Increasing the Autonomy Of "Old Souls"

"Old souls" is the phrase Reed V. Tuckson, MD, uses to describe his elderly patients. Tuckson, president of Charles R. Drew University of Medicine and Science in Los Angeles, talked about some of them in his keynote address at last fall's annual meeting of the American Association of Homes and Services for the Aging (AAHSA) in Orlando, FL.

Tuckson, who spoke the day before the congressional election, warned his listeners that the conservative mood sweeping the nation would result in reduced government spending on healthcare, including care for the elderly. The Medicare cuts currently contemplated by Congress appear to confirm Tuckson's prediction.

As always, patients' autonomy is likely to be one casualty of budget cuts, Tuckson said. To illustrate his point, he described the case of a former patient, an elderly woman he had treated for severe peripheral neuropathy. "With the help of Meals on Wheels and visiting nurses, this 'old soul' was able to remain in her home despite her problems," said Tuckson. "But then funding was cut and she lost the aid that enabled her to be independent. She had to go into a nursing home. I considered that a real tragedy."

Safety regulations limit autonomy, said Sr. Lucia Gamroth.

Even more ominous than likely spending cuts, he said, is the increasing atomization of society. "Pollsters tell us more and more how different we are from each other," Tuckson said. "But we need to remember how *alike* we are. If we just listen, we can hear many of our 'old souls' screaming at 3 in the morning. The truth is that pain, suffering, and death unite all Americans."

Tuckson said he welcomes managed care because it enables healthcare workers to treat communities rather than individuals. But, he told the audience, it also means healthcare workers will have to make a greater effort to identify with their residents and patients. He said he once prescribed a diuretic for an elderly woman with congestive heart failure, but she did not take it and soon had to be hospitalized.

"And that was my fault," said Tuckson. His patient, who rode the bus daily, did not take the diuretic because she was afraid it would make her incontinent. Her fear was compounded by the fact that she had grown up in the segregated South, where journeys via public transportation were in themselves often tense and potentially embarrassing for black people. "I would have guessed this if I had taken the time to know this 'old soul' better," Tuckson said. "We simply have to *connect*."

Aiming at Autonomy

Sr. Lucia Gamroth, PhD, of the Benedictine Institute for Long-Term Care, Mt. Angel, OR, emphasized the importance of autonomy for residents of long-term care facilities.

Long-term care givers can best increase residents' autonomy by "opening up" their facilities and making them more homelike, Sr. Gamroth

"DO NOT ISOLATE YOURSELVES"

Daniel Reingold, associate executive vice president of the Hebrew Home for the Aged, Riverdale, NY, suggested ways that workers in long-term care facilities could create community outreach programs.

- Do not isolate yourselves. Develop a community advisory board that will help link your facility with local schools, churches, and programs for the elderly.
- Develop a senior volunteer corps, elderly persons from the community who regularly visit your facility and help plan activities with your residents. Retired people love to be active and helpful. But be sure to let the volunteers run their own program. Your staff members should provide the required labor; they should not be leaders.
- Create an information and referral service for the community. The Hebrew Home recently launched one, at the cost of four phone lines and a computer. A college intern set up the data bank; the phones are answered by elderly volunteers. The community apparently finds the service useful, because the service is receiving a steadily increasing number of calls.

said. "Giving residents private rooms helps, but unfortunately Medicaid won't pay for them," she said. Care givers should encourage residents to hang family photos, mementos, and awards in their rooms, she said. "Such things aid autonomy by reinforcing residents' self-esteem. They remind them of what they've done, who they are."

Sr. Gamroth said the biggest obstacle to increased autonomy was the safety regulations governing long-term care facilities. "Safety regulations tend to reinforce the old medical model of care—putting residents in hospital-like wards, lining up their beds in rows," she said. "We must somehow overcome the adversarial relationship between care givers and state regulators."

She noted that Oregon was a pioneer in implementing the 1987 federal Omnibus Budget Reconciliation Act (OBRA), which discourages the use of physical restraints. She advised care givers to devise ways to prevent patient falls, thus allaying the concerns of regulators. "You can't implement OBRA unless you profoundly change the way you think about care giving," Sr. Gamroth said. In Oregon, care givers and regulators worked together to drop restraints, she said, changing the formerly "antagonistic" relationship between them into a "collaborative" one.

Beyond the Medical Model

Getting away from the medical model was also the topic of two architects from Reese, Lower, Patrick & Scott, Lancaster, PA. Martin S. Valins, the firm's director of research, noted that the medical model of healthcare was developed during the Civil War. "It was a factory system superimposed on hospitals. It was a way to 'repair' wounded soldiers quickly and get them back to the battlefield."

But the model makes no sense in providing care for the elderly, Valins argued. He said he had been impressed by long-term care facilities he visited in Scandinavia. "Scandinavians try to keep their elderly a part of the community. For example, the dining rooms of long-term care facilities are open to the public, like restaurants. You can go into a nursing home there and find young and old people dining together."

Traditional hospital-like facilities reinforce the loneliness and confusion of persons with Alzheimer's, Dr. Eric Pfeiffer said.

In Great Britain, Valins said, some facilities equip their activities rooms with kitchen equipment. "This seems to be especially important for women residents, many of whom identify so strongly with their cooking skills that they feel robbed when they get old and go to live in a place where they can't cook. A kitchen bolsters their sense of identity and thus their autonomy."

Gregory J. Scott, a partner in the architectural firm, said Japanese care givers were pioneers in experimenting with the uses of light and space to go beyond the medical model. He said hospital-style beds were an anachronism in contemporary long-term care. "The chair, not the bed, is the care base for residents today," Scott said.

Caring for Alzheimer's Patients

Eric Pfeiffer, MD, also called for architectural innovation in the design of long-term care facilities. Pfeiffer, who is director of the Suncoast Gerontology Center at the University of South Florida College of Medicine in Orlando, specializes in the treatment of Alzheimer's disease. He said that the long, hospital-like corridors of traditional care facilities tend to reinforce the confusion and loneliness that already trouble a person with Alzheimer's. "I know it's a costly process, but we really need to explode those corridors and make such facilities more homelike," he said.

He suggested, however, that persons with Alzheimer's disease should be allowed to remain as long as possible in their own homes. "The familiar surroundings will help them keep a grip on their identities, which is important," Pfeiffer said.

Scientists at the National Institutes of Health predict that, by 2000, they will have developed drugs that slow and arrest the disease process, said John Hardy, PhD, director of research at the Suncoast Gerontology Center. "Because the disease kills nerve cells, no way of *reversing* Alzheimer's is yet in sight," Hardy said. "But we're pretty sure we're going to be able to stop the process, which will be wonderful for patients and care givers alike."

—Gordon Burnside