AMERICAN HEALTH CONSULTANTS®

ADULT LEARNING PRINCIPLES • DOCUMENTATION • INFECTION CONTROL • NUTRITION

HOMECARE Education Management™

INSIDE

NOVEMBER 1999

VOL. 4, NO. 11 (pages 133-144)

American Health Consultants® is A Medical Economics Company

Proper management of ALS can mean more independence

Knowledge of this complex disease can help enhance home care

Most people only think about amyotrophic lateral sclerosis (ALS) when someone they know is diagnosed with it. The fatal neurological disorder is known as Lou Gehrig's disease, named for the legendary ballplayer whose battle drew the nation's attention. Only a few months ago, ALS again was in the spotlight when it claimed yet another baseball great, Jim "Catfish" Hunter.

Nearly 5,000 people in the United States are diagnosed with the disease each year, and about the same number die, according to the ALS Association in Calabasis Hills, CA. During the course of the disease, as ALS robs the muscles of vital motor cells, many patients end up in home health care. But because the disease moves erratically, causing different symptoms in different patients, health workers may be confused and disturbed by its progression.

An inservice that explains what ALS is, what it does, and how to help patients and families cope with its physical and emotional burdens can make the difference in keeping patients independent as long as possible, says **Andrea Versenyi**, CSW, of the Greater New York Chapter of the ALS Association. "I really try to move away from the idea that this is an incurable illness and 'there's nothing we can do,' to show that there are a great number of things we can do to address specific symptoms," she says.

Versenyi conducts inservices for home health agencies to educate them about the specifics of the disease and the particulars of care needed by ALS patients. She first outlines the physiology of ALS, which is a progressive neuromuscular disease that destroys the nerve cells that form pathways between the brain, the spine, and the muscles of the body. As those nerve cells, called motor neurons, die, the brain is unable to start or control voluntary muscle movement. "I can think, 'Move my hand,' but unless those motor neurons, the nerves that control motor movement, pass that message along to the muscles, nothing will happen," Versenyi explains.

A person with ALS loses the ability to speak and swallow, eventually becomes totally paralyzed, and ultimately dies of respiratory failure. Because only motor neurons are affected, ALS doesn't harm a person's senses of sight, hearing, smell, taste, or touch. More importantly, a patient's intellectual abilities are not impaired — a point that Versenyi stresses in her inservices.

"One of the biggest complaints that people who have ALS have about their care is that they may be paralyzed and unable to talk, but they're completely alert," she says. "A lot of people say that as they begin to talk with a slurred voice, people tend to ignore them or treat them like they're stupid. I stress that in most cases of ALS, there's a very vital person trapped inside that body — a very frustrated person."

Managing symptoms

ALS occurs all over the world, among people of all races and socioeconomic backgrounds. Patients have been first-diagnosed as young as their 20s and as old as their 80s, but normally the onset of ALS comes between ages 40 and 60. Although its causes are not known, about 5% to 10% of ALS cases occur multiple times in families, and a defective gene is believed to be a possible link.

The average life expectancy from time of diagnosis is only two to five years. But thanks to recent advances in medical care, patients are living longer. Up to 10% survive more than 10 years after diagnosis, according to the ALS Association. Currently, there is only one treatment that has been found to affect the progression of ALS, although there are many other medications to manage its symptoms.

"We do talk to our people about being hopeful; if not hopeful for a cure, at least hopeful that we can manage their symptoms and keep them comfortable," says **Bettie Neal**, RN, BSN, of the Greater Philadelphia Chapter of the ALS Association. "And then, [we look] at their quality of life."

Among the most important issues for patients with ALS, Versenyi and Neal say, are mobility, eating, communication, bowel management, and breathing.

❑ **Mobility:** As ALS progresses in a patient, muscles can be affected in two very different ways, Versenyi says. If the upper motor neurons are affected (those running from the brain to the spinal column), a patient may experience spasticity or stiffness. Lower motor neuron damage, along the pathways from the spine to the muscles of the body, causes the muscles to become weak and atrophy.

"A lot of times, these things are combined," Versenyi says. "So there will be different effects in everybody who has ALS. You can work with 10 different people who have ALS, and they can show completely different symptoms. That's a little bewildering to [health care] workers. They had one person who had ALS, and that person couldn't walk, and suddenly they work with someone else who has ALS, and [that person] can't talk."

Someone suffering from spasticity will walk with what Versenyi calls a "Frankenstein step," stiffly and awkwardly, because he or she cannot bend at the knee. Medications can help relieve the stiffness, helping patients to use whatever strength they have more effectively. Improving range of motion and learning to conserve energy can help patients cope with muscle weakness.

In addition to medical interventions, Versenyi also discusses devices that can help people with ALS remain mobile. For example, a person with foot drop, or a bending of the foot due to muscle weakness, can wear a foot orthosis, a plastic guide that holds the foot in place to help facilitate walking.

"If somebody has hand weakness, they may not be able to write or brush their teeth or go to the bathroom independently," she says. "I may discuss the range of devices that can assist in doing those tasks to maintain independence.

"Perhaps someone speaks and swallows very well, but if the arm is weak, they can't lift the fork to their mouth and there will be nutritional impairment, not because they're unable to swallow but because they're unable to actively lift the food to their mouth. Unless somebody is feeding them or they learn techniques to conserve energy, they'll have problems."

As patients become more immobile, it's important to check on them regularly because they may be unable to call out or even push a panic button to ask for help. Caregivers also should shift the patient regularly to maintain skin integrity.

❑ **Eating:** Versenyi says there are thousands of muscles that allow person to speak and swallow food and liquid. ALS can interfere with those functions in myriad ways. "Maybe a person can swallow well but can't move food to the back of their mouth. Or maybe they can move the food but they can't chew the food."

