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Action from FDA results in some hospice drug shortages

Manufacturers working to update documentation

Hospice medical directors still are finding shortages of certain opioid medications three months after the Food and Drug Administration (FDA) notified manufacturers of certain types of opioid medications that they would no longer be able to manufacture the drugs. Although the manufacturers are addressing the issues raised by the FDA, hospices still are scrambling to find alternative pain medications for some patients.

The most critical drug on the list was 20 mg/ml morphine sulfate oral solution, which is required for hospice patients who cannot swallow pills. In a surprise move on March 31, the FDA amended its action to exclude the oral solution from the list of unapproved drugs until at least one manufacturer completes the documentation and receives approval to manufacture the drug. At that point, other manufacturers

EXECUTIVE SUMMARY

Months after the federal announcement that some manufacturers could not manufacture or distribute opioid medications that hospices rely upon for pain management, shortages are causing physicians to find alternative meds.

- Manufacturers had to submit documentation that had never been filed with the FDA because the drugs had been on the market prior to the FDA's oversight.
- The FDA did allow the continued distribution and manufacture of 20 mg/ml morphine sulfate oral solution until manufacturers met requirements due to the specific need of some hospice patients who cannot swallow pills.
- Pharmacists are compounding medications that cannot be found commercially if it is the only drug that the patient can tolerate or that is effective for the patient.

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have 180 days to complete submission of their documents. The other drugs, which included immediate-release tablets containing morphine sulfate, hydromorphone, and oxycodone, still were included in the action that required manufacturers to meet certain requirements to gain approval for the drugs.

The drugs on the list were not FDA-approved, primarily because some of the data that the FDA now requires are missing on drugs that have been used in hospice before the FDA was charged with their oversight, says **Porter Storey**, MD, executive vice president of the American Academy of Hospice and Palliative Medicine. "Manufacturers are in the process of meeting the documentation requests, and the FDA assured health care providers that they will move quickly to approve the drugs and manufacturers that meet their requirements," he says. Until

then, hospice clinicians will have to continue to find alternative medications during the shortages, Storey adds.

The biggest concern of the hospice industry was the FDA's move to restrict the supply of drugs without talking with health care representatives, says **Phyllis Grauer**, PharmD, CGP, RPh, clinical consultant at Palliative Care Consulting Group, a Dublin, OH-based division of HospiScript Services. "As health care professionals, we don't want tainted products on the market, but if it is a matter of crossing all the T's and dotting the I's on documentation, the FDA should evaluate the effect of shortages that an action such as this will have on patients," she says. "If we had known that this action was being considered, we could have mobilized to recommend time frames that would not have created shortages."

Although physicians are able to try alternative medications, it is not always easy to switch pain medications, points out Storey. "There is a reason that there are so many pain medications on the market," he says. "Every patient reacts differently to the medications. For example, one patient might experience nausea with morphine but not oxycodone, and another patient experiences nausea with oxycodone and not morphine."

Once a physician and patient find a medication that can be tolerated with few side effects, there is usually no change to the medication unless it becomes ineffective, Storey says. "Many patients are reluctant to use opioids anyway; so switching between medications is not easy once they've become accustomed to one," he adds. **(See p. 87 for tips on educating patients about opioid use.)**

Another concern of hospice medical directors and palliative care specialists is the additional cost represented by some of the alternative medications or dosages, says Storey. "In hospice, most of the drugs we use are old, proven drugs that are inexpensive, but effective," he says. "When we face shortages, we often find ourselves forced to buy more expensive, potentially less effective medications."

Grauer says, "We did experience some shortages of oxycodone and morphine solutions initially, but as more companies meet the FDA requirements, the drugs are more available." Hospice and palliative care physicians have switched to other strengths, dosages, or drugs to meet the needs of their patients, she says. "If a patient cannot tolerate another pain medication, or if another drug doesn't work well for the patient, pharmacists can compound medications if they are not available commercially," Grauer says.

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Editorial Questions

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Compounding medications might meet the patients' needs, but there are risks, she points out. "There are no quality checks on the medication when a pharmacist compounds the medication," Grauer says. "I believe that compounding should be used only when there is no other solution to managing the patient's pain."

