hospice care professionals joined a nationwide mobilization of caregivers, public television, and nonprofit organizations to form local networks and coalitions to sponsor seminars and forums to build upon the impact of the series. “I would say over 250 communities have hosted [such] events,” reports **Rose Lynn Marra**, publicist for Public Affairs Television in New York City.

“There are a number of hospices that have sought to capitalize on the series,” notes **David M. McGrew**, MD, medical director of Hernando

Pasco Hospice in Hernando and Pasco counties, FL. "What many hospices did was to set up hot-lines and other opportunities for people to contact them. They networked together so that when the calls and inquiries came in, there was some way of dealing with them. Calls were referred as much as possible to local sources to address end-of-life care issues and answers. Beyond the series, people in many other venues seem to be bringing attention to end-of-life care."

Laying the foundation

An industrywide response, such as the one that accompanied the Moyers series, could not possibly have blossomed in full on Sept. 10 without months of planning.

"When Moyers conceived the idea of this series, we were wrapping up an earlier series on addiction and somehow the issue of end of life came up," recalls **Angela Thimis**, director of communications for The National Hospice and Palliative Care Organization (NHPCO) in Arlington, VA. "I understand that the funding awarded was not just for the series, but also to conduct outreach efforts around it. Before I came on board here there was a meeting in Miami that brought together leaders in hospice care and public TV, which pooled together interested parties that helped with the public relations aspect of the program. The Web site [<http://thirteen.org/onourown/terms/>] is a perfect example of that."

Thimis points out that the focus of the series was far broader than just hospice care. "One of the outgrowths of this aspect of the series was that somewhere between 200 and 400 end-of-life networks were formed, encompassing public TV, hospice programs, clergy, senior citizens, AARP [American Association of Retired Persons], and anyone else concerned with these issues," she notes.

The NHPCO became actively involved with PBS as a national outreach partner. "We attended meetings and encouraged our members to promote and support the series," Thimis notes. "We reported on it in our newsletter, and developed a 'tool kit' for members to help them when series aired. We wanted our members to identify the unique aspects that hospice programming can bring to addressing the challenges laid out in the series."

The NHPCO felt it was critically important to put materials in members' hands for the town meetings and seminars. Its sister organization,

the National Hospice Foundation (NHF), produced three brochures for this purpose:

- *Communicating Your End-of-Life Wishes*: how to converse with someone about what you need;
- *Hospice Care and the Medicare Hospice Benefit*: what hospice care is, and how it can be paid for through Medicare;
- *Hospice Care: A Consumer's Guide to Selecting a Hospice Program*.

"We felt this would be very valuable for consumers," says Thimis. "Once they learn the basics of what a hospice is, they need to know what other questions to ask, what things to look for in a hospice."

The brochures were distributed in August, both to End-of-Life Steering Committees, and on the NHPCO Web site, www.hospiceinfo.org.

The tool kits also included a series of recommended "talking points" for the local meetings. "Depending on the coalition and how active it was, some had series leading up to the Moyers program, as well as during and after," says Thimis. "They included seminars, town halls, and so forth."

After the program aired each night, the NHPCO "blast-faxed" messages of the day to its members and the media to reinforce the earlier messages. "We also wanted to make sure that a uniformly consistent message went out about hospice care," Thimis explains.

Taking it to the local level

The local coalitions also sought to get a head start on enhancing awareness, reports **Claire Tehan**, MA, vice president of TrinityCare Hospice in Los Angeles. "The first thing we did was really push our local public station this summer to pull interested people together in L.A. Without that push, they would just have run the series," she says. "Hospitals, community groups, other hospice providers, and a couple of nursing homes got in touch with each other to see what was going on. That gave us a good jumpstart; KCET [a local public television station] did not pick up that momentum. The providers did their own thing — which is not unusual."