Diet modifications that can help include switching to a pureed diet. Thick liquids tend to

go down more easily than thin ones. Neal says water can be one of the most difficult things to swallow. Also, foods such as a chunky soup that contain both liquid and solid parts present challenges. "Soups with chunks in them are about the worst because [patients are] trying to negotiate two very different things," she says.

If a person is having difficulty eating because of swallowing difficulties or other problems, it's time to suggest a change, Versenyi says. "They have to decide that if a meal is taking two hours, is it just too tiring, and is it time to try something different?" Ultimately, the patient may require insertion of a feeding tube when even swallowing liquids is too difficult.

❑ **Communication:** Loss of muscle control can cause patients with ALS to slur words or lose voice volume, and it an affect tongue and lip movement so they cannot actually form sounds.

"They frequently need in the beginning to see a speech pathologist," Neal says, "to work on communication skills — helping with breath support, helping them accept the need to do alternative communication to supplement their speech either writing or alternative augmentative communication, such as computer-type devices."

Adapt to technology

Versenyi says patients can use a phrase or picture board as well, but these can take time to use and interpret. A common computerized device allows the user to type words, which then are recited by a synthesized voice.

She says it is important when communicating with an ALS patient via computer to ask how the patient wants that communication to take place. Some people prefer that the listener wait for the computer to say the words, while others prefer that the listener read over the patient's shoulder so the conversation can go more quickly.

The technology can cause problems for users. "They have problems with people answering the phone and getting the computerized voice," Versenyi says. "They hang up, thinking it's one of those calls you get from marketers. It's just one of the little things, one of the difficulties and frustrations of living with this illness." She says health care workers need to continue to communicate with an ALS patient, even when that communication becomes difficult or time-consuming.

❑ **Bowel management:** Patients with ALS can suffer from severe constipation for a variety of reasons, Neal says. "There's usually several components of it. One is their immobility; they have loss of abdominal tone and can't push."

Patients also can suffer from excessive saliva, and the most common treatments for that can cause constipation as a side effect. In addition, patients may restrict water intake, either because of difficulties swallowing or because they cannot get to a toilet easily and want to prevent accidents.

"You put all those together, and they can have major problems with their bowels," Neal says. "They need constant assessment of [bowel function], and bowel regimes [need to be] changed. Very rarely does one bowel regime fit the bill for any length of time."

ALS patients are prone to ileus, or bowel obstruction, which requires frequent assessment and early intervention, which usually consists of adjusting liquid, fiber, and laxatives to keep the bowels moving. "That's something that home care nurses in particular need to be aware of," she says. "Therapists need to help with the transfer and toileting issues. If [the patient] can't get to a toilet or a commode, that needs to be addressed."

❑ **Breathing:** Because respiratory failure is the usual cause of death for a person with ALS, continual assessment of breathing capabilities is essential in home care. Neal acknowledges that the assessment can be difficult because the loss of respiratory support, like other ALS symptoms, affects people differently.

One important condition to watch for is carbon dioxide retention, which can cause a person to become confused or lethargic. Home health workers should check routinely for those signs and should ask patients if they experience morning headaches or excessive yawning, other symptoms of CO_2 retention.

Many health professionals also regularly test the patient's forced vital capacity or the amount of air a person can forcefully exhale. "I know when I've talked with people throughout the country who are involved in home care, that might not be something that the local neurologist will recommend, but it's one of the few things that can be a concrete indicator of a change in respiratory status," Neal says. "If the forced vital capacity is declining, then we know that people are at risk for respiratory compromise and respiratory failure."

As the disease progresses, a patient must decide when breathing has become too difficult and assistance such as a trach and ventilator is needed.

❑ **Psychosocial issues:** The wrenching decisions that come with living with ALS — when to

Stay current on ALS

The Amyotrophic Lateral Sclerosis Association offers a variety of publications that can help caregivers and patients with ALS:

• *Basic Home Care for ALS Patients,* revised in 1997.

• *Swallowing Problems: A Caregiver's Manual,* published by Menu Magic in cooperation with the American Speech and Hearing Association; 1991.

• *Maintaining Good Nutrition with ALS,* a guide for families produced by the ALS Association.

• *Living with ALS Manuals — Volumes 1-6.* Topics include an overview, coping with change, managing symptoms, mobility, swallowing and speaking difficulties, and adapting to breathing changes; 1997.

For patients, immediate families, and health care professionals, there is no charge for many of those publications or for shipping and handling. The association also maintains a library of fact sheets about various aspects of managing ALS. Single copies are available at no cost to patients, families, caregivers, and health professionals.

The following videotapes about living with ALS are available at a cost of up to $20, plus shipping and handling; some also are available for $5 plus shipping and handling for a two-week loan from the association:

• "What is ALS?" and "Reason for Hope," which are overviews of the disease.

• "It's Your Choice" and "Ventilation: The Decision Making Process," which are about the decision to use a ventilator.

For more information about any of those resources, write to the ALS Association, 21021 Ventura Blvd., No. 321, Woodland Hills, CA 91364. Phone: (818) 880-9007. Patients can call the Information and Referral Service Line at (800) 782-4747. Fax: (818) 880-9006. E-mail: miriam@alsa-national. org. Web site: www.alsa.org. ■

submit to a feeding tube or a ventilator, for instance — as well as the knowledge that the disease is ultimately fatal can be an overwhelming burden to the patient and the family.

Versenyi and Neal point to outside forces that can worsen the situation, such as financial concerns and insurance hassles. "Is the caregiver forced to stop working in order to care for the patient? Is the caregiver forced to go out and find a job in order to care for the patient? There are all sorts of ways this can affect a family," Versenyi says. "What effect does it have on a child? What effect does it have on a parent to no longer be able to parent their children in the way they would like?"

The strain of watching one's body waste away while remaining mentally alert can be frustrating and can lead to control issues. "The patient is dealing with a tremendous loss of control, and they will exert their control sometimes in very negative ways," Versenyi says. "They will refuse to get up at a certain time — if they know they have a doctor's appointment at 9:30, they won't get up until 9 o'clock, which definitely doesn't enable them to get there on time.

