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LIFE Support

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Gwendolyn Stancell-Smith (second from left), RN, BSN, and Jasmine Perèz (far right), a nursing student at the University of Pennsylvania, join participants in a gardening activity at the LIFE-University of Pennsylvania School of Nursing center in Philadelphia. Stancell-Smith is the center's nursing supervisor. Photo by David Debalko Photography.

Program allows frail elders to live at home and still receive care comparable to that in nursing homes.

Ask elders if they are willing to go to a nursing home, and an estimated 30% will say no. Another 30% refuse to consider it.¹ Even for those who would go, a bed might not be available in their preferred facility, or any facility at all.

Although some fears about nursing home care are unfounded, it's no surprise that most people would rather stay at home than live in an institution. Alternatives for elders such as assisted-living facilities, senior-only housing, and independent living often can't — or won't — provide services for elders who wander, are incontinent, or have complex health needs. So what other choice is there for frail elders, particularly those with mental or physical limitations?

The goal of Living Independently for Elders (LIFE) is to help elders navigate the maze of medical services. Rather than leaving them to struggle with the complexities of payment and providers, LIFE programs provide a one-stop shop of preventive, primary, acute, and long-term services for participants, who must be 55 or older and clinically eligible for nursing home care. Upon enrollment in the program, LIFE takes responsibility for managing their health, mental health, and psychosocial needs.

At each LIFE Center, a medical clinic is staffed by nurse practitioners and a physician, who provide primary and emergent care. Specialty care is also offered onsite by visiting clinicians, including a dentist and hygienist. Physical and occupational therapy are provided in fully equipped rooms, including a working kitchen module.

The centers' adult day care programs provide meals, activities, and social opportunities in homelike dining, recreation, and living room areas. When needed, LIFE vans provide transportation to the centers, outside specialists, and certain community recreation and social events.

LIFE also provides health and personal care assistance at participants' homes. And, of course, nurses are a key component of the care.

"It's satisfying to bring all things together," says Eileen Sullivan-Marx, RN, PhD, FAAN, a former emergency department nurse and adult and geriatric care nurse practitioner, who is now the associate dean for practice and community affairs at the University of Pennsylvania School of Nursing. Penn opened a LIFE program in 1998. At LIFE/UPenn's two centers at Woodland Avenue and Market Street, a staff of 110 full-time equivalents serve 310 participants from 10 ZIP-code areas in west and southwest Philadelphia.



"LIFE integrates science, nursing practice, and education of patients, students, and families," says Sullivan-Marx. Penn's program, the only one in the country affiliated with a school of

nursing, was created to provide a teaching center that demonstrates ideal nursing practices; models community-based nursing and nurse-led care; and supports nursing-based research on topics including caregiver stress and hypertension in African-Americans.

“It’s an excellent model, and through nursing leadership, we can influence the LIFE model,” and expand the use and roles of RNs and nurse practitioners, she says.

In LIFE programs, she explains, “RNs provide oversight of the plan of care on a daily basis, incorporating functional, clinical, physical, and cognitive needs, and integrating financial, clinical and social aspects of care, maintaining that relationship and continuity across transitions over care, usually throughout the rest of the member’s life.”

That continuity decreases the need for acute-care services and substantially increases a member’s ability to remain at home. But to enroll in the program, an elder’s needs must be great enough to qualify for nursing home care.

“The duration of home caregiving is so much longer with the program, because there’s so much support that we give,” says Rebecca Kidd, RN, nurse manager at both of the Philadelphia LIFE Centers opened by St. Agnes Continuing Care Center (SACCC).

The first opened on Columbus Boulevard seven years ago; the second, on Moore Street in the Grays Ferry area, is a collaboration with the Philadelphia Housing Authority at the Greater Grays Ferry Estates. The two St. Agnes centers serve 148 participants with a total staff of 65.

“We can provide equipment, energy-conservation techniques [such as how to help a participant from bed or to dress safely, with minimal exertion]; modify medications; provide respite, day care, home visits, transportation, and the education and support participants and their caregivers need,” says Kidd.

For example, when an elder awakens frequently at night, family caregivers lose sleep, too, affecting their health and other family and work responsibilities.

