

CenterPieces

Sharing our Activities in Research, Education & Clinical Innovation to Advance Healthy Aging

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Volume 2: Dementia Caregiving Research at CARAH

Helping Caregivers to COPE

When Deb Lactman promised her dying father that she would care for her mother, Margaret Rimato, after he passed, she wasn't prepared for the challenges to come. Shortly after he passed, Margaret became increasingly forgetful and delusional. Deb attributed her mother's memory loss to the stress of losing her husband. With time, however, Margaret's condition worsened and she was diagnosed with Alzheimer's disease.

As the primary caregiver of a parent with Alzheimer's, Deb dealt with various complications beyond the memory loss. Her mother continually roamed the house in the middle of the night, for no apparent reason. It turned out that her irregular sleep patterns were due to arthritis in her arm as well as painful kidney infections. Deb had a hard time gauging her mother's pain because her mother couldn't articulate it.

"I carried a lot of guilt since I didn't know about Mom's pain," admits Deb. "She can't describe her current pain, so I've learned to look for non-verbal clues."

Awareness of non-verbal clues of pain was just one of the techniques Deb learned through her participation in Project COPE. Project COPE is a study designed to help caregivers learn new ways to manage the challenges of caregiving and is conducted by the Center for Applied Research on Aging and Health (CARAH) at Thomas Jefferson University.



Deb Lactman with her mother Margaret.

Project COPE is funded by the Pennsylvania State Department of Health Tobacco grant funds as part of the Pennsylvania Center of Excellence in Alzheimer's disease awarded to the Farber Institute for Neurosciences at Jefferson.

Deb was drawn to Project COPE because it focused on both the needs of caregivers and the quality of life of patients. Dr. Laura N. Gitlin, the principal investigator of the study, explains, "Project COPE builds on over 15 years of research conducted by CARAH on family caregiving and dementia care. Taken as a whole, these studies show that there are various non-pharmacological approaches that families can use to effectively manage this devastating disease and enhance the well-being of their family member with dementia and themselves."

Tracey Vause-Earland, clinical coordinator and one of the occupational therapy interventionists at CARAH, worked directly with Deb in her

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Newsletter of the Center
for Applied Research on
Aging and Health (CARAH)

Jefferson College
of Health Professions

Thomas Jefferson
University

Message from the Director

Welcome to the second issue of CenterPieces, the newsletter of the Center for Applied Research on Aging and Health. We dedicate this issue to the topic of dementia and family caregiving, a critical public health issue.

There are 26 million individuals with dementia worldwide, and approximately 5 million individuals with the diagnosis in the US. This number may exceed 16 million in 2050.

For the past 15 years, CARAH has been in the forefront of developing and testing innovative approaches to supporting families in their heroic care efforts and enhancing the quality of life of affected individuals. CARAH's current research focus is on testing non-pharmacological approaches to managing one of the most complex aspects of the disease, disruptive behaviors.

We remain deeply indebted to the many families who have shared their stories and knowledge with us so that we may learn from their experiences as we work together to identify the best approaches to manage the disease. In this issue, you will learn about research studies conducted at Jefferson and the important role of clinical trials in helping to identify effective dementia treatments.

If you are a caregiver, know someone who is caregiving, or a health provider working with families dealing with dementia, we invite you to contact us to learn more about participating in our studies. Call us at 215-503-2897 or visit our web site at www.jefferson.edu/jchp/carah.



Dr. Laura Gitlin,
Director of CARAH

Speaking With Barry Rovner, MD

Q: What Alzheimer's related studies are you involved in currently at the Farber Institute for Neurosciences?

Dr. Rovner: We are evaluating three exciting new disease-modifying drug treatments that may slow down the course of Alzheimer's disease. I am also a Principal Investigator of Jefferson's Center for Excellence in Neurodegenerative Diseases funded by

the Pennsylvania Department of Health Tobacco Settlement grant. We are testing innovative screening methods to identify dementia in community-based agencies serving older adults, as well as

testing in-home skills training services to delay nursing home placement and reduce stress for a racially diverse group of family caregivers. This latter study is being conducted at the Center for Applied Research on Aging and Health, by Principal Investigator Laura N. Gitlin, PhD.

“Participating in research allows families ...to get potentially beneficial treatments for their relatives before they are available to the general public.”

Q: What do study participants gain from being part of these research studies?

Dr. Rovner: We have learned that families derive a lot of hope and support from participating in these trials. In general, participating in research allows families to have the opportunity to get the best possible care for their relatives, including potentially beneficial treatments before they are available to the general public. Being a participant may lead to a decrease in the stress of

Did You Know?

As many as 80 percent of persons with dementia are cared for in their homes by family members.

caregiving, as well as provide the chance to make a contribution to new scientific knowledge. It is an opportunity to share personal experiences so that others may benefit.

Q: Are there any risks of participating in drug trials?

Dr. Rovner: With trials of medications, there are always some risks of side effects, however we closely monitor any possible adverse reactions. Drugs being studied have already been tested before so that we can assure that they are reasonably safe. ■

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Dr. Barry Rovner is Professor of Psychiatry and Neurology and Director of Clinical Alzheimer's Disease Research of the Farber Institute for Neurosciences. The focus of his research is to test novel interventions to improve cognition, prevent depression and enhance quality of life for older adults.

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home to instruct her on practical methods she could use to cope with her mother's progressive illness. She began by assessing Margaret's cognitive level as well as Deb's caregiving goals, understanding of the disease and willingness to learn new strategies. She found that Margaret had a high cognitive level and was receiving unnecessary help from her caring daughter. "Out of concern and an unclear understanding of her mom's abilities, Deb was actually helping her mother too much. Deb needed to learn more about the disease and she was open to new knowledge and adapting strategies to manage better day-to-day," says Vause-Earland.

Based on the assessments, Ms. Vause-Earland designed an "action plan" for Deb to follow. The plan included specific behavioral goals, a summary of Margaret's abilities or what she could still do, and specific strategies for Deb to implement to enhance her mother's participation in daily activities and decrease her boredom and anxiety. Since Margaret was once a housewife, Ms. Vause-Earland

suggested activities such as washing dishes or folding laundry — pain-free activities that brought her satisfaction, a sense of accomplishment, and reflected her previous roles and interests. Ms. Vause-Earland also helped to establish a nighttime routine for Margaret: no coffee, taking a bath, playing soothing music and using a nightlight. The nightly routine prepared her for bed in a relaxed manner and reduced her erratic nighttime behavior.

Beyond these strategies, Ms. Vause-Earland taught Deb how to build her own sense of efficacy as a caregiver. Through stress-relieving techniques and positive reinforcement, Ms. Vause-Earland gave Deb confidence and built her self-esteem. "Tracey taught me that I didn't need to do everything for Mom; that it was okay to let go. She was the first person to tell me that I was doing a good job," says Deb.

Ms. Vause-Earland saw Deb transform as a result of her participation in Project COPE.

"Deb's energy and enthusiasm and readiness to integrate new strategies into her daily caregiving transformed her situation," asserts Vause-Earland. "By the end of her participation in the study, she had much more confidence in her abilities and a sense of mastery. Deb now feels empowered, more in control of her situation."

Today, Deb is successfully coping with her mother's disease and both are much happier as a result. "My mother now feels like she's part of the family, rather than looking in from the outside. She's happier now that I'm letting her be her. She is what she is today. You enjoy it and celebrate it. A tremendous burden has been lifted off of my shoulders."

CARAH is still enrolling participants for Project COPE. For more information or to enroll in the study, please call **215-503-2897**. ■

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