"The caregiver will be furious with them. The patient may be doing that because it's the only way they can have some sort of control, because there's not a lot they're able to actively do."

Offer choices

Home health workers need to offer the patient what control they can by allowing the patient to make choices. "I think it's important when you go in there, to at least say, 'I want to do things the way you want them done,'" Versenyi says.

"If somebody tends to say no, it's never right, oftentimes you can give them options that don't give them room for 'no,' [such as] 'Would you like to have your medication before your shower or after your shower?' 'Would you like apple juice or orange juice?' [Those questions] still give the patient a choice."

Neal says home health staff should be ready to refer patients and families to appropriate community services, including caregiver support groups or other agencies.

Versenyi agrees, noting that it also takes a team of medical professionals to treat someone with ALS. An aide dealing with a very stiff patient can tell a nurse, who can take word back to the physician so a patient might get medication that can help. A speech pathologist can be called in to assist with communication skills.

"I think whoever is in the house should not feel like they have to do it alone," Versenyi says.

Caring for a patient with ALS can be traumatic for home health providers as well, Versenyi and Neal say. Versenyi, a certified social worker, says that before her affiliation with the ALS Association, she worked in hospice and dreaded working with patients who had the disease.

"I think for care providers, usually the ALS patient is of the same age range; they're a younger population oftentimes," she says. "They may have school-age children at home. I think there's something that's emotionally powerful for the

care provider in thinking, 'Here's a person who's sort of my age.'"

Contributing to the burden is the horror of how the disease progresses; it makes patients prisoners in their own bodies and plays on the instinctive human fear of suffocation. "I'll talk a little bit about how respiratory failure with ALS is not like having an asthma attack," she says. "It's a more gentle process. It's not a violent process, it can be a very peaceful death." She encourages home health workers to discuss concerns and feelings with others in the agency so they can refocus on helping patients. Doing so can alleviate feelings of helplessness. "Often what I find happen is the aides or the nurses are furious at the agency because they feel that they're not getting adequate support. And usually it's not that the agency is not providing adequate support, it's that what one can do with someone who has ALS never feels like enough."

Neal says even with the constraints imposed by managed care or other insurance, she rarely has seen problems with necessary support not being covered. "As long as we can justify the changes and what our expectations are for the treatment, they've approved it. I think that's what home care needs to understand. It is a disease that's very tragic, but nobody's going to keep the nurse or the therapist in there because it's a tragic disease. They need to be monitoring and making sure that their treatment regime is appropriate and necessary."

She and Versenyi encourage home health agencies to take advantage of the wide network of support available to ALS patients and caregivers. Information and contacts are available through the national ALS Association and its many local branches, as well as through other groups. **(For publications and videotapes, see box, p. 136. For Web sites, see Internet Connect, above right.)**

"We can give them specific strategies for dealing with ALS, knowing what the illness is, knowing the range of treatments available," Versenyi says. "I love it when home health agencies call me." ■

SOURCES

- **Andrea Versenyi**, Greater New York Chapter, ALS Association, 116 John St., Suite 1304, New York, NY 10038. Phone: (212) 619-1400. Fax: (212) 619-7409. E-mail: versenyi@als-ny.org.
- **Bettie Neal**, Greater Philadelphia Chapter, ALS Association, 500 Office Center Drive, Suite 340, Fort Washington, PA 19034. Phone: (215) 643-5434. Fax: (215) 643-9307. E-mail: bettieneal@aol.com.

Internet Connect

Sites for ALS knowledge

Those interested in finding out more about ALS can find a treasure trove of information on the Internet, beginning with the Web site operated by the ALS Association:

- **www.alsa.org** — This site for the national organization gives the reader a detailed description of the disease, statistics, lists of services and contacts, and access to publications, manuals, and references. It also offers links to local chapters, which can provide more regional contacts.
- **www.bcm.tmc.edu/neurol/struct/als/als7f.html** — Run by the Baylor College of Medicine, this offers a handy four-page explanation of symptoms, treatments, adaptive devices, nutrition, and exercise advice for patients with ALS.
- **www.mdausa.org/publications/alsmats.html** — The Muscular Dystrophy Association, which bills itself as the largest nongovernmental sponsor of ALS research and service, maintains a large library of materials on ALS, many of which can be viewed for free on this Web site. Included is *When a Loved One has ALS: A Caregiver's Guide.*
- **bro@huey.met.fsu.edu** — writing to this e-mail address asking to subscribe will get you on the mailing list of the ALS Digest Online. ■

Lead your home care staff into the new millennium

Nurses need to understand their new roles

As home health educators lead their staffs into 2000, they must show how staff roles are changing in this era of increased regulation and managed care. Home health nurses are responsible for more documentation and outcome-based care planning and for the financial effects of decisions made in the field. They need to know more than ever about the limits on the care they provide and the intricacies of reimbursement, especially with Medicare moving next year to a total prospective payment system.

"Because of all the reimbursement changes that Medicare is putting through, you have to look at each visit as having much more meaning than it

ever did," says **Margo Zink**, RN, BSN, MN, EDD, CNAA, a home care consultant in Timonium, MD.

A focus on cost-effectiveness can be difficult for nurses, who may have been taught that their only concern should be quality care, says **Elizabeth Hogue,** Esq., a Burtonsville, MD, health law attorney. "Part of the education that needs to go on now with nurses is that . . . their job is not just to provide quality care but to provide quality, cost-effective care," she says. "That is especially true in home care, where nurses are really the gatekeepers of the Medicare home care system. But helping nurses see that there are limits and boundaries to home care is really, really tough."