While manufacturers and hospices are working through the current issues, the most critical challenge facing hospices and palliative care providers is still to come, points out Grauer. "The FDA has been charged with examining drugs most commonly associated with abuse and creating a process to limit access to the drugs," she says. The program, Risk Evaluation and Mitigation Strategies (REMS), potentially will limit the number of prescribing doctors, which also can affect access for hospice patients, Grauer reports. (See p. 88 for more about REMS.)

"Because many of the drugs that fall into this category are used in hospice, we hope that they can address the abuse of these drugs without affecting their availability to patients who need them," Grauer says. ■

Start with lowest dosage to allay patient's fears

Opioids meds resisted by some

An added challenge to changing a patient's pain medication due to a shortage of a specific drug is the resistance of many patients and family members to using opioid medications.

"When I was a hospice medical director, I spent much of my time allaying the worries and concerns of patients and their family members about the use of pain medications," says **Porter Storey**, MD, executive vice president of the American Academy of Hospice and Palliative Medicine. "The main concerns are addiction, side effects such as nausea or hallucinations, and development of an immunity to the effects of the medicine that would lead to increased dosage."

Because pain management is an important part of hospice and palliative care, it is important to take the time to educate the families and make sure that the patient receives a drug that will be effective, he says. For the initial start of any pain medication, start with a low dosage that the patient takes on a regular basis, he suggests.

Need More Information?

For more information about hospice drugs affected by the Food and Drug Administration action, contact:

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To find updated information on drug shortages, go to www.fda.gov/cder, select "drug safety and availability" on the home page, then select "drug shortages" on the left navigational bar.

"After the patient realizes how much relief the drug provides, it is easier to adjust the dosage as symptoms change to effectively manage the pain," Storey says.

If a drug shortage makes a change in drug or dosage necessary, you might have to start the process again, he says. "You don't know how each patient will react to a new drug, so you must monitor side effects carefully with any new medication," Storey explains.

No matter which drug you use, pain management is only effective if the patient takes the drug in the manner you prescribe, he points out. "Drug companies are coming out with new methods of delivery, such as a thin wafer that dissolves under the tongue, that can help patients who have difficulty swallowing pills," Storey says.

Transdermal patches that deliver pain medication are another way to help patients comply with medication management, points out **Phyllis Grauer**, PharmD, CGP, RPh, clinical consultant at Palliative Care Consulting Group, a Dublin, OH-based division of HospiScript Services. Patches are not right for everyone, she points out. Everyone's skin is different, so the rate of absorption of the drug varies from patient to patient, Grauer adds.

"The rate of absorption for oral medication is more predictable," Grauer says. "Patches are also more expensive and not cost-effective if the patient can take a drug orally." However, if you

have a noncompliant patient, transdermal patches might be a good last resort, she adds. ■

New challenge coming from FDA

Certification required to prescribe some meds

Although hospices and drug manufacturers are finding solutions and alternatives to pain medications to address the current drug shortage, the more critical challenge is the Food and Drug Administration's (FDA) close look at drugs that are typically considered drugs of abuse, says **Phyllis Grauer**, PharmD, CGP, RPh, clinical consultant at Palliative Care Consulting Group, a Dublin, OH-based division of HospiScript Services.

The FDA's Risk, Evaluation, and Mitigation Strategies (REMS) that are being considered for opioid drugs, especially long-acting products including methadone, might have long-lasting effects on hospice and palliative care, she says.

Long-acting drugs such as methadone, oxycodone, and fentanyl are staples of pain management in hospice, but the FDA is evaluating ways to limit their availability to control the risk of abuse, explains Grauer. These drugs were selected for scrutiny because they do result in higher rates of mortality for people who abuse them, she says.

FDA recommendations include creation of a registry of physicians and pharmacists who can prescribe or distribute the medications, says Grauer. "Physicians would need to attend classes to obtain the certification and meet requirements to maintain certification," she says. "I believe that doctors who don't prescribe these medications or who rarely prescribe the medications won't go through the certification process. Hospice medical directors and physicians who frequently care for patients at the end of life will pursue certification."

Hospices are concerned that this certification will take away from reliance on community physicians to continue caring for their patients even while they are in hospice care, says Grauer. "Many internal medicine specialists or family practitioners will not pursue the certification because they know the hospice has a physician who can prescribe the drugs," she says. "Even though hospices are required to have a medical director according to Conditions of Participation, the reduction in numbers of community physicians who can prescribe

certain pain medications will greatly increase the medical director's responsibility and involvement with all patients."