“If they’re getting up five times a night to help Mom to the bathroom, we may need to change her diuretic, or see if other meds are making her sleepy during the day,” she says. “Or it may be best to provide respite care at night.”

National network of care

In other states, LIFE is known as the Program of All-Inclusive Care for the Elderly, or PACE. (Pennsylvania uses “LIFE” to avoid confusion with the preexisting PACE program that provides prescription medications for financially eligible elders.) The concept was authorized nationally for reimbursement through Medicaid and Medicare in 1997.

There are 40 PACE programs in 19 states, including two LIFE programs in Philadelphia and two in Pittsburgh. More are slated to open, including one in Scranton, Pa. (See sidebar for “Life Centers in Pennsylvania.”.)

“The philosophy is based on the belief that we best serve chronically ill elders and their families, enabling them to remain within their own homes and community when possible, by providing a seamless continuum of care that respects them as individuals,” says Jennie Chin Hansen, RN, AARP president elect and former executive director of San Francisco’s On Lok Senior Health Services, the prototype for PACE. “Rather than looking at people as patients who passively receive care, we refer to them as participants [or members], because they are actively engaged in the program.”

Participants resemble their nursing home peers. The average participant is age 80, has eight medical conditions, and limitations in approximately three major activities of daily living (bathing, dressing, feeding, toileting, and transferring), according to the National PACE Association (NPA).

Almost half of PACE participants are diagnosed with dementia. But despite these complexities, which often increase with age, the LIFE program services enable more than 90% to remain in their community home, rather than requiring admission to a nursing facility.²

Quality aside, PACE programs appeal to participants and government payors because most cost less than alternatives, reports the NPA. “The state estimates we save 15% to 20% compared to nursing homes,” says Sullivan-Marx.

Giving elders what they need

The extent of care and services is comprehensive and extensive. Working from a center that is open five or six days a week, LIFE offers participants medical care from a clinic provider (a physician — or in some states, including Pennsylvania, a nurse practitioner) who has a caseload of only 50 to 60 participants; all necessary prescription drugs and medical equipment; and specialist services, such as audiology, dentistry, optometry, speech, and podiatry, including routine and preventive care.

Through an adult daycare program, participants have a place to gather, socialize, and participate in recreational activities. They also receive nursing care and monitoring; meals; nutritional counseling; social services; personal care, including bathing and foot care; and physical, speech, and occupational therapy.

The LIFE programs provide transportation to the center and other required services. If their functional or mental status changes, participants receive a same-day evaluation by a nurse or physician.

“Without LIFE, most members would have to leave their homes and neighborhoods, which are very critical for their personal well-being,” says Sullivan-Marx. “They have ethnic and cultural communities where they feel at home.”

More than medical benefits

The social component is important to participants, particularly those who otherwise have few opportunities for interaction and limited or no family contact. At a time when death has ended many longtime relationships, friendships can still flourish. So does romance; in several programs, members have fallen in love and married.

Existing relationships benefit, too. “Families tell us that members who are involved in the program and part of something on a daily basis improve in self-esteem,” says Sullivan-Marx. “They say they

feel they have their mother back — gardening, sewing, doing what she did in the past, feeling she can contribute again — and go back to the emotional aspects of their relationship.”

LIFE also provides personal, health, and respite care in their own homes. And if a participant needs hospital or nursing home care (for short-term rehabilitation or long term), LIFE pays for it, and continues to coordinate care and services.

“We enrolled a sick, lethargic man who had a lot of mental status changes, who wandered, couldn’t call for help,” Kidd says. “We got him into our senior housing program and on a routine, diagnosed and addressed his medical problems, gave him aides at night, and cue his meds. He’s a totally different person now. He volunteers in the kitchen and dining room, and he knows he’s needed.”

Care for all

LIFE includes families in care planning and provides services and support helpful to the caregivers, as well as participants.

“Every six months, we assess families’ burdens and need for different services,” says Sullivan-Marx. “They feel that they have an advocate for them, as well as for the member.”

Caregivers need rest and energy for their other responsibilities, relationships, and interests. When freed from some caregiving tasks and supervision, they can relax and resume their role as the participant’s life partner or child.