One area Hogue says needs attention is assessment of those patients who should not receive home care. Diligent attention to the criteria needed for successful home care — the ability to meet a patient's needs at home, a reliable caregiver or ability to self-care, and an adequate home environment — can ensure patients are in the best setting for treatment. It also can prevent accusations of abandonment if an agency decides later it can no longer treat a patient. "When patients don't meet those three criteria, they just gobble up resources that the agencies just don't have any more," she says.

A new time crunch

Reimbursement changes also are driving an increased focus on outcome-based care — using realistic endpoints to manage delivery of care, often in an abbreviated time frame, Zink says. "Unfortunately, I think a lot of staff still look at a Medicare time frame, and then when they get patients for whom the HMOs only allow them four visits, it's difficult for them to adjust their goals. You can't project for nine weeks if you don't have those granted to you, and I think that places staff in a real ethical dilemma.

Education can help nurses set realistic goals that include an accelerated patient and caregiver teaching component.

"They need to look at doing more work teaching family members to assume that role more quickly. They can't just think about it. They have to make a decision right away and start their teaching," Zink says. "The whole time crunch is really difficult to deal with when, in home care, you never had that time crunch before."

She says the greater emphasis on self-care requires keener observation skills and a willingness to make tough choices on the part of both nurses and aides. "I think the issue of teaching vs. doing is something that nurses especially have to adjust to. By virtue of the nature of nursing as sort of an altruistic, helping-type profession, to say to this 80-year-old woman, 'You're going to learn how to give your own injections,' is a more difficult thing than to say, 'I'm going to come every day and give this injection for you.'

"I think it goes with being an aide, also. The home health aide has to give a bath and must determine whether Mrs. Jones can go in and do a partial bath in the bathroom. It's easier for her to not ask Mrs. Jones and just give her a bed bath."

Hogue says the problem is compounded by the fact that patients and families don't always understand the role of home care. They may believe that the home health nurses will perform the same role they did in the hospital — taking care of all the patient's needs.

"During the admission visit, staff should be very direct with primary caregivers about the role they must play," Hogue says. "They must further make it clear that if the primary caregivers fail to fulfill their role, patients simply cannot remain in home care."

The time crunch has another result as well: It places a premium on precise, detailed documentation, not just to safeguard reimbursement but to ensure that care is smooth and consistent, with no gaps or overlaps in treatment or training.

"For example, the nurse says [in the patient's chart] that she's going to teach the patient how to do an insulin injection," Zink says. "How does she go about it? How does she assess the patient? If I'm reviewing the chart, what are the steps? Can I tell the steps she's going through to do that?

"Every visit has to blend with the next one. If I go out and do this teaching after this other nurse has been doing it, and I don't have a clear picture if she's finished steps one and two, then I'm either going to be repeating it or I'm going to be skipping over something," she says. "Each visit has to be much more closely interlocked with the previous visit and the future visit."

The drive to provide cost-effective care and to shorten care plans coincides with the continuing referral to home care for patients who are sicker with more complex ailments. The convergence of all of those factors places a greater burden on case managers, who are responsible for coordinating care. Zink says the concept of case management should be better defined for nurses and more rigorously emphasized.

"I was just working at this big agency, I would say a sophisticated agency, and the nurse who was

supposed to be the case manager didn't even know if a contracted physical therapist was still on the case or not," she says. "I said to this person, 'Aren't you the case manager?' And the response was sort of, 'Well, am I supposed to know that?'"

She says training should emphasize the accountability of a case manager to ensure the patient's goals are met by the entire team and that disciplines are not in conflict with one another.

With more technically advanced medical equipment and medications introduced every year, even a well-trained nurse can find it hard to keep up. Agencies should be sure they're supporting staff by providing continuing education before nurses are asked to use such advances in the field, Zink says. "If they're getting high-tech cases, they're getting high-tech equipment, the system needs to continually make available to nurses who are not familiar with technology a way to feel comfortable and not put them in a liability standpoint and just expect them to learn on the job by themselves."

The advantage of some of those advances is that they actually make the care easier, more readily lending themselves to use by patients or family members.

"It's a trend we've been seeing for a number of years," Zink says. "It's amazing what patients or family members can do themselves, with a nurse monitoring it, because of the advancement of say, infusion pumps. It's much more user-friendly and can be done safely by a layperson."

As home health agencies continue to draw staff from hospitals, educators need to focus on preparing those newcomers for the different environment in which they'll be working. Zink says she has worked with good, qualified nurses who still had problems because they hadn't gotten the necessary grounding in the particular challenges of home care. "I was working with a wonderful nurse, a cardiac specialist, but she had never been oriented to home care. She had the assessment skills, a wonderful manner with patients, but she didn't know how to document effectively because no one had taken the time to mentor her in this system."

Hogue says agencies need to continue to place focus on educating their employees about rules designed to combat Medicare fraud and abuse. "They need to have a corporate compliance plan, and part of the corporate compliance plan is that employees need to receive 2½ to three hours of education every year about compliance issues."

Staff often don't understand that regulators don't have to prove staff knowingly claimed services that weren't provided, Hogue says. "Court decisions say that if enforcers can prove that providers knew or should have known of a pattern of fraudulent conduct, enforcers may conclude that staff had intent."

Hogue says nurses need to know that every health care provider, regardless of his or her position, can be held responsible for fraud and abuse compliance. She cites fraud charges brought against a home health agency in Florida regarding billing for visits that were never made. In that case, action was taken against managers at the agency and individual nurses. "I know that people feel a little bit jaded about this now, but it remains very, very important." ■

SOURCES

- **Elizabeth Hogue**, Health Law Attorney, 15118 Liberty Grove, Burtonsville, MD 20866. Phone: (301) 421-0144. Fax: (301) 421-1699.
- **Margo Zink**, Consultant, 740 Chapel Ridge Road, Timonium, MD 21093. Phone: (410) 561-8046. Fax: (410) 561-7731. E-mail: rzink@aol.com.

