CenterPieces

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

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

Jefferson College of Health Professions

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Volume 2: Dementia Caregiving Research at CARAH

Helping Caregivers to COPE

When Deb Lacktman 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 Lacktman 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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Message from the Director

Dr. Laura Gitlin, Director of CARAH

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**.

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