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Report card gives states low grades in providing end-of-life care

State-by-state analysis points to limited hospice use and low LOS

A state-by-state report card on hospice services shows most states are doing a poor job of caring for the dying. According to the report, patients are spending less time in hospice care than they did in the early 1980s when the movement first started in the United States.

The report, by the Last Acts organization in Washington, DC, found that states are doing little to encourage terminally ill patients to seek hospice care, or to do so earlier in their illness to take the greatest advantage of hospice benefits.

In the report, states were graded on key elements of end-of-life care. This included: advance directive policies, the number of people who die at home, hospice use, hospital end-of-life services, nursing home care, pain management policies, and the number of providers trained in palliative care.

Overall, most states earned C's and D's, with few states scoring high marks in any of the categories. More states earned the lowest grade, an E, than those that earned higher marks.

"As this report points out, although we have begun making progress on many fronts, today we find ourselves at a crossroads," says **Steven Schroeder**, MD, president of The Robert Wood Johnson Foundation in Princeton, NJ. "We need the dedicated support of policy-makers and health care leaders to put us on the path to establishing end-of-life care once and for all as an integral part of American medicine."

Here is a synopsis of the report's findings in key areas:

- **State advance directive policies:** Some states' laws include confusing language or create bureaucratic hurdles that make it difficult for citizens to express their preferences or to designate appropriate surrogate decision-makers.

- **Location of death:** Although research shows that 70% of Americans

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would prefer to be at home with loved ones in their final days, only about 25% die at home. Where people die — in a hospital, a nursing home, hospice, or at home — depends on the state or community where they live and the health care resources available there. Research has shown that these factors outweigh patient preferences as influences.

- **Rate of hospice use:** Hospice care is a "gold standard" for end-of-life care. However, hospice is not widely used in most states. Furthermore, the average length of stay in hospice has dropped to well below the 60 days considered necessary for people to get maximum benefit. In fact, dying patients commonly have the support of hospice care for less than a week. (See chart, p. 3.)

- **Hospital end-of-life care services:** Though the number of organized palliative care programs in hospitals is increasing, such programs are not yet the norm. Nor do a sufficient number

of hospitals offer pain management programs and hospice services.

- **Care in intensive care units (ICUs) at the end of life:** Nationwide, 28% of Medicare patients who die are treated in ICUs in their last six months of life. This rate varies widely, even within individual states. Patients in ICUs typically are subjected to heavy use of technology. This may be at the expense of attention to comfort or against expressed treatment preferences — often expressed as "I don't want to die hooked up to machines."

- **Persistent pain among nursing home residents:** Nearly half of the 1.6 million Americans living in nursing homes have persistent pain that is not noticed and not adequately treated.

- **State pain management policies:** All states have laws addressing the use of controlled substances. Some are effective, but others create formidable barriers to good pain management.

- **Numbers of physicians and nurses certified in palliative care:** Palliative care training for the nation's physicians and nurses lags far behind the needs of the aging U.S. population. This is true for medical and nursing students, as well as for the hundreds of thousands of professionals already in practice.

"Dying patients and their families today suffer more than they should," says **Judith R. Peres**, deputy director of Last Acts and leader of the report's research team. "We still have a long way to go to improve health care and policy for this segment of the American population."

The National Hospice and Palliative Care Organization (NHPCO) in Alexandria, VA, agreed with some of the findings of the national study and cited late use of hospice as a significant impediment to end-of-life care. "There's a lack of information about what hospice offers and how it's paid for," said NHPCO president **Don Schumacher**, "and we're hoping that this state ranking will prompt individuals to discuss end-of-life options with their physician and family so they can make informed decisions when the time comes."

A member of the contributing panel, Schumacher says the rankings reflect the use of end-of-life care more than the quality of it.

"There is no doubt that earlier and more widespread use of hospice and palliative care would benefit patient and family," says Schumacher. "The heartbreaking truth is that this high-quality, optimal end-of-life care is available in most parts of America, but it's not

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Editorial Questions

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People Over 65 Who Used Hospice in the Last Year of Life, by State, 2002

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Source: "Means to a Better End: A Report on Dying in America Today." Last Acts, Washington, DC.

being used until patients are at death's door. Hospice was never designed to be brink-of-death care, and it shouldn't be.