The comment period on the FDA recommendations ended June 30; at press time, hospice and palliative care specialists were watching for a decision, says **Porter Storey**, MD, executive vice president of the American Academy of Hospice and Palliative Medicine in Glenview, IL. He adds, "The American Academy of Hospice and Palliative Medicine will offer training to physicians as soon as it is defined and becomes available." ■

Care for caregiver to avoid low morale and burnout

While concept is not new, discussion gains traction

Due to the altruistic nature of most health care providers, members of the giving professions often put their own needs last, often to the detriment of themselves, their colleagues, their personal lives — and sometimes their patients.

The American Nurses Association (ANA) code of ethics "clearly states in the fifth provision that nurses have the same obligation to self as to others, including their own personal renewal, well-being, and integrity," according to **Cynda Hylton Rushton**, RN, PhD, FAAN, clinical nurse specialist in ethics at Johns Hopkins Children's Center in Baltimore.

"I think it is actually an ethical imperative that nurses care as well for themselves as they do for others," she says. "And that quality of care can't be achieved without a healthy work force, which includes self-respect and care for one's own well-being."

Although the ANA code of ethics clearly spells out the need for self-care, there is no similar provision in the code of ethics for physicians. However, one physician who has written about self-care for physicians says he thinks that "in terms of just clinical practice and ethical practice, I think there is an imperative to prevent [burnout] from happening — and not just for the personal reasons of avoiding burnout on the individual level, but because of the implications it has for patient care." This advice comes from **Michael K. Kearney**, MD, who practices in palliative care service at Santa Barbara (CA) Cottage Hospital, as well as Visiting Nurse and Hospice Care of Santa Barbara.

The two typical results of the lack of self-care and renewal in physicians, particularly those caring for patients at the end of life, are burnout and compassion fatigue, according to an article Kearney's published in the *Journal of the American Medical Association (JAMA)* on this topic.¹

Some of the symptoms of burnout are overwhelming physical and emotional exhaustion, feelings of cynicism and detachment from the job, a sense of ineffectiveness and lack of accomplishment, and overidentification and lack of accomplishment, according to the *JAMA* article, citing Maslach et al² and Vachon.³ From a health care team perspective, burnout can lead to low morale, high job turnover, and staff conflicts, among other things, according to the article.

Rushton and Kearney say lack of self-care can lead to the kind of "disruptive behavior" on the part of health care providers cited in a July 2008 *Sentinel Event Alert* issued by The Joint Commission as behaviors that can threaten the quality of patient care not to mention the provider team dynamics.

Disruptive behavior is a "symptom" of lack of self-care, Rushton notes. "People who are not doing a good job of taking care of themselves are at higher risk of having behaviors that are not respectful or are maybe [manifesting] as lateral or horizontal violence in the workplace. To me, that's a symptom of this very issue — often," she says.

Providers reluctant to discuss feelings

For those caring for seriously ill patients or those at the end of life, burnout and compassion fatigue pose a threat, primarily because some health care providers are reluctant to admit to such emotions before it's too late, Rushton and Kearney say.

"Our focus has been on caring for others — caring for patients and families," Rushton says. "And I think the culture within most of medicine and nursing has been one of not really acknowledging those needs and sort of suppressing them, or denying them. And I think it makes it very difficult for people to stay connected to the meaning of their work and to the more fundamental commitments that they have for their professions."

Rushton says nurses, in particular are "always — always — privileging everybody else before our own self-care. And some people interpret [self-care] as we're being too self-focused, and yet at the same time, we see everyday consequences of lack of self-care on our team, on our individuals and,

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quite honestly, on patient care."

The lack of self-care has reached a point in recent years where, according to Rushton, providers say, "Oh my gosh, it's gotten so bad; maybe we ought to look at this and see if there is something we could do."

Kearney echoes the fact that physicians are often so busy caring for others, they forget to care for themselves. "You know, I think a lot of people who are drawn to the caring professions in health care are genuinely altruistic and see their role as being primarily there for others, so it's not that we don't realize that as physicians we have our own limits and have our own needs," Kearney says. "It's just that it's very much a sense of, 'We'll get round to those later; first things first.'" Therefore, Kearney says there "may be a certain reluctance to focus on oneself and one's feelings," because within the "hierarchy of priorities within health care, this has been seen as not the first thing we need to attend to."

