



Visiting Nurses Association home health aide Liz Fitzenz (left) lends a hand to Mrs. Haskell Gibson

Taking Care

The Campaign for Home Health Services

By Bob Johnson

Early last year an elderly Santa Cruz area woman returned home from the hospital after a stroke still in need of help from a physical therapist. Over months of continuing recovery she was visited at her home regularly by a therapist from Santa Cruz Samaritan Home Services. Her progress was steady, if slow, and the federal Medicare program picked up most of the tab for her rehabilitation.

This woman made the mistake, however, of needing help at a time when cost-conscious federal administrators were on a crusade to save money by cracking down on home health care. The Medicare reimbursement rate was cut across the board by 1 percent last year and a second, 2 percent, cut was averted only by last-minute congressional intervention. Administrators moved to save even more money by rejecting as unwarranted an increasing number of requests for help at home.

The stroke patient's slow rate of recovery landed her in violation of Medicare regulations: Home health care is provided only for those ailments that can be cured in specific, relatively short periods of time. Medicare first rejected a request for payment of the therapist in October

1986; Samaritan Home Services was left holding the bag for months of treatment; and the visits by the physical therapist were cancelled. The restriction on long-term care extends most brutally to those with permanent ailments. "It is difficult for us to see terminally ill patients," said

Samaritan administrator Ann Garrett, "because the condition is chronic."

While medical headlines can be made implanting the heart of a baboon into the breast of a human, the old among us believe their most vital medical needs are of a simpler variety: A warm meal at the door, a friend to scrub the kitchen floor, a nurse to administer medicine, and a physical therapist who won't cut us off. Four years ago a Gallup poll revealed that the need for financial help with long-term health care is overwhelmingly the number-one concern of the nation's elderly and that nearly all seniors would prefer to receive that care at home. Two years later those same findings were reaffirmed in a second survey conducted for the National Association for Home Care.

Failing to recognize the healthy affects of the comforts of home, however, our public health care system courts disaster by refusing to

come to the rescue until disaster strikes. An investigation by the House Committee on Aging concluded recently that 2.5 million Americans are in institutions needlessly because Medicare would not give them help at home.

Chronic financial uncertainty has plagued the major state home help program—In Home Supportive Services—which serves more than 1,000 elderly and handicapped people in Santa Cruz County, even though it is available only to those with the very lowest incomes. The most vital resource for those living at home with ailments remains the millions of relatives and close neighbors—many themselves older and nearly all of them women—who provide constant free care and are even denied an occasional day off by the public health system.

Santa Cruz County is in the forefront of the movement to expand home health services. Local representatives in both Sacramento and Washington are among the leaders in calling for a guarantee of the right of the elderly to live and recover at home. These efforts of local politi-

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cians to prevent the institutionalization and premature death of the elderly—efforts less noticed than their fight against exploitation of the

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ocean—are spurred by a senior community that is among the most persistent and aware in the nation.

More than a year ago the number of homebound seniors asking for home-delivered meals took a startling jump throughout California. In Santa Cruz County the need was more than 15 percent higher than anticipated by administrators of the Meals on Wheels program. Only the enthusiastic fundraising of the program's drivers, and an earlier decision to eliminate Sunday deliveries, made it possible to avoid placing the homebound on waiting lists for food.

Other localities, however, were

the bill to the government. To combat this, new regulations were adopted that pay hospitals a flat fee based on the patient's ailment, rather than on treatment actually provided. Since hospitals began receiving the same amount of money from Medicare regardless of how much care they provide, they have been sending older patients home, in the words of one health care analyst, "quicker and sicker."

"Many of our people come home and the next day they are back in the hospital," said Caroline Ackerman, who runs the home-delivered meals program in Santa Cruz County. Ackerman estimated earlier this year that, of all the people coming onto the home meals program from the hospital, between 15 percent and 20 percent return to the hospital within a few days.