Not just for the young: AIDS and HIV hit seniors

Teach staff about older HIV/AIDS patients

As the epidemic of human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) matures in this country, health care providers are seeing new populations threatened by the disease. Among them are older patients, infected through long-ago blood transfusions or more recent sexual activity or IV drug use.

Patients ages 50 and older make up only a small portion of the total AIDS population — 72,161, or a little more than 10% of the total 688,200 U.S. cases reported to the Centers for Disease Control and Prevention through 1998. But the number appears to be growing, particularly in areas that serve a large geriatric population. Because home health workers deal with a largely older client population, they should be alert to the possibility of geriatric AIDS patients and the special needs of older clients with the disease.

In Broward County, FL, health providers are dealing with a relatively recent increase in AIDS cases among seniors, local experts say.

"It's estimated that five to 6% of the hospice population here locally is geriatric and HIV-positive," says **Bart Strang**, PhD, clinical gerontologist, and director of the Center for Gerontology in Fort Lauderdale, FL. "There is a study being conducted now that indicates that other than black women, the elderly population is fastest growing [infected] population locally."

And that's not taking into account the many older patients who do not realize they have HIV, because no one has thought to screen them. This is a particularly crucial point because the earlier HIV infection is detected, the more likely it is that the newest medicines can help retard the progression of AIDS.

AIDS and HIV are "absolutely not diagnosed as soon in the older population," says **Martha Harrop,** ARN, MSN, MBA, director of client services for Broward House Inc., a Fort Lauderdale facility that provides a wide range of services to AIDS and HIV-infected patients. "The biggest problem is that physicians, especially private physicians, do not think to put HIV in the differential diagnosis, so a lot of the cases are not caught until late."

The most common illnesses associated with AIDS, including a form of pneumonia, are similar to conditions often found among noninfected seniors. Strang says a particular form of AIDS-related dementia often isn't diagnosed properly in older patients because it is assumed to be Alzheimer's disease.

Home health workers should keep in mind the following issues as they care for their clients:

• **Infection control:** "They've got to use universal precautions at all times, period," Harrop says. "I know especially as they get very familiar with a certain client, they may become lax. They shouldn't."

• **Assessment questions:** Home health nurses can help call attention to high-risk seniors by asking direct questions in assessments about risk factors for HIV. Items to check for include past blood transfusions, unprotected sexual activity (particularly with multiple partners), and drug use.

"One of the most overlooked things in seniors is drug and alcohol abuse," Harrop says. "That includes legal and illegal drugs. I've had several folks over 50 who were crack addicts."

Strang has rarely found elderly patients who have used illegal intravenous drugs, but he points out that certain forms of dementia can result in a decrease in social control in both men and women and can lead to increased sexual promiscuity.

Now that the incidence of infection through heterosexual sex is increasing, heterosexual seniors, like anyone else having sex, should use protection such as condoms to prevent the spread of AIDS or other sexually transmitted diseases. Strang said an education program now is under way in the Broward area to educate seniors about AIDS prevention.

AIDS is an immune system disorder brought about by infection with HIV. The disease leaves the patient susceptible to a host of debilitating illnesses, often called opportunistic infections. Many of the most common AIDS-related infections, such as *Pneumocystis carinii* pneumonia and Kaposi's sarcoma, are extremely rare among people who do not have AIDS. As the body becomes weaker, the patient eventually dies from one of these opportunistic infections.

Proper dose, proper time

Although no cure has been discovered for AIDS, recent advances have led to a successful drug cocktail that, when used by an infected patient, can lower the measurable level of HIV in the blood. The drugs are taken on a strict schedule; missed doses can help the virus become resistant.

"Unfortunately with geriatric patients, I think you've got more of a problem of forgetting to take medication," Strang says. He cites a study that showed seniors taking eye drops for glaucoma would often forget to take it for two or three days, then take a large dose to compensate.

Home health workers should emphasize to patients how important it is to take the medications at the proper times, and they should monitor medication use.

One of the hallmarks of AIDS is a wasting of the body, related to a host of factors that include diarrhea, vomiting, and malabsorption. Harrop says a proper diet is vital, one high in calories but low in fat. "It's kind of like everything your mother ever taught you: Eat your vegetables, get plenty of rest, get a moderate amount of exercise, take your medicine, see your doctor regularly," she says. "But if you have a senior population that is not caring for their nutritional needs, it's going to compound their HIV." She suggests making sure seniors have access to Meals on Wheels or another service that helps them eat a balanced diet.

In general, Strang says, the progression of AIDS among seniors does not appear to be significantly different than it is for other patients. Older patients do not appear more likely to be infected

SOURCES

- **Bart Strang**, Clinical Gerontologist/Director, Center for Gerontology, 2110 N.E. 30th St., Fort Lauderdale, FL 33306. Phone: (954) 565-4858. Fax: (954) 561-1168. E-mail: agedoc@bellsouth.net.
- **Martha Harrop**, Director of Client Services, Broward House Inc., P.O. Box 350367, Fort Lauderdale, FL 33335. Phone: (954) 522-4749. Fax: (954) 522-9357. E-mail: bhaids@aol.com.

by exposure to HIV and don't seem to progress more quickly from HIV infection to AIDS. However, their battle against the disease is often complicated by other illnesses. For example, he points out that a common drug for AIDS, stavudine, can be neurotoxic and so could affect a person who already suffers from Alzheimer's disease.

AIDS can cause its own form of dementia as the disease attacks nerve cells in the brain. Strang estimates that 20% to 30% of all people with AIDS develop AIDS dementia complex. "It's a little harder to get an estimate in the elderly population directly, because obviously you've got the incidence of Alzheimer's dementia in the elderly that can mask the AIDS dementia," he says. The only way to discern the difference between the two is through sophisticated testing or an MRI.

But home health nurses can be alert for signs of dementia and report them quickly so a patient can be screened as soon as possible. AIDS-related dementia can be lessened significantly by another AIDS drug, zidovudine.