Kearney et al's paper weaves in the story of "Dr. C," who, for example, notes that "The stuff that burns me out has nothing to do with loss . . . It's fighting insurance companies . . ."¹

However there is growing attention and discussion of the issue in published papers on initiatives to address and support self-care in pediatrics at Johns Hopkins and in articles such as Kearney's focused on strategies for physician self-care.

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Paper highlights initiatives, interventions

Initiatives for pediatric palliative care

About 12 years ago, **Cynda Hylton Rushton**, PhD, RN, FAAN, and others at Johns Hopkins University set about to examine the issue of nurse self-care and the quality of care being delivered in pediatric palliative care. These individuals wanted to foster a culture of self-care and, as a consequence, developed four interventions for the pediatric unit. The description of those initiatives and the level of participation in the initiatives was captured in a published paper titled “Interdisciplinary interventions to improve pediatric palliative care and reduce health care professional suffering.”¹

The first step in the development of these initiatives was to conduct an assessment of the quality of care that was being delivered, at a baseline level.

“The impetus for the assessment was a question about, were we providing the kind of quality care that we aspired to in our institution,” Rushton recalls. “And so we undertook a process of talking with clinicians and patient families to see where we were doing a good job and where we had opportunities for improvement.”

To improve the quality of care given to dying children and their families, the Johns Hopkins Children’s Center (JHCC) had developed a pediatric palliative care program, the study notes. However, the initial assessment found “significant distress among health care professionals,” according to the paper. Rushton and her team set about developing programs toward the goal of alleviating this distress.

The assessment survey was developed “after a thorough review of the literature on family-centered care and ethical guidelines for the treatment of children near the end of life, addressed issues specific to pediatric decision making, as well as a wide range of ethical and legal issues in end-of-life care,” Rushton’s article states. “Although the needs assessment underscored the importance of caregiver suffering, its not a new concept,” the authors wrote. “Suffering and loss are intrinsic and inevitable dimensions of caring for children with life-threatening conditions.”

According to the article, “the team’s underlying hypothesis is simple: Health care professionals will provide better care and support to seriously ill children and their families when they feel

supported personally and professionally in their work.”

The action plan developed by the JHCC included the following goals:

- Increase their competence and confidence in providing pediatric palliative care.
- Increase their ability to manage responses of grief.
- Restore and maintain their sense of professional integrity.

The first initiative in the quality improvement program was the establishment of the Compassionate Care Network (CCN), which “provides an open forum for interdisciplinary networking and education.” The goal of the CCN was to “to integrate palliative and end-of-life care information and expertise across all units in the Children’s Center.” Recruitment targeted “key clinicians and leaders in the JHCC,” with attention focused on recruiting diverse disciplines. At the time the paper was published in 1996, there were 69 members of the CCN, including physicians (22%), nurses (49%), social workers (13%), child-life specialists (8%), and other health care professionals (7%).

“In its first two years, the network sponsored three intensive training sessions and held six quarterly meetings,” the article states.

The second intervention was the organization of Palliative Care Rounds (PCR), which were “monthly educational sessions [that] used the familiar model of Attending Rounds.” To accomplish this, the health care providers identified a patient case “that exemplified the need for palliative care and/or end-of-life care. Often, a physician resident or fellow presented the medical facts of the case, the goals of care for the patient, and members of the interdisciplinary team shared psychosocial, emotional, and spiritual information about the patient and family.”

The 79 participants reported the PCR program provided reinforcement of their mission, by stating such things as “learned feelings of other team members,” “shows need for pastoral care perspective,” and “learned specific ways to help patient and family in terminal phase.”

The third initiative was patient care conferences (PCC), interdisciplinary team meetings that were “designed to help identify and clarify goals and plans for care for individual patients.” The format for the PCC included “patient demographics, reason for the conference, summary of the child’s illness, identification of patient/family/staff needs and issues, creating a palliative care plan, formulating a discharge plan, and follow-up.”

“The Family Care Coordinator (FCC) played a vital role in case finding and in implementing the patient care conference intervention,” the article states, and this “highly competent and respected nurse” had responsibility for “identification of family needs and actual or potential conflicts between families and the health care team.”

The fourth initiative centered on bereavement debriefings, and the format was adapted from the “traditional critical incident stress debriefing model. Initially designed to address responses to unusual situations, the sessions were adapted to help health care professionals realize that the physical, emotional, social, and spiritual responses they experience after patient deaths were normal, natural responses to situations they regularly encounter,” the authors said.