"We want to see more people use hospice and we're always striving for greater awareness, but our frustration with late referrals shouldn't overshadow our gains in serving the terminally ill. Hospice programs are serving diverse populations

and caring for more types of illnesses than ever before, notably Alzheimer's and heart failure. There's much work to be done, but we've come a long, long way."

(Editor's note: To see a complete copy of the report, go to www.lastacts.org and click on "Means to a Better End: A Report on Dying in America.") ■

How some states fared: Lousy to above average

Most don't meet organization's overall standards

Even states that ranked high in hospice use earned low grades overall on a national report card prepared by the Last Acts organization in Washington, DC.

Arizona, for example, scored the highest in hospice use, but did not meet Last Acts' overall standards. The state scored well in providing palliative care and having trained personnel in palliative care. The state's policies regarding advance directives were also found to be strong. On the downside, many Arizona hospitals do not have palliative care or hospice programs, and the state's nursing homes do only a fair job of managing persistent pain among the dying. According to the report, Arizona's findings indicate that the state needs to do more to prepare for the needs of the frail elderly and the dying, both now and in the future, when the number of Americans over the age of 65 will be rapidly increasing.

Here is how the state scored on each of the report's criteria:

- **Hospice use** — With 42% of residents over 65 who died in Arizona using hospice care in the last year of their lives, Arizona topped all other states in this measure. Nevertheless, this earned the state a B grade, because even this high number falls short of Last Acts' expectations for hospice use. In an evaluation of the number of days spent in hospice, Arizona earned a D grade. The median length of stay in hospice in Arizona was close to 28 days, which is well below the 60 days considered necessary for maximum benefit from hospice. (See chart, at right.)

- **Palliative care-certified physicians and nurses** — The state received B grades for the number of physicians and nurses trained to provide palliative care, suggesting that Arizona's health care work force is preparing better than those of other states for current and future needs of the frail elderly and dying, the report says.

- **State advance directive policies** — Arizona's policies earned a B grade. This means they support good advance care planning in the form of living wills and medical powers of attorney, which designate a health care decision-maker should the patient become unable to communicate.

Median Number of Days in Hospice, by State, 2001

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Source: "Means to a Better End: A Report on Dying in America Today." Last Acts, Washington, DC.

- **Pain among nursing home residents** — Nursing homes in Arizona do a poor job of managing patients' pain, earning a D grade from Last Acts. Forty-seven percent of nursing home residents were found to be in persistent pain. Experts agree that 90% to 95% of pain can be successfully managed.

- **Hospital end-of-life care services** — Arizona's hospitals offer average to poor end-of-life care services. Forty-six percent of hospitals reported offering pain management programs, rating a C grade. However, far fewer hospitals said

they offer hospice or palliative care programs.

- **Location of death** — Only 26% of Arizona residents die at home, although most Americans say they prefer to die at home in comfortable surroundings with their loved ones. The state earned a D grade in this category.

How New Mexico fared

New Mexico is among a group of states that scored better than most in hospice use, but earned scattered marks. On one hand, the state's policies regarding advance directives were rated highly. New Mexico also had a high percentage of physicians and nurses who are trained to provide palliative care. On the other hand, many New Mexico hospitals do not offer hospice or palliative care programs. The state's nursing homes also do a poor job of managing the pain of the dying. These and other findings indicate that the state needs to do more to prepare for the needs of the frail elderly and dying.

Key findings on the status of end-of-life care in New Mexico include:

- **State advance directive policies** — New Mexico's state advance directive policies earned an A grade, because they support good advance care planning in the form of living wills and medical powers of attorney.

- **Palliative care-certified physicians and nurses** — The state received the highest grade of A for the percentage of physicians trained to provide palliative care, and a B grade for the percentage of nurses trained in the same field. This suggests that the health care work force is doing a good job in preparing for current and future needs of the frail elderly and dying.