TrinityCare Hospice held four community forums, one private forum — a board member invited a large group of people to his home — and one at a senior life care community. "A couple of good things came out of these forums," Tehan observes. "One community forum was held in Malibu, which is geographically isolated from L.A., and those who attended were very

interested in end-of-life care. We have scheduled a follow-up meeting for November to explore our options, since we serve that area. This is a very well-educated, well-organized group of people who want more for their community. As result of some of the other community forums, a number of local hospitals have picked up the interest and will be sponsoring some ongoing lectures.”

The community forums attracted a good mix of consumers and professionals. Tehan spoke with three interested consumers herself. “In all three cases, they were people who potentially needed hospice,” she recalls. “In one case I talked with a woman with particularly advanced amyotrophic lateral sclerosis. She and her husband were definitely in need of support and guidance, and received much help at the forum. They had been struggling alone.”

In almost all instances there were people at the forums who were or would be in need of hospice, Tehan notes. The forums also reminded her of just how difficult it is for most people to wrestle with the topic. “They resist looking it square in the eye,” Tehan says. “Many women in the house meeting said their husbands didn’t want to deal with it, didn’t want to come. The need to avoid it is very strong.”

But all of the people who attended the forums “came away with a lot of information, feeling better, and knowing where to go for help,” says Tehan.

Benefits are clear

Participants in this wide-ranging awareness effort are already reaping the benefits. “We have four different sites that serve Los Angeles County,” says Tehan, “and in the week that followed the series, our volunteer director says we received eight phone calls; that just doesn’t happen. The fact that eight people found their way here saying, ‘I want to get involved’ is very significant. I suspect other programs have had a similar response.”

McGrew admits he has not seen evidence that Moyer’s program has been effective, but he has little doubt that it will be — particularly in society at large. “Hopefully, hospices will indirectly benefit, but communities will *directly* benefit by having a greater understanding of the issues and become engaged with them. We have a death-denying society, so anything that will help people face it is a positive move.

“I know large numbers of people viewed the

series,” he continues. “I certainly hope that made a difference, but my only concern is we were preaching to the choir. We’ve got to get past the choir in order to get change.”

Despite the possibility that the program may not have reached those who need it most, the Moyers series was an incredible opportunity, says Thimis. For the first time people were given a center-stage forum to discuss a difficult topic. “They opened the door; it was a true launching pad for people to talk about hospice care, to start thinking and looking at it,” Thimis adds. “With people holding forums the night of the shows or a couple of nights later, we were able use them as an opportunity to educate.”

Follow-ups still are taking place, she says. The NHPCO continues to encourage its members to use the brochures produced in conjunction with the program and hold seminars. The NHPCO recently presented the Hospice Month Quilt at the White House, and used the event to promote October as a community education month among its members.

The NHF Web site has become very popular since the series; there have been more than 3,500 hits since Sept. 11. Thimis reports that almost 600 downloads of the consumer guide, 500 of the Medicare hospice benefit brochure, and about 500 of the communicating brochure. The education effort spurred on by the Moyers program is just the beginning of an ongoing effort, Thimis says. “This isn’t just a one-shot deal,” she asserts. “We have to use every opportunity and every forum to go out there and educate people.” ■

Art therapy: Healing for all generations

Opportunities for creativity are limitless

In some hospice settings, it might mean children playing with clay or with finger paint. In others, it could mean adults creating quilt squares symbolizing lifetime achievements — or just playing in the dirt. But whatever age group is being served, hospice professionals agree that art therapy presents a powerful opportunity for healing.

It is perhaps its universality that makes art therapy so effective. It represents such a broad range of activities and therapies that hospice professionals have a hard time agreeing on a single definition.

“Art therapy can, for example, include guided visualizations,” says **Sherry Showalter**, MSW, LCSW, an acute-care worker at the Halquist Memorial Hospice Center in Arlington, VA, part of the Hospice of Northern Virginia, headquartered in Arlington. “It’s like reading a story book to a kid — they look at pictures while you read to them. Adults also create while you give them words, which can help them let go of the boundaries of their thoughts.”

But Showalter, a bereavement coordinator for five years at the VNA Community Hospice, now a part of the Hospice of Northern Virginia, adds that art therapy can include “anything where you work with your hands — coloring; digging a hole in the earth and screaming your emotion into that hole; planting a tree so that something grows from it; dance or movement. The AIDS quilt is a perfect example of art therapy.”