Rushton says the initiatives developed and implemented by her team have been able to be sustained over time, and the team was pleased with the results.

The “environment of interdisciplinary support” established by the initiatives allowed the health care professionals “a safe forum within which to experience interdisciplinary dialogue that witnessed and honored emotions, intellectual confusion, shared vulnerability, and grief,” according to the article.

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Self-care of physicians: Strategies for care

Self-awareness and mindfulness help with self-care

Physicians may be operating in burnout mode, or suffering from other maladies related to distress and stress, long before they are even aware of it, according to **Michael K. Kearney, MD**, one of the authors of a paper published in the *Journal of the American Medical Association* titled “Self-care of physicians caring for patient at the end of life: “being connected . . . a key to my survival.”¹

In addition to a certain reluctance to discuss or examine personal feelings related to care of such patients, such as grief or a sense of loss, there’s

also “a genuine problem in not recognizing burnout in its early stages.”

“I think oftentimes, it’s our colleagues who recognize it before we do — colleagues and family members . . . who notice the emotional exhaustion, the cynicism, the irritability,” Kearney says. “And often, we’re the last ones to recognize it ourselves.”

One reason to pay attention to physician self-care and the need for it is that “the figures are really quite alarming, those that show that the prevalence of burnout among U.S. physicians and nurses is about 30%,” he says. Kearney practices in palliative care at Santa Barbara (CA) Cottage Hospital, as well as Visiting Nurse and Hospice Care of Santa Barbara. That doesn’t mean that physicians who are experiencing burnout automatically leave the profession; however, he says there is a spectrum of burnout ranging from mild to severe.

“It can get to a point where it’s really compromising, and the physician just can’t go on,” he says.

(For information on the difference between burnout and compassion fatigue, see story, p. 92.)

Care of physicians is not just an individual matter; it’s an imperative for institutions to care for their employees and create facilities that promote self-care, Kearney says. Patient satisfaction, staff retention, and the effectiveness of care delivered — those are all reasons that health care institutions should care about the self-care of physicians and other providers, he suggests.

Kearney says several institutions “are providing opportunities in the workplace” for staff to practice self-care. One simple intervention is to mandate that staff complete a “self-care inventory,” i.e., “something that makes [clinicians] think about: well, what is my self-care plan — not just outside of work, but also at work,” he suggests.

Solutions begin with an awareness of a problem, and there can be no solutions without identification of some problem or weakness. Kearney’s paper focuses on self-awareness and mindfulness as the path to self-care. According to the article, “Physicians with burnout who use self-care without self-awareness may feel as though they are drowning and barely able to come up for air; whereas, self-care with self-awareness is like learning to breathe underwater.”

There are strategies for self-care that can be incorporated into the workday, and Kearney and his co-authors outline several actions physicians can take during their day to keep them focused. The strategies are all from practicing clinicians. “We said to some of these clinicians: Can you share with us some of your pearls — those things

that through sort of trial and error have really worked for you and helped you maintain yourself over the years?" he says.

Among some of the strategies that clinicians shared with Kearney and the other authors were:

- "As you walk from your car to your workplace or through the corridors of your workplace, attend carefully to the sensation of contact between your feet and the ground.
- Reward yourself after the completion of a task, i.e., an early coffee break.
- Take a half-minute of silence or take turns to choose and read a poem at the beginning of weekly interdisciplinary meetings.
- Stay connected to the outside world during the day, e.g., check in with loved ones."¹

Factors that mitigate burnout, fatigue

"The personality characteristic of hardiness — a sense of commitment, control, and challenge," has been shown to be associated with a greater sense of personal accomplishment, according to the article.

Other strategies, such as teams with shared decision-making responsibilities, also were cited in the article.

Compassion satisfaction also is a means to self-preservation for physicians, i.e., the "pleasure derived from the work of helping others." Kearney and the authors cite Stamm² as identifying compassion satisfaction as "a possible factor that counterbalances the risks of compassion fatigue and suggested that this may in part account for the remarkable resiliency of the human spirit."

But one thing that Kearney particularly notes is "post-traumatic growth and vicarious post-traumatic growth." As the article notes, "Post-traumatic growth is characterized by positive changes in interpersonal relationships, sense of self, and philosophy of life subsequent to direct experience of a traumatic event that shakes the foundation of an individual's worldview."