- **Hospital end-of-life care services** — A majority of hospitals in New Mexico do not offer hospice and palliative care services. The state earned the lowest possible grade — an E — for the small percentage of hospitals reporting hospice programs (20%) and the small percentage of hospitals reporting palliative care programs (15%). New Mexico also earned a D grade from Last Acts for its 24% of hospitals self-reporting pain management programs.

- **Pain among nursing home residents** — Nursing homes in New Mexico do a poor job of managing patients' pain, earning a D grade from Last Acts. Forty-five percent of nursing home residents indicated that they are in persistent pain.

- **Hospice use** — Even though hospice is the

most commonly available form of palliative care, only 30 percent of people over age 65 who died in New Mexico used hospice in the last year of life. Moreover, the average length of hospice care in the state was 35 days, which is less than the 60 days considered necessary for the maximum benefit from the program.

- **Location of death** — New Mexico earned a C in this category because a majority of the state's residents do not die at home, although most Americans say they prefer to be at home in comfortable surroundings with their loved ones.

While no state scored an A for hospice use, three states — Rhode Island, Maine, and Alaska — were singled out as failures in making hospice available to its residents. All were given the lowest grade, an E.

In Rhode Island, state policies encourage good pain management for the terminally ill, but the state fared poorly in a number of measures of hospice use. Hospice use is low, and few residents die at home, the report notes. Few hospitals in the state offer hospice or palliative care programs. The state also has very few physicians trained to provide palliative care. These and other findings indicate that the state is not well-prepared to provide for the needs of the frail elderly and dying.

Key findings on the status of end-of-life care in Rhode Island include:

- **State pain policies** — Rhode Island state policies regarding pain management earned a B grade from Last Acts, because they allow physicians to treat pain at the end of life without undue scrutiny.

- **Hospice use** — Hospice care is not widely used in Rhode Island. Even though hospice is the most commonly available form of palliative care nationwide, only 18% of people over age 65 who died in Rhode Island used hospice in the last year of life. Moreover, the median length of hospice care in the state was 14 days, well below the 60 days considered necessary for the maximum benefit from the program.

- **Hospital end-of-life care services** — Very few hospitals in the state (6%) report offering hospice or palliative care programs, earning the lowest possible grade — an E — from Last Acts.

- **Location of death** — Only one-fifth of state residents die at home. The state earned a D grade from Last Acts on this measure.

- **Palliative care-certified physicians and nurses** — The state's health care work force needs to be better prepared to meet the current

and future needs of the aging and dying. The number of registered nurses trained in palliative care earned the state a C grade. However, the number of physicians with such training earned Rhode Island a grade of E.

Maine is another state that seemed to score poorly in most aspects of end-of-life care, including hospice use. Maine's policies regarding advance directives were strong, and the state's policies allow physicians to treat pain at the end of life without undue scrutiny. Compared to other states, Maine has a high percentage of physicians who are trained in palliative care.

On the downside, the rate of hospice use in Maine is very low, and most hospitals do not have hospice or palliative care programs. A majority of the state's deaths do not occur at home, and nursing homes in the state do only an average job of managing the pain of residents. These and other findings indicate that the state needs to do more to prepare for the needs of the frail elderly and dying.

Key findings on the status of end-of-life care in Maine include:

- **State advance directive policies** — Maine's advance directive policies earned an A grade because they support good advance care planning in the form of living wills and medical powers of attorney, designating a health care decision-maker should the patient become unable to communicate.

- **Palliative care-certified physicians and nurses** — The state received an A grade for the percentage of physicians trained in palliative care, and a grade of B for the percentage of nurses trained in the same field. This suggests that the state's health care work force is doing a good job in preparing for current and future needs of the frail elderly and dying.

- **Hospital end-of-life care services** — Hospitals in Maine offer low levels of hospice and palliative care services. The state earned the lowest possible grade — an E — for the small percentage of hospitals (18%) reporting hospice programs and the low percentage of hospitals (15%) reporting palliative care programs. Such programs are considered the "gold standard" of end-of-life care. Maine earned an average C grade for the 45% of hospitals reporting pain management programs.