Robin McMahon, LCSW, BCD, the director of grief and loss services at Hospice of Northern Virginia, employs a variety of materials for drawing, such as chalk, pencil, crayon markers, and paint, as well as clay in the hospice’s “Healing Art Program,” which targets children ages 5-18. However, she also considers the “healing circles” employed at the hospice’s weekend camps to be art therapy.

For **Barbara Trauger Query**, an art therapist at Cleveland’s Hospice of the Western Reserve, it’s not *what* you do, but *why* you do it that defines an activity as art therapy. “There’s a difference between art making and art therapy,” she asserts. “A lot has to do with the underlying intent, and with the environment in which it occurs. Art therapy requires a safe, nonjudgmental environment that supports the art *and* the person in a way they might not find if they were just doing crafts. In such an environment, *all* art activities have a healing potential.”

Transcending generations

Art therapy can be as effective with adults as it can be with children, but only if adults are encouraged to think like children, asserts Showalter. While her focus at VNA Community Hospice was clearly on children, Showalter spent a good deal of time in 1999 working with adults.

“Children are much more honest in their feelings,” she explains. “Kids grieve a little bit, then play a little bit. As adults, we’ve been taught ‘better,’ but we could learn from children how to be honest about what we feel.”

“I tend to believe that we often have to look at everything as a whole, so while we are adults we are also children,” adds Showalter. “If we can touch that inner part of ourselves that plays in the mud and remembers when we were not so civilized as children, we can touch the real core of our grief and impending death issues.”

“Often during times of trauma, stress, and grief, our hearts and heads get conflicting messages. Rationality says one thing, but it doesn’t make sense emotionally,” she continues. “But if adults who are newly diagnosed are given crayons and paper or finger painting and allowed the opportunity to be less ‘civilized,’ they will be able to work directly from the heart and not let their heads get too involved,” says Showalter.

She experienced this process on a large scale when she had a group of adults create a “remembrance quilt.” The quilt was made of 13-inch squares, each of which contained one person’s life memories. “The participants had to be very particular, and they would make some of the most elaborate and simplistic things you’ve ever seen,” she says. “The results would send a very cathartic, very healing message; people would send me letters about how it made them feel.”

Working through their grief

Again and again, Showalter emphasizes the variety of avenues available. “Men would talk about the power of sanding, of polishing wood to a bright sheen,” she observes. “You can work your grief tremendously through this energy.”

Even adults as old as 80 or 90 benefited from expressing themselves through painting, says Showalter. “It’s amazing how people can tap that part of themselves they did not know was there; they are vulnerable and in a hurting place, and painting allows that to come out. It helps them to recognize that they are forever changed, and that the threat of loss or grief has made them different. Art allows them to speak to the wholeness of themselves; it’s *that* powerful.”

Trauger Query works exclusively with adults in a more traditional framework. “I’d have to say that we have stayed fairly consistent with spontaneous art [the program is seven years old],” she says. “By that, I mean we’re not doing a lot in the way of directed therapy, asking people to draw this or that.”

In this, says Trauger Query, “We reflect the teachings of [Elizabeth] Kubler-Ross. I truly believe that the heart does not stray far from

that which hurts it the most. People can just be putting colors down, or choosing pictures for a collage; left to their own devices, they will bump up against those things that hurt them most. The art really has to come out of their need.”

Healing power of art

In hospice, she asserts, the staff work with people who are *healthy*. “The person who is dying is still potentially healthy, both psychically and emotionally,” she says. “No one comes in and asks for psychological intervention; they come for the healing power of the art. They still have opportunities to express themselves and to heal.”

At Hospice of the Western Reserve, any team member can refer a patient to expressive therapy; music and art therapy coexist under a single umbrella. “When the referral comes in, we determine what the needs are,” says Trauger Querry. “When the program began, even staff people had the impression you had to be good at art to participate, but very quickly they learned that art therapy works so well we were getting the more difficult cases. We would go in when people were threatening suicide, or had bad family dynamics.”