Strang suggests providers regularly administer the Folstein Mini-Mental State Examination. "It's a cognitive screen for dementia in the elderly," he says. "It gives baseline estimates as to cognitive functioning in memory, language, visual/spatial capabilities, speech, that type of thing." He says it's important to establish a baseline for those functions so they can be tracked over time.

Strang also suggests administering another test, the Geriatric Depression Scale, which gives a quantitative score for degree of depression in a patient. He notes that even without the introduction of an incurable, fatal illness, seniors are at risk for depression. "Aging is a depressing experience for just about everybody. It's characterized by loss of capabilities, loss of social status, loss of memory, loss of friends and family."

Harrop says that in her experience, older clients deal with a diagnosis of HIV or AIDS with more maturity than younger ones, but they often lack the support network that younger clients have. They may feel uncomfortable discussing their illness with friends their own age or their family.

"There's a measure of isolation and, also with this population, a lot of shame and guilt that you don't see in the younger population," she says. "Certainly, younger people are sorry they got HIV, but there's a certain bravado about being very sexual that you don't find in older people."

Older patients with HIV may not realize how much help there is, particularly in larger cities, to assist them in coping with the disease, Harrop says. "They have access to a large network of support specifically aimed at HIV and AIDS patients in virtually every metropolitan area. They can get everything from mental health to chiropractic services to massage therapy."

She encourages home health workers to become knowledgeable about what agencies provide help to AIDS patients and to inform their clients. "If seniors are not in the system at all, they may lose out on the services completely." ■

Tips **From the Field**

Simplify dressing use by categorizing products

Teach nurses basics of alternatives to gauze, saline

There are thousands of choices of products to dress patients' wounds. So how does an agency teach its nurses which to use and recommend? At Johns Hopkins Home Care in Baltimore, nurses have focused on a few categories of important wound care products and learned to look for the best alternative to the traditional gauze and saline order given by physicians.

The need for more potent alternatives stems from the difference between wound care in a hospital setting and under the very different conditions of home care, explains **Brenda J. Hensley,** MSN, RN, CETN, clinical nurse specialist at Johns Hopkins Home Care. She says hospitals are sending home patients earlier with more complex wounds that can take longer to heal.

"We're doing more extensive surgeries on people who are more and more debilitated, compared to maybe 10 years ago," she says. "Of course, the older you are and the more compromised you are, the more difficult and slower the healing process."

Meanwhile, she says, hospital physicians are not always as knowledgeable about the more technologically advanced — and substantially more expensive — wound care supplies now available. "At the hospital, you have a wonderful nurse who goes to change dressings three times a day. You also have medical residents and interns, and they all want to look at the wounds. The newer products are designed not to be changed very often, so if you're in a hospital, it's not going to be cost-effective to use these dressings. They don't have a reason to use them [in the hospital], so they don't know that much about them."

But in home care, where a nurse's time is at a premium, the added expense of the newer dressings can be more than offset by the savings due to fewer visits. Most importantly, Hensley says, the use of newer dressings can actually help wounds heal more quickly. "Wounds heal faster when the dressings are changed less often. The less you disturb them, the faster the cells can regenerate. It makes sense, if you can maintain a good environment, to only change them two or three times a week."

Extra training

At Johns Hopkins Home Care, all new employees take a three-hour wound class. The agency also has a trained group of resource nurses, including one on each of its geographically defined teams. Those resource nurses receive an extra one-hour training session every month. The program consists of case studies and product reviews, so the resource nurses can go back to their regions and serve as a resource for other staff.

At the next level of training are six certified wound, ostomy, and continence nurses (WOCN), wound care specialists such as Hensley who meet monthly to sort through the vast array of new products on the market. "We are introduced to new products in different ways," she says. "In our system, we have an outpatient wound healing center. That's all they do is treat chronic wounds. They get a lot of the newer products, and we get them and try them that way, too."

Some successful products are added to the agency's inventory. Others are dropped after proving to be less than effective.

When teaching nurses to deal with different wounds of varying complexity, the agency has tried to reduce the number of dressings to four major types that Johns Hopkins Home Care calls its primary dressings:

- The **gauze and saline combination** typically ordered by physicians.
- **Calcium alginate**, which Hensley says is the most common dressing recommended for home care patients with draining wounds such as pressure ulcers and surgical wounds. She says the seaweed-based dressing absorbs 10 times its weight in wound drainage while lowering the pH in the wound bed, which retards the growth of bacteria.

"So it actually decreases the incidence of infection in the wounds, and, therefore, we don't need to change it so often," she explains. "If you use a traditional gauze dressing, it's very much compatible with bacterial growth. If you use calcium alginate dressings, because you're not going to have that problem with bacteria, it's safe to change it two or three times a week instead of two or three times a day, which is what the traditional gauze dressing requires."

- **Wound hydrogels**, used on drier wounds that aren't draining as much, where the goal is to continue healing. "[The wound] is clean, it's pink, it's healing, and we just want to keep it that way," Hensley says. The gel comes in tubes or sheets or is impregnated in gauze. It absorbs a small amount of drainage but won't stick to the wound bed and promotes healing. It generally requires daily dressing changes.
- **Dry hypertonic solutions** for wounds that are grossly necrotic, infected, or malodorous. This is a solution that's placed on gauze then dehydrated. When placed in the wound, it pulls drainage out of the wound through osmotic pressure and helps debride dead tissue. Hensley says such dressings clean up infections faster than traditional gauze dressings. The most common such product used at Johns Hopkins Home Care is called Mesalt.

She says nurses are taught that when they assess a new patient with a standard order for gauze and saline, they should look for signs that another type of dressing might be more effective and to call the physician for an order change.