- **Hospice use** — Hospice care is not widely used in Maine. The state earned an E grade on this measure because only 9% of people over age 65 who died in the state used hospice in the last

year of life. Moreover, the median length of stay in hospice care in the state was 27 days, which is less than the 60 days considered necessary for the maximum benefit from the program.

- **State pain policies** — Maine's policies regarding pain management earned a B grade from Last Acts, because they allow physicians to treat pain at the end of life without undue scrutiny.

- **Care in intensive care units at the end of life** — Maine received a B grade from the Last Acts report for the relatively small percentage of elderly residents (7%) who spent a week or more in intensive care units during the last six months of life. This suggests that health care providers in the state do not provide overly aggressive care that does not take the patient's treatment wishes into consideration.

- **Location of death** — A majority of Maine residents do not die at home, earning the state a D grade in this category. ■

Lack of pediatric care makes bad situation worse

An adult model is inadequate for kids

When Katie Westbrook was 14 years old, she and her mother, **Beth Westbrook**, made a monumental decision together. Katie, who had been battling osteosarcoma since she was 12, had already endured several rounds of chemotherapy, surgery to remove a tumor in her lower back, a leg amputation, and an inoperable tumor in her neck. She decided she was ready for hospice.

Yet, as her mother called hospices near their home in Pittsburgh, she was suddenly faced with the cold reality that there weren't any programs set up to handle children.

Only adult hospice programs existed, and some wouldn't take the dying teenager because they weren't equipped to handle her or her mother's special needs. For example, none of the adult programs offered respite care for the caregiver, an element of most pediatric hospice programs.

There is no question that American culture goes out of its way to deny the existence of death, but nowhere is this more evident than in the way we treat dying children.

"We're in denial," says **Ann Armstrong-Dailey**, president of Children's Hospice International, an Alexandria, VA-based advocate for pediatric hospice. "Children aren't supposed to die. So we ignore the fact that they do. When children get sick, we expect a cure."

In the United States alone, from 75,000 to 100,000 children die each year, and an additional 1 million are seriously ill with progressive medical conditions. Despite these numbers, too little is known about treating the dying child outside the major children's medical centers, and very few end-of-life programs target children's special needs.

According to the Washington, DC-based Institute of Medicine (IOM), children's end-of-life needs aren't being met. Last July, the IOM released a 400-page report that detailed what's wrong with pediatric end-of-life care and made recommendations to improve care for dying children and their families. The report concluded that pediatric palliative care is either missing or woefully substandard because of poor training among health care providers, conflicting parental goals, cultural barriers, and insurance regulations.

Westbrook's story is one example of what happens to scores of children and their parents in countless communities across the country that do not have pediatric hospice programs or that try to care for terminally ill children using the adult hospice model.

According to Armstrong-Dailey, access to pediatric hospice programs needs to be increased. That means hospices, regarded as the gold standard in palliative care, must apply their expertise to providing services that go beyond the Medicare model, which is designed specifically for older adults.

Under today's reimbursement rules, pediatric hospice programs are more than likely non-reimbursable, because parents must be willing to give up aggressive treatment in favor of palliative care. In most cases, the only way a hospice can provide pediatric palliative care is if it is provided for free while the child continues with interventional treatment.

Despite these problems, there are trends that offer some hope that the reimbursement barrier will be lifted. (**See related story, p. 8.**)

Although the cost of caring for children is high under the current reimbursement structure, hospices need to make pediatric hospice part of their mission because hospices should be the experts in end-of-life care, regardless of the age of their

patients, says **Stacy Orloff, LSW**, child and family support program manager for the Hospice of the Florida Suncoast in Largo.

Under an adult hospice model, patients must choose between curative treatment and palliative care. Choosing hospice signals the patient's desire to be cared for in a way that emphasizes quality of life in the child's final weeks or days. Not only is treating children different compared to adults, but children also die quite differently from adults. Most adults die from heart failure, while children often succumb to their diseases more slowly as a result of respiratory failure. While most adults die from a handful of diseases, cancer and congestive heart failure among them, children die of a wide variety of diseases.