Often, issues will show up in art therapy that hadn’t been apparent before, says Trauger Querry. “There was one fellow who came in only once, and he would only choose the color green [the hospice had 10 to 12 different shades],” she recalls. “He could only squeeze his right thumb and forefinger, so he would indicate an area of the paper and we would drop the paint on it. I asked him what the green reminded him of. He said, ‘Money,’ but I replied, ‘That’s only paper; what does it *really* mean to you?’ Finally, he said money meant he could buy a car so he could leave the hospice and go where he wanted to go. He was struggling with being confined to a wheelchair. He never came back, but the session alerted the team to a critical issue.”

The Hospice of Northern Virginia has always focused on children, says McMahon. “Initially, we offered the program to children of hospice patients or those who were part of hospice families — while the patient was still alive, and up to 13 months after the death.” The Hospice of Northern Virginia provides individual art therapy sessions with certified art therapists. “The children use a variety of art materials to express some of the emotions they may not be able to verbalize, or to give them a vehicle for verbalizing,” McMahon explains.

The hospice also offers weekend camps and

day camps for grieving children after a death. These are open to the entire community; again, the primary vehicle for expressing emotions is art. “Art is used to memorialize the person, to enable the children to express their feelings, and to have somewhat of a catharsis,” McMahon observes.

These camp sessions also include healing circles, which give the children the opportunity to talk about their feelings. The camp sessions include up to 20 children, each one having a “big buddy” who spends the weekend with them. In addition, art therapists work with the children on individual art projects. “They are encouraged to share their art with the group, but they don’t have to,” says McMahon.

McMahon sees tremendous benefits for the children who participate in the program. “It gives them a vehicle for talking about their feelings, and for being able to describe them a little better through art,” she explains. “It lessens anxiety. A lot of what we do is helping them to normalize the grief, to understand that they’re not doing anything wrong, and that their emotions are really appropriate.”

All in the family

Hospice of Northern Virginia has some exciting plans for the future. “Our basic structure has remained the same,” says McMahon, “but now we’re expanding to more of a family model. In one camp in particular, we have noticed that when parents drop off and pick up their kids, or when we deal with a caregiver facing his own loss, they also have tremendous needs.”

McMahon’s goal is to design a variety of programs to meet the needs of the adults, as well. “Not only can we help bereaved parents, but the children will also heal more completely if the person taking care of them can deal with their own grief,” she says.

Some changes already are on the calendar. For example, in November, the hospice usually sponsors a “Coping with the Holidays” workshop for children and adolescents. “This year’s workshop will be intergenerational, including art therapy,” notes McMahon. In addition, the hospice will be shifting from children’s camps to family camps next summer. “The activities will be somewhat the same, but there will probably be a greater emphasis on verbalizing,” she says. “We see that as a really positive modality for adults, as well.”

Whether they work with children or adults,

hospice professionals agree that art therapy can be extremely efficacious. “That’s because we work with issues of importance to the individual,” Trauger Querry explains. “Art can be the complete therapy in itself, or in other cases, it can be the springboard to verbalization of what’s going on. You can really make some progress, reduce anxiety, and help patients find peacefulness they had not had before. I really believe that people get to where they need to be before they die; they get in touch with the divine.”

“I’m constantly amazed at the resiliency of the human spirit,” says Showalter. “If you can be taught to look at things through different eyes, then you have different options. Art allows people to speak to the wholeness of themselves — to their spiritual side. Suddenly, you’re able to say, ‘I miss this person so much.’ You can also help ease your own journey through drawing, and through other things that are notoriously used with children.”

Art therapy *can* be used successfully with

adults, she re-emphasizes. “If given the opportunity, adults can be pretty open to what you give them if they think it will help them heal, and if it will give them a different lens through which to feel their pain.”