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What is burnout vs. compassion fatigue?

What is the difference between burnout and compassion fatigue?

The three primary characteristics of burnout are: emotional and physical exhaustion; depersonalization, or feelings of cynicism and detachment from one's job; and sense of lack of personal accomplishment, according to **Christina Maslach**, PhD, professor in the Psychology Department, University of California, Berkeley. Maslach has done a great deal of research on burnout, also known as "a sense of not really getting the job done," says **Michael K. Kearney**, MD, an author of a recent paper published in the *Journal of the American Medical Association* on self-care of physicians.¹

Burnout, Kearney says, is generated by stressors related to a physician's work environment, be they work-related stressor or institutional-related stressors, something akin to the administrative hassles or the daily grind. It also can result from the clash of one's personal values with the values of the institution or not feeling as if one has control over his or her work environment, he says.

Compassion fatigue, on the other hand, "is very different," Kearney notes. "Compassion fatigue is what results from stresses generated between the clinician and the patient's suffering." That kind of fatigue also is known as secondary traumatic stress disorder, he says, and it "essentially means that by being close to our patients, physicians, and nurses, in an empathic way, are at risk of being traumatized by the patient's suffering."

Compassion fatigue can lead to burnout and its myriad symptoms. "It's a personal tragedy, but it also leads to a failure of and breakdown in patient care, because of all the features — the exhaustion, the detachment, the cynicism — lead to a clinician who is less engaged, who is detached. So, to be a patient on the receiving end of that is maybe to be on the receiving end of the physician who is still doing the right thing, technically, but who is not able to be present in an engaged, humane, warm way, because they literally don't have it in them anymore," Kearney explains.

That fatigue can lead not only to a question of the quality of patient care, but the effectiveness of patient care over time, he adds.

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of physicians caring for patients at the end of life: 'Being connected . . . a key to my survival.' *JAMA* 2009; 301:1,155-1,164. ■

Tips for moving those with special needs

Hurricanes present special circumstances

People with special medical needs need to plan their evacuation before a hurricane hits.

They should have extra refills of medications in case the storm forces stores to close down for several days, says **Jeff Kalina**, MD, FACEP, associate director of emergency medicine with The Methodist Hospital in Houston. Also, if they have to go to the hospital, it's good to have a list of their medical conditions, medications, and allergies written down.

The elderly will need some extra attention during the evacuation, he points out. Putting an older person in the back of a car in the middle of summer puts them at risk for heat exhaustion and dehydration, Kalina says. It's imperative to have plenty of water and, if possible, ice or some kind of a fan that can cool them off if traffic comes to a standstill, he says. During the Houston evacuation of Hurricane Rita in 2005, several elderly people died in their cars from the intense heat.

Sitting in a car for hours also puts an older person at risk for deep vein thrombosis (DVT). It's important that everyone, but especially the elderly, get up and walk around at least every two hours if they are not bedridden.

Kalina urges people to evacuate early if they are in the evacuation zone to prevent being stuck on the road with nowhere to go. If they have to ride out a hurricane at home, he offers some tips:

- They should not wait until a storm threatens to purchase provisions. They should put together a survival kit now. They also should make sure they have a hurricane kit: battery-powered radio, battery-powered flashlight, canned food, and at least three gallons of water per person. They should not forget to pack a manual can opener in their hurricane kit.

- Before the storm, they should fill their car's gasoline tank. They should make sure their cell phone is charged. If they have an extra battery, they should make sure it is charged as well.

- If they do not have text messaging, they should sign up for the service. When the cell phone towers

are down, it can be the only other way to get through.

- If they are on home oxygen or nebulizers, they should make sure they have backup medication and power sources in case of a mass power outage.

- They don't have to buy drinking water at the store. They can rinse out plastic milk jugs and refill with tap water before the storm hits. They should fill buckets and their bathtubs with water, also.

- They should protect their property. They should put away anything — lawn chairs, toys, tools, etc. — that can become a missile during high winds. Taping the windows of their home will not work. They should use plywood to secure windows.

- If the power goes out, they should not use candles unless they absolutely have to. Candles can be a fire hazard.

- Inland cities and counties might not receive hurricane surge flooding, but they can be susceptible to high winds and heavy rainfall. They should take the same precautions as they would for a tornado, as these are more likely during a hurricane.

