Free Stanford Program, Study to Build Better Caregivers Debuts Locally

By Carol Harrison

In the space of a little more than two years, Lynn Robbins provided end-of-life care for her father, husband and mother.

“It was devastating, and devastating emotionally to be left alone to rear a 10-year-old child who was traumatized by that much loss,” she said last week.

The last of the three died in 1997, but Robbins said she’s still dealing with numerous personal health challenges that began during that stressful time.

“I impaired my body, which is very common for caregivers,” she said. “I’d have been in real trouble if my husband did not pass as quickly as he did. That’s why people need a caregiver class, so they can learn to make good decisions and understand when they need corrective action so as not to impair themselves and, in so doing, the person they are caring for.”

According to the Family Caregiver Alliance, 17 percent of caregivers feel their physical health in general has gotten worse as a result of their caregiving responsibilities and 40 to 70 percent of family caregivers have clinically significant symptoms of depression.

More than one-in-five caregivers are exhausted when they go to bed at night, and many feel they cannot handle their caregiving responsibilities, the FCA says.

Stressful caregiving situations lead to harmful behaviors, including increased levels of alcohol and substance use, greater levels of hostility, and a greater likelihood of abusing their loved one. Nearly three-quarters of caregivers fail to go to the doctor as often as they should and more than half missed doctor’s appointments.

Dr. Kate Lorig hopes to decrease those numbers. The Stanford University expert on chronic disease self-management has created a Building Better Caregivers workshop that will be rolled out to 250 volunteers from Los Angeles, San Jose, Sacramento and Humboldt by the end of March 2015. Aligning Forces Humboldt, which is based in the California Center for Rural Policy at Humboldt State University, is partnering with Stanford to recruit 10 to 15 local family caregivers for each of the five workshops scheduled over the next six months.

Lorig developed the content after conducting focus groups with potential participants, reviewing the online posts of about 200 caregivers taking a similar program online, pulling themes from a dozen caregiver books and getting professionals to rank the themes in order of importance. She conducted a two-day training of leaders at the four sites, then utilized their input to tweak the workshop into what will launch this fall.

The workshop will help participants learn to break the cycle of stress that caregiving creates; manage a family member’s difficult behaviors; communicate better with family, friends and the medical team; get help when you need it; and take better care of your own health.

Workshops meet for 2.5 hours once a week for six weeks at the same day and time and are facilitated by trained caregiver leaders, one of whom is the 66-year-old Robbins.

Anyone 18 years and older who is a caregiver for a family member or friend with cognitive impairment such as Alzheimer’s or other dementia, traumatic brain injury, Parkinson’s, post-traumatic stress disorder, stroke, or other diagnosed memory impairment may participate in the workshop.

Maggie Hinchliff outlines the agenda for one of the Building Better Caregiver workshops debuting next month. The workshops are free and part of a research study conducted by Stanford University, the designer of the workshop. Photo by Judy Sears
The workshops are free and are part of a research study conducted by Stanford and funded by the Archstone Foundation. In addition to attending each of the six workshop sessions, participants will complete three questionnaires by mail over the next year.

“You get to have a part in developing the class,” said Marcia Bonham, who will team with Maggie Hinchliff to co-lead a Eureka workshop that will meet from 2 to 4:30 p.m. on Mondays, Sept. 8 through Oct. 13.

Robbins and Toni Martin will co-lead a second workshop offered in Arcata from 2-4:30 p.m. on Fridays, Oct. 17 through Nov. 21.

The remaining three workshops will start in mid-January and early February.

“The skills people could learn in this workshop should give them the means to handle the situation so much better,” Robbins said. “It’s all about the mental, emotional knowledge to care for yourself and others at the same time. They really can’t afford not to go.”

Bonham, three years removed from caring for her father, said “the experience for the care partner will be better as the care provider learns ways to cope.”

“I know I needed all the help I could get,” she said.

“I was too tired, too busy, too full of the ‘I can’ts,’” said Cena Marino, a caregiver who will co-lead a BBC course next year. “But if you are not in good shape to take care of a loved one, you might go first.”

Over the past five years, Aligning Forces Humboldt has worked with Lorig and Stanford to help 1300 North Coast residents graduate from a chronic disease self-management course known locally as Our Pathways to Health. Another 45 have participated in newly-launched chronic pain workshops designed and licensed by Stanford.

“From our point of view, Humboldt was a natural as they had a great track record of offering other Stanford Self-Management Programs and were also a rural area,” Lorig said via e-mail.

Area 1 Agency on Aging Executive Director Maggie Kraft is upbeat about the five BBC workshops and their focus on helping caregivers help themselves.

“They are a great complement to the Caregiver Training Series we offer,” she said. “You cannot offer too much support to caregivers. You just can’t.”

The Stanford workshop is brand new, but Aligning Forces Humboldt Project Director Melissa Jones said it’s undetermined when it will be offered in Humboldt after the March cutoff for the study.

“I encourage people to register now,” Jones said.

To learn more and register for one of the Building Better Caregiver workshops, call Aligning Forces Humboldt at 707-445-2806, ext. 4.

Area 1 Agency on Aging paid Carol Harrison to write this article.