At its core, what art therapy does is help people live with the differences that now exist in their lives, says Showalter. “Who you are now is not who you’ve been, and you can’t go back there,” she says. “But after going through art therapy, people will look at me as if they’ve just discovered gold. They *get* it, and that’s the way they want think about it. When you are threatened with loss, you see through the eyes of a mouse; when you become more empowered, you look through the eyes of an eagle, and you see there is a way you can heal.

“Once you can begin to heal the spirit, and line up what the eyes see and what the heart feels, you’re on your way. People *will* walk in beauty again — they just need to do it in *their* time.” ■

News From the End of Life

Overprescribing of pain meds still a concern

Fear of being investigated for overprescribing pain medication is taking its toll in Oregon, where a recent poll showed many dying patients spent their last weeks in moderate to severe pain.

In October, a study by Oregon Health Sciences University’s Center for Ethics in Health Care was presented at a statewide conference on end-of-life care. Researchers interviewed 103 families in 1998 whose loved ones had died in the state’s hospitals. The study was prompted by a 1997 study that showed a rise in the number of families who reported that their hospitalized family members spent the last week of their life in “moderate to severe pain.”

What it showed

The latest study showed:

- Although 89% of families rated the medical staff’s attention to patient comfort, including pain medication, as “good” or “excellent,” 54% said

their family members spent the last week of life in “moderate to severe” pain.

- In follow-up interviews with 411 doctors and nurses, researchers found that 96% said “families’ expectations of good pain management are higher than in the past.”

- Sixty-six percent of doctors and nurse said “doctors are prescribing less pain medication.”

- Fifty-nine percent said “nurses are administering less pain medication.”

Most physicians explained that fear of state or federal investigation was a strong reason for limiting pain medication, with fear of media attention and fear of a colleague suspecting assisted suicide listed as lesser concerns, study leader **Susan Hickman, PhD**, says. ▼

Maine considers law on assisted suicide

To kill or not to kill, that was the question before Maine voters during the November elections. At the time of publication, Maine voters appeared poised to legalize physician-assisted suicide.

Called the Maine Death with Dignity Act, the proposal would allow adults of sound mind facing

death from a terminal illness to seek a doctor's help in getting drugs with which to take their own life.

The measure is modeled after the Oregon law, which has been in effect for three years.

Supporters call the proposal a practical law that gives patients the right to meet death on their own terms, while opponents decry it as something that would undermine the practice of medicine and lead to euthanasia.

Voters' support

Polls taken prior to election day show support among voters.

"I think it . . . reinforces the power of the individual to determine their choices around end-of-life care," says **Elizabeth Weiss**, MD, a Bangor internal medicine specialist and supporter of the referendum measure.

For **Laurel Coleman**, MD, an Augusta internist and an opponent of the act, "it's asking physicians to participate in suicides, actively helping people kill themselves. That changes the roles of physicians and could cause some patients not to trust doctors," Coleman says.

Among other provisions, the bill would:

- require two physicians to confirm the diagnosis and prognosis;
- require a second opinion from a specialist in the patient's disease;
- require consultation with a specialist in palliative or comfort care, to ensure the patient is receiving appropriate pain relief;
- prohibit sanctions against health care providers who decline to help a patient get a life-ending prescription;
- prohibit euthanasia or mercy killing;
- require the patient to make three requests for medication, two verbally and one in writing;
- require two waiting periods, one of 15 days, the second of 48 hours.

Opponents include most of the state's major medical organizations, including the Maine Medical Association, Maine Hospice Council, the Maine Hospital Association, and the Portland Diocese of the Roman Catholic Church. Together,

they are allied under the name Maine Citizens Against the Dangers of Physician-Assisted Suicide. ▼

Spirituality ranks high in patients' quality of life

According to a survey of hospice patients, spiritual well-being ranked as a significant part of their quality of life.

The longitudinal study of home care hospice patients sought to quantify the relationship between spirituality and health in a scientific way that would be meaningful to physicians and other health care professionals. The results of the study were published in a recent issue of the *Hospice Journal*.¹

On a scale of 1 to 4, patients' spiritual well-being average score was 2.6, which was behind social well-being (3.3); above physical well-being (2.2); and above overall quality of life (2.4). From the sample, however, no conclusions could be reached concerning the effects of spiritual care interventions over time. Instead, the study provides a snapshot of hospice patients' spiritual well-being in the context of overall quality of life.