The need for home health care began to jump at the same time, and for the same reason, that Meals on Wheels programs were flooded with requests. The demand for help from the Visiting Nurses Association went up 15 percent in barely over a year, according to local VNA Administrator Delorme McKee-Stovall. Samaritan had a 20-percent increase in its home health business. At other agencies the experience was similar. This jump in need for care by people being sent home early from the hospital came while federal administrators were gearing up for austerity in home health services.

When the federal Medicare program was created in 1965, Congress pledged that all Americans have the

protection—we are growing more vulnerable to the threat of physical decline that stalks virtually all of us.

Local Representative Leon Panetta (D-Carmel Valley) has introduced a bill, the Older Americans Alternative Care Act, that would greatly expand the coverage of home health care under Medicare. Panetta's bill would allow payment for household chores that millions of elderly Americans cannot perform for themselves. Up to 52 days a year of relief for the millions of wives, daughters and daughters-in-law who provide full-time care would also be included. Most important, however, Panetta's bill would eliminate Medicare's requirement that only the homebound can receive care at home—a provision that withholds care until the patient deteriorates to the point of being homebound.

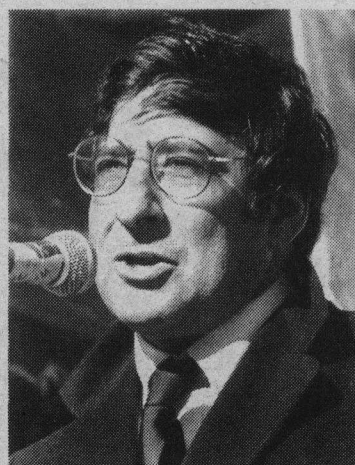
"Two-and-a-half million persons could be kept out of institutions," Panetta said when he introduced the bill earlier this year. And perhaps shrewdly sensing that Congress would be more willing to save mom if it also looked like a good way to save money, he pointed out, "The cost of care in a nursing home averages \$24,000 annually; home care may cost one-third that of nursing homes."

Panetta's proposal, a variation of his previous unsuccessful attempts at reform, was assigned to three different committees in the House. Although it has been in the hands of those three committees since shortly after its introduction more than seven months ago, none of them has yet had time to set a date to talk about the Older Americans Alternative Care Act.

While Congress moseys, Medicare administrators continue to tighten the screws on the homebound elderly. "We're seeing a significant drop in the number of visits authorized by Medicare," said McKee-Stovall from the VNA. "Two years ago they paid for an average of 21 visits per patient but that is down to between 10 and 13 visits—that's a significant drop in the care people are being given."

While only a handful of the elderly are poor enough to receive the limited home care that is available, or wealthy enough to pay for it, most of the homebound rely on institutions supposedly long since dead—the family and the neighborhood. "One of the things I say in talking to groups of seniors is that the death of the family is a myth," said Jennifer Davis, Executive Director of the Seniors Council of Santa Cruz & San Benito Counties. "Different studies show that between 68 and 85 percent of the elderly needing care are receiving it from a wife, daughter, daughter-in-law, or a female neighbor."

But for many the gift of full-time care is a slow road toward deteriorating health of the caregiver. The burnout by those caring for loved ones has landed untold thousands in institutions and it has led to a call for help in finding relief for those giving themselves to the ailing.



Representative Leon Panetta

For the last 12 years Betty Hartley has given live-in care to 92-year-old Santa Cruz real estate agent Noel Patterson. During those 12 years the only vacation taken by Hartley, herself in her 60s, was a three-week trip to Europe in the summer of 1986. Betty Hartley is among the tens of thousands of Californians—nearly all of them women—who give full-time care with virtually no relief.

"Most of the caregivers are women—by the time they are done taking care of their husbands they're ready to move into a convalescent home with them," Hartley said. "Maybe if they had a break for a few hours or a few days they could hold out a little longer."