- After the storm, people should resist the urge to go outside and look around. There might be hazards, including downed power lines. They should listen to a local radio broadcast to learn when it's safe to venture outside.

- The water supply might be unsafe after a storm. Local authorities will know if floodwaters have tainted a neighborhood's water supply. ■

Bill calls for more informed choices at end of life

Longer coverage, counseling, better planning

Health reform legislation introduced by Sen. Mark R. Warner (D-VA) strengthens the quality and availability of counseling, support services, and care management for patients with life-limiting illnesses. The legislation addresses unorganized care planning that might result in tests, treatments, and hospitalizations that many individuals might not choose if presented with options, such as palliative care or hospice.

The legislation, which is expected to be incorporated into comprehensive health reform legislation currently being considered by Congress, has been endorsed by several leading organizations, including the National Hospice and Palliative

Care Organization and the National Association for Home Care and Hospice.

“This legislation will not deny health care to patients and families that want it,” Sen. Warner said in a released statement. “But I firmly believe that any comprehensive health reform should include more information, counseling and resources that will allow patients, their families, their caregivers, and others to consider and discuss decisions about when and how long to pursue treatments at the end of life.”

By some estimates, 27% of Medicare costs occur in the final year of life. Studies suggest that the nationwide application of the enhanced care planning tools included in Sen. Warner’s legislation could reduce Medicare spending by an estimated \$15 billion over 10 years, even as it provides more structured information and planning services that will better support the patient’s wishes and improve their quality of life.

Sen. Warner’s Senior Navigation and Planning Act of 2009 includes the following items that directly affect hospice:

- Enhanced Medicare and Medicaid coverage of advanced illness care management services.

Beginning in 2011, individuals diagnosed with a life expectancy of 18 months or less will have access to a new advanced illness care management benefit administered by hospice providers. The current Medicare Hospice benefit only applies to individuals diagnosed with a life expectancy of six months or less, and it requires patients to give up curative treatment.

- A requirement for physicians to provide certain Medicare beneficiaries with information on advance directives and other planning tools.

Beginning in 2014, Medicare reimbursements will not be provided until physicians provide individuals with information on advanced care planning for patients specifically diagnosed with end-stage cancer, renal disease, congestive heart failure, progressive neurodegenerative disorder, oxygen-dependent chronic pulmonary disease, or any other condition with a similar level of medical necessity determined appropriate by the secretary of the Department of Health and Human Services (HHS).

- Incentives for providers to achieve accreditation and certification in hospice and palliative care.

If an eligible inpatient hospital, inpatient critical access hospital, or skilled nursing facility has an accredited palliative care program and meets utilization criteria, the hospital or skilled nursing facility would receive a Medicare bonus payment

of 2% for fiscal years 2011 through 2016 and a bonus payment of 1% for fiscal years 2017 through 2020. After fiscal year 2020, if an eligible hospital or skilled nursing facility does not have in place an accredited palliative care program, the hospital would see reimbursements decreased by 1%.

- **More comprehensive discharge planning for facilities.**

By Jan. 1, 2013, discharge procedures for hospitals, skilled nursing facilities, and home health agencies and admission procedures for hospice programs must include a discussion with patients and their families about the general course of treatment expected, the likely impact on the length of life and function, and the procedures they should use to secure help if an unexpected situation arises.

- **Increased public awareness about the importance of end-of-life planning.**

HHS will design and implement a national education campaign to raise public awareness of the importance of planning for care near the end of life. This grant-funded campaign will focus on the need for readily available legal documents that clearly express an individual’s wishes through advance directives, including living wills, comfort care orders, and durable powers of attorney for health care.

“Overall health reform should include a thoughtful process that informs patients, their families, and caregivers on how to navigate and think through decisions about when and how long to pursue treatments at the end of life,” said Warner. “This will allow us to foster a culture in which all of us will have the ability to age well, with dignity, based on our own wishes and in the setting of our choosing.” ■



JOURNAL REVIEWS

Palliative sedation is option for intractable pain

Although palliative sedation is used in hospitals to control intractable pain, there is little literature describing its use in a home setting for hospice patients. A study in the *Journal of Palliative Care* demonstrates the effectiveness of palliative sedation at home and the opportunity to grant the

patient's wish to die at home.¹

The retrospective study evaluated the records of 36 terminal patients who received palliative sedation. Cancer was the diagnosis for 35 patients, and most patients suffered from one or more symptoms. The most common symptom was intractable pain, followed by agitation and existential suffering.