“Giving baths, if they’re needed, is one of the hardest things. We encourage families to let us do it so they can conserve physical and emotional energy,” says Kidd. “For them to bathe and dress [a loved one] can take 1 1/2 hours a day. They have no time free to recuperate. If we do it, there’s less agitation between them, and they can enjoy each other more.”

LIFE nurses also teach families effective ways to provide care and the extent of participants’ abilities and disabilities. Onsite educational support meetings offer solutions while showing caregivers they aren’t alone.

Kidd relates the story of a 17-year-old who was in charge of

monitoring and administering diabetes medications for her grandparents. “They didn’t have the strength or desire to do their own meds, so the husband, a brittle diabetic, was often in the ED,” she says. Kidd taught the teen how to use a home blood glucose monitor daily and how to inject insulin twice a day, using prefilled syringes LIFE provided. The girl helped stabilize her grandparents’ health, eliminating most emergencies.

PACE for LIFE

PACE nurses attribute the low turnover of nursing positions in their field to job satisfaction and a collaborative environment. Nurses, physicians, therapists, and direct-care providers meet each morning to review participants, discuss changes, and brainstorm solutions.

While relishing the clinical variety, LIFE nurses cherish the continuity of care that allows them to develop relationships and assess their effect on participants’ daily lives. “In hospitals, everything’s so rushed, some patients don’t get a report or know their doctor’s name,” says Kidd. “We’re getting patients in a whole new world.

“At the center, beyond the clinic setting, we can see them during meals and social activities. When you do [participant and family] assessments sitting in their homes, you tell them you have time, ask their most important needs and concerns and what they’d like help with, and they realize, finally, there’s hope for them.”

For families and participants, LIFE can alleviate more than daily responsibilities. It can relieve worries about how to handle future problems. Other than a few exceptions, such as a participant asking to leave or moving outside the service area, LIFE will be there for them, to the very end.

Living With LIFE

Five years ago, at age 59, a stroke left Eleanora Satchell completely paralyzed on her right side.

“I couldn’t stand; I was in a wheelchair. I was totally bored with nothing to do,” Satchell says. She depended on family and home health caregivers for even her basic needs. “They had liked my independence, and they expected me to do more,” she says. “There was nothing I could do, except try to get along with everybody.”



When the Area Agency on Aging interviewed her for an article about her experience, Satchell was recommended as a candidate for the Living Independently for Elders (LIFE) program. She scheduled a home interview, and enrolled in the LIFE program operated by the University of Pennsylvania School of Nursing.

“I told them I’d had a rich, full life, and I wanted to have my life again,” she says. “My right arm is still paralyzed, but we’re working on it. Now I get myself up, I’m dressed and showered and ready to go, and I’m allowed to walk by myself to catch the bus. I can go where I want to go without having to wait for somebody.”

Three times a week, she goes to the LIFE center, which offers her more than therapy. “Since joining, I sing in the choir and do plenty of arts and crafts. I like ceramics, and I make cups and vases for my family. I even do my own laundry here.” She and her new circle of friends are in touch outside the center, talking regularly on the phone and getting together to visit and go out.

Although Satchell still lives with her daughter, her family life has changed from when she was dependent. “This Wednesday, we went out to dinner,” she says. “We seem to be closer now than when I relied on her for support.”

Satchell now serves as a reporter and representative to LIFE's Council of Elders, where she speaks on behalf of participants and staff. "We have a certain amount of power, and can express ourselves," she says. "If something concerns enough people, we make strides and changes."

LIFE centers in Pennsylvania

For a complete list, visit the [National PACE Association](#) website or call (703) 535-1565.

- Community LIFE, Pittsburgh
(412) 436-1320
- LIFE-Pittsburgh Inc., Pittsburgh
(412) 388-8042
- LIFE-University of Pennsylvania School of Nursing, Philadelphia
(215) 573-7200
- LIFE St. Agnes, Philadelphia
(215) 339-4747
- LIFE Geisinger, Scranton

*Scheduled to open in May Contact Director Amy Minnich at aminnich@geisinger.edu

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2. Who Does PACE Serve? Available at: [National PACE](#)

[Association](#) website. Accessed April 3, 2006.

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