Economic sense

To test the hypothesis that "spiritual well-being is a major component of hospice patients' overall feeling of well-being," the researcher hand-delivered questionnaires to home care hospice patients admitted over a four-month period. The questionnaire was also given to the patient at intervals of one month, three months, and six months after admission to hospice. Of 73 patients, 16 (22%) returned 23 questionnaires: 10 returned one, five returned two; and one returned three.

Also, the author notes that pastoral care may be a direct cost to the hospice but not to the insurer. Therefore, if further study shows that an increased sense of well-being translates into

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reduced requirements for other more expensive — and billable — services, providing pastoral care may make good business sense for the hospice.

Reference

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Physicians confused by terminal illness

Physicians agree that pain control, patient and family comfort, and quality of life are the most important aspects of palliative care and could reduce costs while improving quality and continuity of care. They expressed concern, however, that under managed care, expensive medications that could help bring about the desired improvements may not be allowed.

These attitudes were garnered from small focus groups of community hospital physicians where end-of-life issues and palliative care were the topic of discussion.¹ Palliative care, which is offered to patients whose disease is no longer responsive to curative treatment, has as its goal to improve their quality of life, including helping patients control pain and providing psychological, social, and spiritual support for them and their families. Because physicians are the most involved of health professionals in palliative care, researchers believed their viewpoints on how it can be made more effective are especially important.

What was found

Researchers conducted four focus groups of 23 physicians (generalists and specialists) at a community hospital. A professional facilitator used a written guide to cover major issues of palliative care, including current providers' behaviors, perceived needs, and suggestions for improvement in providing palliative care. The transcripts of the proceedings were analyzed to determine primary themes and then were coded and analyzed for patterns and variations in beliefs. Among their findings were:

- **Physicians agreed that informing patients**

of their terminal illness is the first step toward implementing palliative care. But physicians expressed confusion on the legal definition of terminally ill, and they differed in their opinions on which type of physician (hospital-based specialist or office-based generalist) was best suited to inform the patient; what style of communication (direct and blunt or overly optimistic) was best; and how much to involve family members.

- **The physicians saw benefits to having a specialized palliative care unit or designated team that would coordinate hospital and home care, with a focus on keeping the patient at home as much as possible with complete pain control.**

- **Many of the physicians expressed discomfort dealing with the legal and ethical issues of terminally ill patients, including advance directives.**

“Physicians perceived legal issues in palliative care as having many ambiguities and gray areas.”

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the researchers wrote. "Lack of clear guidelines on palliative care can expose both patients and physicians to unnecessary pain and suffering."

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HCFA offers reassurance on hospice certification

Don't fear long-living patients

The Health Care Financing Administration (HCFA) is putting out the word that hospice physicians won't automatically be in trouble if their elderly patients outlive their doctor-certified eligibility for Medicare's hospice benefits.

According to the law, a Medicare beneficiary becomes eligible for hospice benefits when the person chooses palliative or other care from a hospice, and when a physician and a hospice medical director certify that the patient has a medical prognosis of six or fewer months to live.

Recertification needed

Some physicians have been audited for not properly diagnosing patients then inappropriately enrolling them in a hospice. "Nevertheless, that is very different from situations in which a terminally ill patient has had the good fortune to live longer than predicted by a well-intentioned physician," notes a HCFA official.

Under HCFA rules, hospice patients can continue to receive Medicare benefits after six months as long as a physician "properly and conscientiously" recertifies the end-of-life prognosis. About 10% of Medicare patients receive hospice benefits longer than six months, according to HCFA.

To minimize future confusion over this six-month requirement, HCFA plans to develop a voluntary program in which physicians and hospice directors can turn to Medicare contractors for advice on a patient's hospice eligibility. This, in effect, would be akin to getting preauthorization to enroll that senior in a hospice program. ■

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