Drugs used for sedation were midazolam, morphine, haloperidol, fentanyl TTS, and promethazine. Symptom control occurred within 24 hours, and good symptom control was achieved in 28 of the 36 patients. The median duration of the sedation was three days.

Researchers concluded that palliative sedation is an effective option for patients who want to remain at home at the end of life.

Reference

1. Rosengarten OS, Lamed Y, Zisling T, et al. Palliative sedation at home. *J Palliative Care* 2009; 25:5-11. ▼

End-of-life education important for doctors

Although physicians play a key role in providing end-of-life care, they do not receive training specific to palliative care in residency programs. A study was conducted at five medical schools in Canada to assess internal medicine residents' knowledge and perceptions regarding end-of-life care.¹

Of the 185 internal medicine residents participating in the survey, the majority (81.7%) agreed that learning from dying patients was meaningful. However, 48.1% of the respondents who felt that the experience was useful also reported feeling guilty, and 40.6% reported feeling like a failure at least sometimes after a patient died.

Two-thirds of the respondents had provided care to more than 10 dying patients, and 73% had conducted at least three family meetings. Respondents reported that 26.7% of the family meetings never were observed by another physician to provide feedback and support.

When asked about their competencies in end-of-life care activities, respondents reported record keeping as the highest competence and use of nonpharmacologic interventions the lowest competence. The internal medicine residents identified the use of opioids for management of pain as the highest priority for further learning.

The authors recommend that evaluation of medical residents' perception of their competencies in providing end-of-life care and the areas in which they need additional knowledge can be used to develop an effective educational program.

Reference

1. Schroder C, Heyland D, Jiang X, et al. Educating medical residents in end-of-life care: Insights from a multi-center study. *J Palliat Med* 2009; 12:459-70. ▼

Caregivers, providers view short enrollment differently

Although hospice providers say hospice enrollments of less than two weeks are inadequate for symptom control and counseling support for the family, patients' families don't view short enrollments in the same way.

A study published in *Palliative and Supportive Care* shows that although providers view a short admission as chaotic, most family caregivers focused on the positive assistance and support they received from the hospice providers.¹

The study was conducted in two phases with Phase I surveying hospice staff members and Phase II interviewing family members of patients who died from cancer within two weeks of hospice admission. Factors such as physical and emotional resources and informational needs that families need to cope with the process were evaluated from both perspectives.

Hospice professionals primarily described the psychosocial dynamics from a deficit perspective and in terms that illuminate distress and urgency, according to the author. Rather than focus on the urgency, family caregivers' perspectives focused

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more on the significant need for assistance, powerful emotions, and communication.

The author suggests that an assessment tool designed specifically for short admissions can help hospice providers quickly identify the immediate needs of the family. Being able to prepare for care that might involve only a few visits will help clinicians and family members feel like the short stay is less chaotic.

Reference

1. Waldrop DF, Rinfrette ES. Can short hospice enrollment be long enough? Comparing the perspectives of hospice professional and family caregivers. *Palliat Support Care* 2009; 7:37-47. ■

Web site promotes venue for cancer patients

Caring Voices is a web site (www.caringvoices.ca) set up to promote communication among cancer survivors and cancer patients and also between patients and providers.

On this site, there are discussion boards where people post messages to discuss such topics as living with cancer. Also featured are live chats. There are drop-in chats where people can come anytime and find others who are online. There are scheduled chats, which are moderated sessions, and also educational chats where a clinician, such as a dietitian, will answer questions. These chats are generic, says **David Wiljer**, PhD, director of Knowledge Management and Innovation Oncology Education/Radiation Medicine Program at Princess Margaret Hospital in Toronto.

A section for posting questions for physicians also is available. It is not a clinical care tool but is designed for more generic questions, he explains.

There also is a feature that will match up people for a more personal support experience. To participate in this personal matching service, people fill out a survey with a multitude of questions, such as whether they wish to interact with someone like themselves or at a different point of care. There are even questions about sexual preference, so a lesbian woman with breast cancer can communicate with another lesbian woman with breast cancer.

Currently, there are three communities on Caring Voices. One is designed for the general community, a second for breast cancer patients, and a third for those with gynecological cancer. ■

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