Family dynamics are different for dying kids

Aside from differences in causes of death, the family dynamic is different for children at the end of life. Caregivers of adults are traditionally spouses, siblings, or grown children who often look upon caregiving as a burden. On the other hand, parents or guardians of dying children have a strong desire to continue caring for their children. As a result, families of dying children are usually reluctant to contemplate hospice as an alternative to curative treatment.

Children communicate differently from adults in ways that make it difficult for them to express the degree of pain they are experiencing. Communication differences also present challenges when discussing death with children.

Experts say hospices should take the following steps when launching a pediatric hospice program:

- Determine need.
- Identify staff who are suited to exclusively care for dying children and serve their families.
- Set cost limitations. Set a target cost that your hospice is willing to accept for individual cases.
- Develop an educational program for physicians and social workers who will in turn educate parents who could benefit from a pediatric hospice program.
- Develop relationships with pediatricians, and appoint a pediatric medical director.

A decision to create a pediatric hospice must be made at the highest level of the organization, including members of the governing board. The decision must include a financial commitment from the hospice's charitable foundation to

subsidize the cost of care.

Equally important is for hospice leaders to be willing to adopt the following principles to govern the program:

- **Admission criteria for a pediatric palliative care program should be unlike admission criteria for adult patients.**

Rather than requiring a six-month terminal illness diagnosis, children should be admitted based upon the prediction that the child will not survive into adulthood.

- **The unit of care should be the child and the family.**

"Family" is defined as the people who provide physical, psychological, spiritual, and social comfort to the child, regardless of genetic relationships.

- **Care should focus on relief of physical, social, psychological, and spiritual pain experienced by the child and family, despite not choosing to end life-sustaining care.**

This is one of the biggest reasons why caring for dying children is different from, and more difficult than, caring for adults. Hospice workers must walk the fine line between encouraging parents and helping them accept the inevitable. Despite hospice workers' own feelings about whether life-prolonging efforts are no longer working, workers must respect parents' wishes, support their decisions, and continue to provide palliative care.

- **Pediatric interdisciplinary team members must have pediatric knowledge. Hospices need to provide substantial training to nurses, physicians, social workers, spiritual counselors, and volunteers.**

According to the palliative care handbook of the Alexandria, VA-based National Hospice and Palliative Care Organization, there are seven challenges in creating a course to train interdisciplinary team members in pediatric palliative care:

- defining educational objectives;
- determining content of training;
- selecting teaching methods;
- exploration of personal attitudes about death, dying, and bereavement;
- promoting interdisciplinary collaboration;
- evaluating training;
- choosing educators who are experienced in pediatric palliative care.

The handbook stresses the need to approach pediatric palliative care education from a practical perspective, highlighting specific knowledge, skills, and attitudes needed to deliver proper care, rather than hours of classroom lectures.

Training must include interactive methods of teaching. With all that hospice workers must assimilate — learning pediatric palliative care goals, understanding personal feelings about childhood death, and being taught how to interact with patients and their families — education is facilitated through hands-on methods, such as role-playing and active participation in palliative care activities.

- **Regardless of cause of death, supportive and bereavement care should be provided to all those who are affected by the child's death, for as long as they need it.**

Of course, bereavement care is the hallmark of hospice care. Grief following the death of a child can be prolonged and can require longer periods of follow-up care. Bereavement care for parents, siblings, and others following the death of a child should be expected to go beyond the traditional one-year period that adult-focused hospices employ.

On June 2, 2001, Katie Westbrook turned 15 years old. She died the next day. Despite her tribulations, she ended life on her own terms. She used the 1½ years the chemotherapy bought her to surround herself with old and new friends. She even attended law school classes.