"Our nurses know automatically to call the physician or the nurse practitioner, whoever is sending the patient, and immediately try to make an order change for one of these three products, depending on what the wound sounds like. If we're not sure what we have to deal with, we

might just leave it with the original saline and gauze until somebody gets out to the house to evaluate it," she explains.

After changing to a new type of dressing, the nurse continues to reevaluate the wound, to look for improvement or for signs of infection. If after a week to 10 days there are no signs of healing, the nurses can request that a WOCN come out and look at the patient to determine what to do next. In those cases, the agency can turn to an arsenal of secondary dressings, usually much more intensive and expensive than the first, to see if they will do a better job. Some of those options include the following:

• **Regranex gel**, specifically used to treat diabetic foot ulcers that won't heal.

• **Iodasorb gel**, which Hensley describes as a favorite first choice for wounds that aren't healing using the normal primary dressings. Iodasorb gel has a small amount of iodine in it and has some antiseptic properties, while also keeping the wound bed moist and absorbing wound drainage.

"You're combining a hydrogel with an antiseptic with absorptive properties, so you get kind of three effects," she says. "You don't want to dry your wound out, and a lot of traditional dressings we used in the past are very drying to the wound bed. In the olden days, we thought that was good, but now we know you want it to stay moist."

Iodasorb gels have been found to work quite well on lower leg wounds, diabetic foot wounds, or post-op surgery wounds that aren't healing properly.

• **Collagens**, which promote wound healing through the stimulation of fibroblasts. Used in a gel or sheet form, they can sometimes jump-start healing in a chronic or non-healing wound when nothing else is working, Hensley says. "The collagens need to be applied twice a day, but you teach the families how to do that. If you don't have a compliant patient or an individual that's caring for them, you might not even be able to use some of these products. Everything kind of gets weighed when you're trying to decide what to use."

• **Vacuum-assisted closure (VAC)**. In this procedure, a sponge is inserted into the wound, connected through tubing to low-level, continuous suction through a portable suction machine. "This actually will increase the amount of red blood cells that are feeding the wound, speed up the healing process," Hensley says. "What I've learned is that it works really well on wounds that have tunnels, steep tracks that take forever to heal. If you've got a lot of wound drainage you can't control with any other type of dressing — the family tells you they're changing dressings three times a day, it's draining everywhere, and you're having nurses going in more frequently — those are reasons we might try the VAC."

That high-tech relief comes with a high price tag — Hensley estimates that it costs about $3,500 a month to operate the VAC. But the dressing only needs to be changed twice a week.

"Think about an insurance company that is paying for 14 nursing visits a week, and the wound isn't healing," she says. "If we go down to two a week, even though the treatment is much more expensive, if you cost out the visit, the cost of the nurse, $100 a visit, that's $200 a day. The VAC is still cheaper. Plus, it will help the wound to heal faster. There's nothing more expensive than a wound that won't heal."

Such intensive efforts are discontinued if they don't make a significant impact on the wound in up to two weeks, Hensley says. Knowing that, insurance companies have been agreeable to paying for the pricier options, if it results in reduced visits. "That's exactly what they're interested in: How can we heal the wound, prevent infection, prevent complications, and have as few nursing visits as possible? Those are everybody's goals."

Fortunately, doctors have become more knowledgeable in recent years about the benefits of newer dressings and are more willing to order them. "Some of the physicians will say, 'It doesn't matter what I order. One of your nurses is going to call me to change the order,'" Hensley says with a laugh.

Even with the use of more advanced dressings and wound treatments, Hensley stresses that every wound is different, and the same products won't work for every patient. When evaluating a patient with a wound, nurses should look at a number of other factors, such as nutrition, since bodies need calories and protein to promote healing; resources, including caretakers and the money or insurance coverage to afford the dressings; and the cleanliness and safety of the home. ■

SOURCES

- **Brenda J. Hensley**, Clinical Nurse Specialist, Johns Hopkins Home Care, 2400 Broening Highway, Baltimore, MD 21224. Phone: (410) 499-8024, Fax: 410 633 3863. E-mail: bhens@erols.com.

United States Postal Service

Statement of Ownership, Management, and Circulation

1. Publication Title	2. Publication No.	3. Filing Date
Homecare Education Management	1 0 8 7 - 0 3 8 5	9/24/99
4. Issue Frequency	5. Number of Issues Published Annually	6. Annual Subscription Price
Monthly	12	$319.00

7. Complete Mailing Address of Known Office of Publication *(Not Printer) (Street, city, county, state, and ZIP+4)*
3525 Piedmont Road, Bldg. 6, Ste. 400, Atlanta,
Fulton County, GA 30305

Contact Person: Willie Redmond
Telephone: 404/262-5448

8. Complete Mailing Address of Headquarters or General Business Office of Publisher *(Not Printer)*
3525 Piedmont Road, Bldg. 6, Ste. 400, Atlanta, GA 30305

9. Full Names and Complete Mailing Addresses of Publisher, Editor, and Managing Editor *(Do Not Leave Blank)*

Publisher *(Name and Complete Mailing Address)*
Don Johnston, 3525 Piedmont Road, Bldg. 6, Ste. 400, Atlanta, GA 30305

Editor *(Name and Complete Mailing Address)*
Suzanne Koziatek, same as above

Managing Editor *(Name and Complete Mailing Address)*
Lee Landenberger, same as above

10. Owner *(Do not leave blank. If the publication is owned by a corporation, give the name and address of the corporation immediately followed by the names and addresses of all stockholders owning or holding 1 percent or more of the total amount of stock. If not owned by a corporation, give the names and addresses of the individual owners. If owned by a partnership or other unincorporated firm, give its name and address as well as those of each individual. If the publication is published by a nonprofit organization, give its name and address.)*

Full Name	Complete Mailing Address
American Health Consultants	3525 Piedmont Road, Bldg. 6, Ste 400
	Atlanta, GA 30305

