

The Caregiver's Tool Kit Initiative: Second Summit, September 26 – September 29, 2013

The Pabst Charitable Foundation for the Arts is proud to present our second report on the Caregiver's Tool Kit Initiative. The Foundation sponsored a four day summit of experts in the fields of gerontology, medicine and the arts. This was the second in a series of summit events planned for the Initiative, to culminate in the published product in 2015, ready to present at the White House Conference on Aging in 2015.

On September 26, a Think Tank was convened by UCF College of Arts and Humanities, The National Center for Creative Aging and the Pabst Foundation to focus on the main elements of the Caregiver's Tool Kit. They discussed the parameters of the design the field testing and research around the elements of the Tool Kit. Dr. Jose Fernandez, Dean of the College of Arts and Humanities, hosted the Think Tank at UCF. Faculty from the College of Arts and Humanities and UCF Medical City researchers met in a round table discussion with Dr. Gay Hanna and Dorothy Wohlschlager from the National Center for Creative Aging in Washington and the artists designing the Tool Kit.

Dr. Adam Golden, Associate Professor, College of Medicine, has taken on the responsibility of providing consultative support for the research phase of the project from Scripps Institute at Miami University. The Pabst Foundation is pleased to sponsor the research that will be conducted in Central Florida where non-profits focusing on Alzheimer's and dementia patients and their caregivers can participate in the field testing and assessment phases administered by humanities faculty and students at UCF.

The need for this project is great. Dr. Golden noted that the majority of dementia patients stay in the home. Many areas of the country have few or no resources for education and support for in-home caregivers. These factors increase the stress of isolation, emotional drain, and the physical work load on the caregiver, leading to affective disorders and illness. The goals of the Tool Kit are to provide both the support and the research on the effects of that support.

It is important to note that there is no cure for any of the types of dementia including Alzheimer's. Supportive care in the form of drugs to control behavior or relieve anxiety and depression do not work in randomized controlled research trials and often produce unwanted and dangerous side-effects. There is, however, existing research (albeit preliminary) to show that creative expression improves the quality of life, the day-to-day existence of dementia/Alzheimer's patients.

The arts may improve mental, emotional and physiological states. It is the premise of the Tool Kit that the caregiver's day-to-day existence is lightened and brightened by a structure that helps her/him to participate along with the patient in these activities. The improvement in the caregiver's well being can be measured with psycho-social assessments and medical/physiological tests.

Dorothy Wohlslagel reported on a literature review of arts-based resources for caregivers carried out by Liz Tsang. The review found little research about the effect of art activities on the well-being of caregivers of Alzheimer's/dementia patients. NCCA maintains that the guiding principle and focus of the research for the Tool Kit must be the "voice of the caregiver": that is, caregivers sharing their "experiences of using the arts as part of the caregiving journey." "Caregivers listen to caregivers", says Margery Pabst.

NCCA has identified three main elements of the Tool Kit. 1. The "artist's lens" meaning an understanding of how the arts can be woven into daily routines, 2. Artistic activities, 3. Caregiver stories of experiences with the Tool Kit. The field testing will help refine the activities in the Tool Kit and provide an avenue for groundbreaking research. In collaboration with UCF Medical and Humanities faculties, NCCA will plan and design the field tests to be implemented during the Fall of 2014.

UCF is unique among universities in its ability to collaborate openly across schools and departments. Another boon to the testing and research phases is the wealth of caregiver support groups in Central Florida that are not usually found in such abundance in other parts of the country. Willing and eager non-profits can immediately identify many caregivers who can participate in the field testing.

Dr. Wan, Associate Dean of the College of Health and Public Affairs and a nationally recognized expert in the field of assessment discussed the issues surrounding the research phase. Among the questions to be answered are:

- how big a population will be tested?
- how big an effect is expected?
- regarding the artistic activities, how many dimensions of perception and affect will be measured?
- do the researchers want a control group?
- will the caregivers' emotional and medical well-being be assessed before field testing the activities as well as after?

The complexity of the design of the tests will depend on what the researchers expect as the outcomes. For instance, will changes in attitude be expected, will greater knowledge be expected? Will improvements in memory, affect, expression, cognition and other parameters be assessed? With these measurements, the researcher can then begin to conclude to what degree artistic activity serves to reduce the burden on caregivers and serves as a coping mechanism.

The IRB process was discussed and it was generally agreed that the potential benefits outweigh the effort of an "expedited review". Informed consent and risk/benefit analysis were discussed and it was concluded it should be a smooth process with the possible exception of the dance component. The UCF College of Health and Public Affairs will handle and store the data collected as they are experienced with assessment tools and biostatistics.

The first step in the design process is for the artists, medical faculty and humanities faculty to collaborate on content using the first draft of the Tool Kit. It will be distributed to all participants with opportunities for the humanities to provide activities for the kit. The humanities departments already have small and large projects dealing with aging populations and are ready to participate. During the design of the Tool Kit, the Think Tank members, in collaboration with the NCCA and the artists, will develop and conduct field testing.

It was agreed that lines of communication between Dr. Golden, Dr. Wan and the Arts and Humanities faculty will yield more and more imaginative activities that can be efficiently isolated and assessed in the field. The possibilities for both the content of the Kit and the research seem endless.

THINK TANK PARTICIPANTS

Dr. Jose Fernandez, Dean, College of Arts and Humanities, University of Central Florida

Dr. Gay Hanna, Executive Director, NCCA

Margery Pabst, Director, Pabst Foundation for Arts and the Community

Dorothy Wohlslagel, Director of Education, NCCA

Liz Tsang, NCCA Intern, graduate student in Gerontology, Miami University

Laura Pooser, Director of Development, UCF

Adam Golden, MD, Assoc. Chief of Staff of Geriatrics & Extended care, Orlando VA Medical Center; Assoc. Professor, UCF College of Medicine

Dr. Tom Wan, Professor, Research Assoc. Dean, College of Health and Public Affairs

Denise Gammonly, Assoc. Professor, Social Work, College of Health and Public Affairs

Mary Lou Sole, Orlando Health Distinguished Professor of Nursing, Interim Dean, UCF College of Nursing,

Jeff Moore, Chair, UCF School of Performing Arts

Ke Francis, Professor, Studio Art, UCF School of Visual Arts and Design

Kristin Weatherbee, Assoc. Director, Research Programs/Services, UCF College of Arts and Humanities

Patrick Murphy, Chair, UCF English Department

Chris Neiss, Chair, UCF Theater Department

Terry Thaxton, Assoc. Professor, UCF English Department

Gary Glasner, Poet, Director, Alzheimer's Poetry Project

Maria Genne, Dancer, Director, Kairos Alive

Judith-Kate Friedman, Songwriter, Director, Songwriting Works

Sept. 26, 5:30 pm: ARTS AND WELLNESS: A Symposium on Memory Loss and Caregiving on the UCF Campus

Sept. 27: Artists and Caregivers share stories, ideas on the Atlantic Center For the Arts Campus

Sept 27 - Sept 29: Artists share ideas and activities on the Atlantic Center for the Arts Campus