Still, her mother wonders about those final months. "We need a better system to allow maximum quality time," Westbrook says. "If we had a better system, it could have been so much better." ■

Reimbursement attitudes may be changing

Case managers and the PACC model

Most hospices that provide pediatric palliative care must do so without reimbursement. But there are trends that suggest the days of care wholly subsidized by community support may be on its way out. Private insurers and Medicaid demonstration projects are investigating ways to integrate palliative and curative care, and to remove the reimbursement barrier that forces parents to choose between efforts to cure their sick children or to provide physical and emotional comfort.

The solution to integrating palliative and curative care is a relatively simple one, says Joyce **Hagan Schifano**, BSN, MBA, president of Passport Health Plan, a 120,000-member HMO that covers 15 counties surrounding the Louisville, KY, metropolitan area. Health plans can improve the quality of care for dying children by changing their reimbursement policies to allow hospices or other palliative care providers to offer support services and consultations to both the family and treating physicians without a terminal illness certification.

"It's easily implemented and easily adaptable to most health plans," says Schifano. "It takes a two-pronged approach: Change your policy, and develop internal resources."

Those resources include networks of local hospices, physicians, volunteers, hospitals, and community organizations that can meet the diverse needs of dying children. Like most hospices around the country, Genesee Region Home Care and Hospice in Rochester, NY, formerly had to admit dying children only if their parents elected to give up aggressive treatment. Under Excellus Health Plan, a Rochester-based group that covers 1.7 million members and includes three New York State Blue Cross Blue Shield Plans, including Blue Cross Blue Shield of the Rochester Area, Genesee Hospice is allowed to accept children with potentially life-limiting illnesses even though the patient may still be undergoing treatment for the disease. This is done under Excellus' CompassionNet program.

Like Passport, CompassionNet case managers handle patients and their families throughout the continuum of care, including social worker assessments and patient advocacy at the time of disease diagnosis.

By using a case manager, Passport and CompassionNet officials are able to introduce palliative care and other services earlier in the disease process, in recognition of the fact that many patients are in need of pain management and counseling from the point of diagnosis.

"It works because it removes not only the reimbursement barrier, but also the access barrier to the care they need," says **Jeanne Chirico**, MPA, director of family life services and CompassionNet at Genesee Region Home Care and Hospice in Rochester, NY.

Both Schifano and Chirico say the policy changes within their programs have benefited care, but there are financial incentives, as well, they say. "I think that one of the reasons why

other health plans don't do this is that there is a fear that the cost would be exorbitant, but we're not seeing that," says Chirico.

In addition, Passport is studying the case manager approach in end-of-life care among adult Medicaid patients diagnosed with cancer. Through a grant funded by the Robert Wood Johnson Foundation, the health plan is measuring both quality and financial outcomes. "With better education about their options, I believe parents will choose what is best for their child, which will translate into reduced costs," Schifano says.

Ins and outs of the PACC model

The case manager model, however, is not the only model being used to revolutionize the way dying children are cared for. Children's Hospice International, an Alexandria, VA-based patient advocacy organization, developed its own model similar to the Program for All-inclusive Care for the Elderly, which blossomed in the 1990s. Program for All-inclusive Care for Children (PACC) is now a Medicaid demonstration project in six states.

The guiding principle, says **Ann Armstrong-Dailey**, president of Children's Hospice International, is that children and their parents are made aware of all their options at the time of diagnosis. "Looking at the needs of kids and their parents at the time of diagnosis is critical," she says. "Parents who have gone through the process tell us that it's when they need us the most, and that the actual death was anticlimactic."

The beauty of the PACC model is its flexibility. Participants must adhere to a set of requirements, but are left to design their own programs.

The basic requirements of the program include:

- **Access to Care** — PACC services for children and their families offer developmentally appropriate, concurrent palliative and supportive care and disease treatment to any child with a life-threatening condition in any appropriate setting. Children are admitted to PACC services without regard for diagnosis, gender, race, creed, handicap, age, or ability to pay.

- **Child and Family as Unit of Care** — PACC programs provide family-centered care to enhance the quality of life for the child and family as defined by each child and family unit. The child and family are included in the decision-making process, including choices regarding services and treatment.