11. Known Bondholders, Mortgagees, and Other Security Holders Owning or Holding 1 Percent or More of Total Amount of Bonds, Mortgages, or Other Securities. If none, check box → ☐ None

Full Name	Complete Mailing Address
Medical Economics Data, Inc.	Five Paragon Drive
	Montvale, NJ 07645

12. Tax Status *(For completion by nonprofit organizations authorized to mail at nonprofit rates.) (Check one)*
The purpose, function, and nonprofit status of this organization and the exempt status for federal income tax purposes:
☐ Has Not Changed During Preceding 12 Months
☐ Has Changed During Preceding 12 Months *(Publisher must submit explanation of change with this statement)*

PS Form **3526**, September 1998 *See instructions on Reverse)*

13. Publication Name: Homecare Education Management

14. Issue Date for Circulation Data Below: November 1999

15. Extent and Nature of Circulation			Average No. of Copies Each Issue During Preceding 12 Months	Actual No. Copies of Single Issue Published Nearest to Filing Date
a. Total No. Copies *(Net Press Run)*			524	500
b. Paid and/or Requested Circulation	(1)	Paid/Requested Outside-County Mail Subscriptions Stated on Form 3541. *(Include advertiser's proof and exchange copies)*	344	256
	(2)	Paid In-County Subscriptions *(Include advertiser's proof and exchange copies)*	0	0
	(3)	Sales Through Dealers and Carriers, Street Vendors, Counter Sales, and Other Non-USPS Paid Distribution	0	0
	(4)	Other Classes Mailed Through the USPS	0	0
c. Total Paid and/or Requested Circulation *(Sum of 15b(1) and 15b(2)*			344	256
d. Free Distribution by Mail *(Samples, Complimentary and Other Free)*	(1)	Outside-County as Stated on Form 3541	0	0
	(2)	In-County as Stated on Form 3541	0	0
	(3)	Other Classes Mailed Through the USPS	0	0
e. Free Distribution Outside the Mail *(Carriers or Other Means)*			12	12
f. Total Free Distribution *(Sum of 15d and 15e)*			12	12
g. Total Distribution *(Sum of 15c and 15f)*			356	268
h. Copies Not Distributed			168	232
i. Total *(Sum of 15g, and h.*			524	500
Percent Paid and/or Requested Circulation *(15c divided by 15g times 100)*			96	96

16. Publication of Statement of Ownership
Publication required. Will be printed in the November issue of this publication. ☐ Publication not required.

17. Signature and Title of Editor, Publisher, Business Manager, or Owner: Publisher — Date: 9/24/99

I certify that all information furnished on this form is true and complete. I understand that anyone who furnishes false or misleading information on this form or who omits material or information requested on the form may be subject to criminal sanctions (including fines and imprisonment) and/or civil sanctions (including multiple damages and civil penalties).

Instructions to Publishers

1. Complete and file one copy of this form with your postmaster annually on or before October 1. Keep a copy of the completed form for your records.
2. In cases where the stockholder or security holder is a trustee, include in items 10 and 11 the name of the person or corporation for whom the trustee is acting. Also include the names and addresses of individuals who are stockholders who own or hold 1 percent or more of the total amount of bonds, mortgages, or other securities of the publishing corporation. In item 11, if none, check the box. Use blank sheets if more space is required.
3. Be sure to furnish all circulation information called for in item 15. Free circulation must be shown in items 15d, e, and f.
4. Item 15h., Copies not Distributed, must include (1) newsstand copies originally stated on Form 3541, and returned to the publisher, (2) estimated returns from news agents, and (3), copies for office use, leftovers, spoiled, and all other copies not distributed.
5. If the publication had Periodicals authorization as a general or requester publication, this Statement of Ownership, Management, and Circulation must be published; it must be printed in any issue in October or if the publication is not published during October, the first issue printed after October.
5. In item 16, indicate date of the issue in which this Statement of Ownership will be published.
6. Item 17 must be signed.

Failure to file or publish a statement of ownership may lead to suspension of second-class authorization.

PS Form **3526**, September 1999 *(Reverse)*

Homecare Education Management™ (ISSN 1087-0385) is published monthly by American Health Consultants®, 3525 Piedmont Road, Building Six, Suite 400, Atlanta, GA 30305. Telephone: (404) 262-7436. Periodical postage paid at Atlanta, GA 30304. POSTMASTER: Send address changes to **Homecare Education Management™**, P.O. Box 740059, Atlanta, GA 30374.

Subscriber Information

Customer Service: (800) 688-2421 or fax (800) 284-3291, (customerservice@ahcpub.com). Hours of operation: 8:30 a.m. -6 p.m. Monday-Thursday; 8:30 a.m.-4:30 p.m. Friday.

Subscription rates: U.S.A, one year (12 issues), $319. Approximately 18 nursing contact hours annually, $369; Outside U.S.A., add $30 per year, total prepaid in U.S. funds. One to nine additional copies, $191 per year; 10 to 20 additional copies, $128 per year. Call for more details. **Back issues**, when available, are $53 each. (GST registration number R128870672.)

This continuing education offering is sponsored by American Health Consultants®, which is accredited as a provider of continuing education in nursing by the American Nurses Credentialing Center's Commission on Accreditation. The provider is approved by the California Board of Registered Nursing, provider number CEP 10864, for approximately 18 contact hours. Opinions expressed are not necessarily those of this publication. Mention of products or services does not constitute endorsement. Clinical, legal, tax, and other comments are offered for general guidance only; professional counsel should be sought for specific situations.

Editor: **Suzanne Koziatek**, (koziatek@intertek.net).
Vice President/Group Publisher:
Donald R. Johnston, (404) 262-5439, (don.johnston@medec.com).
Managing Editor: **Lee Landenberger**, (404) 262-5483, (lee.landenberger@medec.com).
Production Editor: **Terri McIntosh**.

Editorial Questions

Questions or comments? Call **Lee Landenberger** at (404) 262-5483.