Hundreds of full-time caregivers in Santa Cruz County will now have an easier time taking a break since Senior Network Services opened the Respite Registry at its office on 17th Avenue and Capitola Road. The registry screens and trains applicants

to work with the homebound and matches them with caregivers in need of relief.

"We're trying to keep people from going to nursing homes because their caregivers burn out," said Pat Russell, who coordinates the program. "If it keeps people out of nursing homes it will be a success." Up to 50 matches have been made since the program began operations in August and the registry is actively seeking both work applicants (462-0880 from 9am to 4:30pm) and people needing relief (462-0880). The charge for the service is \$6.50 an hour and all of the money goes to the relief caregiver.

The Respite Registry is one of only 10 pilot programs set up in California to help state legislators learn whether years of caregiving without relief leads to burnout. The Seniors Council and Senior Network landed funding to set up one of the handful of experimental registries in Santa Cruz County with considerable help from the local Older Women's League, including respite activist Betty Hartley.

Hartley was among the charter members of the Santa Cruz OWL chapter—the seventh chapter formed after the national organization was born seven years ago in Des Moines, Iowa—and has been among the local leaders in the movement to provide respite care. She has been active on the boards of the Visiting Nurses Association, the Women's Crisis Support Program and the county's largest senior organization, the California Grey Bears.

"We're not doing this because we want a lot of attention," Hartley said of the OWLs and their friends. "We're doing this because we want to get something done."



Respite activist Betty Hartley

less fortunate: By last summer there were at least 16,000 homebound seniors on the waiting list for meals statewide, according to the Department of Aging's conservative estimate. State Senator Henry Mello (D-Watsonville) introduced emergency legislation—as he had in previous funding shortages—to bail out Meals on Wheels. As is the way in Sacramento, a compromise was struck: Most of the 16,000 will be allowed to eat now while the remainder continue to wait for meals.

The major cause of the surge in demand for home-delivered meals were money-saving Medicare reforms that encouraged moving old people out of hospitals more quickly. For nearly two decades many hospitals fattened at the Medicare trough by piling on the treatment and sending

right to access to quality health care. The program has been a resounding success for the medical, insurance and legal industries, which profited from the Medicare-inspired boom that boosted the nation's medical bill from less than \$50 billion to more than \$450 billion in two decades. The verdict on Medicare's success in protecting the elderly, however, is more ambiguous: The average American senior last year paid medical bills, for services not covered by Medicare, more than 10 times as large as in the first year of the program.

Congress is likely to adopt this year protection against catastrophic illness by guaranteeing a ceiling on the combined hospital, physician and prescription drug bills of anyone covered by Medicare supplemental insurance. But while politicians make headlines discussing catastrophic illnesses that will strike only a handful—far fewer than 10 percent of all seniors will ever use this catastrophe

"Light Up a Life"

Every year nearly 3,000 Santa Cruz County residents receive the help of the Visiting Nurses Association. The large majority of the patients are elderly but many are homebound, acutely ill, younger people. As Christmas approaches the VNA asks the community to give back by purchasing an ornament on the "Light Up a Life" Christmas trees that will be decorated at the Capitola Mall and at Pacific Western Bank in Watsonville.

"We're providing over \$50,000 of free medical care a year," said Robin Gaither, local VNA community relations director. "We just go ahead and do the nursing and worry about the money later." Around 85 percent of the VNA's patients are on Medicare, which has reduced its support for home health care. The younger patients are almost all on Medi-Cal, which pays an average of 78 percent of the cost of providing home care. The VNA is the care provider of last resort, receiving the many patients who find they can get no help from the county or the numerous for-profit home health agencies.

The lion's share of the free care is funded by individuals and businesses who pay for ornaments placed on the VNA's Christmas tree in the name of a loved one. This year's tree got off to a running start when the Santa Cruz Board of Realtors donated \$2,500 and Pacific Bank got into the spirit to the tune of \$500. Those wishing to become a part of the "Light Up a Life" fundraiser can contact the VNA at 475-8422 or 688-6434.

—Bob Johnson