- **Interdisciplinary Team Services** — Children

with life-threatening conditions and/or those who are facing serious stages of an illness and their families have a variety of needs that require a collaborative and cooperative effort from practitioners of many disciplines, working together as an interdisciplinary team of qualified professionals and volunteers under one plan of care.

- **Continuity of Care** — PACC is an integrated system of home, outpatient, community-based, and inpatient care. PACC programs provide seamless continuity among various care settings from the time of admission to the conclusion of bereavement services.

- **Pain and Symptom Management** — PACC programs strive to keep children as symptom-free as possible. Pain and/or other symptoms of their illness should be managed to achieve the greatest possible comfort.

- **Bereavement Program** — PACC programs incorporate grief support following the death of a child because families of children who die may continue to need appropriate professional and supportive services for a period following death.

- **Utilization Review/Quality Improvement** — PACC programs should monitor and ensure the appropriate allocation and utilization of resources and effectiveness of services.

The success of the 3-year demonstration project will depend greatly on not only improving the quality of care, but on programs' ability to save money. Like other pediatric end-of-life care experts, Armstrong-Dailey says she is confident that reduced hospitalization, emergency room visits, and costs related to illnesses resulting from stress following the death of a child will dramatically reduce the cost of care. ■

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Mathis, Earnest & Vandeventer

Cedar Falls, IA

It happens to the best of us. You need to call a potential donor, but you just can't seem to pick up the phone. You stare at it. You find another task to complete. You procrastinate. Something, anything seems better than having to make your calls. The mental anguish is almost unbearable.

It may even become physical. Beads of sweat form on your brow. A knot tightens in your stomach. We call this inability to make personal contact with potential givers "call aversion." But no matter what you call it, it gets you nowhere.

People experiencing call aversion fall into one of four categories:

- those who fear rejection and thus keep their feelings to themselves, always stressing about technical details and ignoring relationships with prospective donors;
- those who hide their insecurities by making

showy presentations and flaunting their achievements;

- those who apologize because they think others view what they do as professionally unimpressive;
- those who don't want to appear too aggressive, waiting for the perfect time to make a call — a time that may never come.

Dealing with call aversion

Call aversion doesn't have to keep you from making those calls. First, think of the last time you experienced call aversion. Create a mental movie of how you felt. The next time you feel those same emotions, detach yourself by watching your "movie."

Second, do something physical when you first experience those emotions. Stand up and walk around your office. Say out loud what you are thinking.

Third, substitute that negative experience with a positive one. Recall a successful phone call, how easy it seemed at the time and how good it made you feel.

Finally, give yourself a reward after every call, even if you didn't connect with the potential donor. Your reward can be anything, from coffee to a piece of candy. It will positively reinforce the experience of making the call and increase the likelihood that you will make another.

It is imperative that hospices train their volunteers in how to avoid call aversion because volunteers play such a large role in fundraising.

Volunteers are the group most prone to call aversion because they don't make donor calls every day like professional fundraising staff.

If you are a fundraising professional who oversees volunteers, proper training can lessen or even eliminate call aversion. During a scheduled volunteer training session, include a section on call aversion.

Begin training by clearly outlining the goals and objectives of the campaign. Don't assume the volunteers have the same motivation you do for the campaign. Set an example for them by being enthusiastic yourself.

Provide volunteers with a time line and job description, and make sure they understand what is required. Cover the types of call aversion and how to deal with it, and then have volunteers participate in role-playing exercises. Include some worst-case scenarios, followed by discussion on how best to handle the situations. This can be a great confidence-booster for them and can help you determine areas where volunteers need more training.

Once the training session ends, stay in touch with your volunteers until all the calls are completed. This gives them an opportunity to discuss their concerns and allows you to address any small problems before they become bigger ones.

For those volunteers who have more difficulty than others in overcoming call aversion, let them accompany you while you make calls. By joining you on calls, they will observe you and gain confidence in their ability.

Give credit to volunteers when they do stare call aversion in the face and make contact with potential donors. This positive reinforcement will keep them focused and motivated for the duration.

Other tips to keep in mind that will help avoid call aversion:

- **Nothing happens unless someone is asked.**

The No. 1 reason people don't give is because they're not asked. Give them the opportunity to experience the joy of giving.

- **A "no" is one step closer to a "yes."**

A "no" isn't always a "no." Sometimes the timing isn't right, or the donor needs to speak with a

spouse, attorney, business partner, or family before making a gift.

- **The worst that can happen is someone says "no."**

In fact, the person turning you down may feel as uncomfortable saying "no" as you were making the call.

- **Don't take it personally.**

There are many reasons a person may decline to give. Rarely do those reasons include you.

- **Be proud to ask.**

Don't be ashamed of working for a nonprofit. The gift you're asking for will make the world a better place, for both the giver and the receiver.

- **Make a gift yourself.**

A fundraiser who authentically supports a cause is a powerful draw for a financial campaign. If you don't make a gift yourself, how you can ask someone else to?

So the next time your hand shakes before picking up the phone, remember these tips, take a deep breath, and let your love of hospice shine through.

[Editor's note: Dee Vandeventer is president and Justin Tolan is chief fundraising adviser of Mathis, Earnest & Vandeventer, a marketing and fundraising company. They can be reached via e-mail at dee@meandv.com or jtolan@meandv.com, or by telephone at (319) 268-9151.] ■

Lawsuits over withholding support are called myths

Few court cases involve end-of-life care

Health care providers are understandably concerned about the legal climate in which they live, observes **Marshall B. Kapp, JD, MPH**, professor in the department of community health at Wright State University School of Medicine in Dayton, OH. But physicians can rest easier than

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many. Even though malpractice cases abound, the reality is that very few medical malpractice claims or other adverse legal actions happen due to thoughtful decisions to withhold or withdraw treatment for dying patients in the intensive care unit.¹

Kapp notes that there is pervasive worry, apprehension, and anxiety among physicians and other health care providers about the possible legal consequences of reducing or removing life support for terminally ill patients.

"There's a myth that it's difficult if not impossible to withhold or withdraw life-prolonging treatment in the ICU without judges roaming the hospital halls overlooking every move," Kapp says. "That's really contrary to the reality."

Certainly, Kapp notes, there are legal boundaries within which physicians and others must operate, but the vast majority of decisions to limit treatment for terminally ill patients are made without formal legal involvement. Most decisions are made through negotiations between the patient's physician, family or surrogate, and clergy person, Kapp observes.

"The legal system is reactive; courts only get involved when someone goes to them and says, 'We can't figure this out on our own.'"

Medical malpractice, Kapp points out, is largely a problem of missed diagnosis and botched operations. "If you look at what constitutes the bulk of medical malpractice claims, it's lots of things other than end-of-life medical decision-making," he says. Obstetrics, orthopedic surgery, and emergency department treatment in which the physician missed a diagnosis are far more likely candidates for lawsuits. "The percentage of lawsuits arising from ICUs is very, very small," he says.

Kapp says one of the explanations for the low incidence of ICU-related claims is that in a malpractice case, the plaintiff has to show that physician negligence directly caused the patient injury. Even if an ICU physician is negligent, that's difficult to prove in court, because the patient is already critically ill or dying; otherwise, the patient wouldn't be in the ICU in the first place.

This is not to say there aren't any ICU lawsuits, but Kapp says their number is dwarfed by the number of cases arising from obstetrics, emergency departments, and surgical specialties. Headlines about court involvement in end-of-life situations rarely represent malpractice claims in which a lawsuit resulted from withholding or withdrawing treatment, Kapp adds.

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"End-of-life court cases almost always revolve around a decision that needs to be made because the informal discussion process breaks down," Kapp says. "Either the family disagrees among themselves, or there's a fundamental disagreement between the family and physician, in which case the family usually transfers care to another physician, moves the patient to another facility, or the hospital's ethics committee becomes involved and mediates the disagreement."

Reference

1. Curtis JR, Rubenfeld GD, eds. *Managing Death in the ICU: The Transition from Cure to Comfort*. New York: Oxford University Press, 2000. ■

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