

# The VOICE of FTD

SPRING 2022

## Featured Researcher: Dr. Laura Gitlin

*Making life better for persons diagnosed with dementia & their caregivers*

It's about family — hers and yours — and supporting families who are dealing with devastating diseases.

Laura N. Gitlin, Ph.D., specializes in aging, dementia, Alzheimer's Disease, geriatrics, healthcare delivery, education, and promotion. She has spent more than 35 years applying a family-directed approach to her research. Currently, she does this from her position as Distinguished University Professor and Dean of the College of Nursing and Health Professions at Drexel University in Philadelphia, PA.

An expert on home and community-based interventions for those diagnosed with dementia and their caregivers, Dr. Gitlin seeks solutions that support people's strengths and best functioning. She collaborates with community organizations, health and human service professionals, fellow researchers, families, and others to ensure the interventions she and her teams develop are relevant, impactful, and reach populations who do not traditionally have access to participation in clinical studies or evidence-based practices.

Compassion and understanding are traits that can be found in Dr. Gitlin. Having a sibling with a life-threatening disease who was in and out of hospitals,

including the National Institutes of Health (NIH), her childhood and into adulthood involved managing daily uncertainties and being shuffled between relatives' homes and weekends at the hospital.

"It's not the same as dealing with FTD, but it made me ask questions about how do you make life better for families who are dealing with significant adversities including life-threatening diseases or traumatized exposures or structural racism that affects health," she said. "My experiences growing up informed who I am and the research questions I seek to answer, and led me to focus on people as they age with different traumas."

An applied research sociologist, Dr. Gitlin is nationally and internationally recognized as an intervention scientist for developing, evaluating, and implementing interventions that improve the quality of daily life. This includes for persons diagnosed with dementia and their caregivers.

"I didn't come to aging through formal training in gerontology," she explained. "I was trained as an 'action' and community-engaged researcher. Upon completion of my Ph.D., I had a serendipitous

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opportunity to serve as a research coordinator on a large NIH-funded grant evaluating the biopsychosocial benefits of exercise for healthy older adults, and I became hooked on the field.”

## RESEARCH PROJECTS

Frontotemporal degeneration (FTD) is one type of dementia that has been included in several of the clinical trials in which Dr. Gitlin has served as principal investigator.

All of the work she has done includes the underlying goal of finding ways to help people.

“What are people’s unmet needs and their daily functional goals, and how can we address them to make life better?” she said.

Four of her most significant research projects are explained briefly below.

### **WeCareAdvisor (2021-2025)**

Dr. Gitlin’s most recent study, WeCareAdvisor, aims to support family caregivers in the management of challenging behavioral symptoms to improve the lives of persons diagnosed with dementia and their family. An initial pilot test done in 2015-2016 showed great promise.

A Phase 3 clinical trial currently in progress is evaluating whether this online tool reduces caregiver distress, improves their confidence in managing behaviors, and reduces the frequency and severity of the symptoms in people living with dementia.

Dr. Gitlin collaborated with Helen C. Kales, MD, of the University of California, Davis, to develop WeCareAdvisor. The tool walks caregivers through a



step-by-step process to understand why a dementia-related symptom is occurring. Based on the caregiver’s answers to specific questions, a set of strategies are generated that are customized to the situation to help the caregiver manage the behavior.

Additionally, there is a section of the tool, the Caregiver Survivors Guide, that provides disease education. Caregivers also receive daily tips for managing stress through text messaging.

“We will enroll 326 family caregivers across the USA,” Dr. Gitlin said. “If we have sufficient numbers in our samples of families with FTD disorders, then we may be able to evaluate if this tool is effective for certain kinds of challenging behaviors that are more prevalent within these disorders.”

The study will enroll caregivers of people living with any type of dementia and who are managing at least one behavioral symptom. Participants must be 21 years old or older, speak English, have been caregiving for at least six months, and live in the United States or one of its territories. They must also have an email account and own a smartphone, tablet, laptop, or desktop computer with access to the Internet.

### [READ MORE ABOUT WeCareAdvisor](#)

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## **Tailored Activity Program (2013-2019)**

The Tailored Activity Program (TAP) is another evidence-based program developed by Dr. Gitlin and her teams. It assesses the interests and abilities of people living with dementia.

Delivered by occupational therapists at home, in hospitals, in adult day services, or in residential facilities, TAP has been tested in various randomized trials. One such trial conducted in Australia showed that TAP reduced behavioral symptoms of people living with FTD disorders.

“We recruited from clinics specializing in FTD disorders and were able to show in this well-characterized group that our approach improved the quality of life of both the caregiver and person living with the dementia,” she explained.

In addition to the United States, TAP is being used in nine countries that include Brazil, Chile, Italy, Hong Kong, and Australia.

## **[READ MORE ABOUT THE TAP STUDY](#)**

## **Project COPE (2005-2010)**

The COPE Program (Caring for Older People in their Environment) is yet another proven intervention designed by Dr. Gitlin and her team of occupational therapists and nurses. The program extends the TAP approach and addresses the daily challenges of families in addition to behavioral symptoms.

The COPE program is now being used at locations in the United States, such as PACE programs, as well as throughout Australia.

## **[READ MORE ABOUT COPE](#)**

## ***Beat the Blues (2007-2012)***

Beat the Blues was a home-based intervention for African American older adults with depressive symptoms. It was a five-year random clinical trial based in urban Philadelphia and was led by Dr. Gitlin's team in collaboration with Center in the Park, a vibrant senior center.

“The intervention provided education about depression, care management, referral and linkage, and stress reduction techniques. Most importantly, it helped people identify and re-engage in valued activities and social involvement,” she said.

The study, based upon a strong community and academic partnership, was one of the first to rigorously test a multi-component intervention derived through community engagement, to address depressive symptoms in African Americans. It showed that senior centers, as trusted community organizations, can have an important and effective role in detecting, educating, and treating depression, and particularly for communities that may have limited access.

## **[READ MORE ABOUT BEAT THE BLUES](#)**

## **BACKGROUND**

Dr. Gitlin completed a bachelor's degree in anthropology and social psychology at Temple University in Philadelphia, PA. She earned her master's and doctorate degrees in sociology from Purdue University in West Lafayette, IN.

After finishing her Ph.D., Dr. Gitlin returned to Philadelphia and taught at Saint Joseph's University

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and Rutgers University–Camden (New Jersey) before accepting a position in the College of Health Professions at Thomas Jefferson University, also in Philadelphia. During her 24-year tenure at the institution, she was the co-director of the Center for Collaborative Research, then the founding director of the Center for Applied Research on Aging and Health and co-founder of Jefferson Elder Care, a service division aimed at providing evidence-based programs at home for older adults with physical and/or cognitive challenges.

Dr. Gitlin then joined the faculty at Johns Hopkins School of Nursing (JHUSON) in Baltimore, MD, where she was the founding director of its Center for Innovative Care of Older Adults. In 2017 she was also appointed as the Isabel Hampton Robb Distinguished Scholar.

While at Johns Hopkins, Dr. Gitlin also collaborated with Nancy Hodgson, Ph.D., RN, FAAN, now Chair of Penn Nursing Department of Biobehavioral Health Sciences, to develop a massive open online course on dementia care which has educated over 100,000 participants (caregivers, health professionals, researchers) from more than 169 countries.

In February 2018, she once again returned to her native Philadelphia to become the distinguished professor and Dean of the College of Nursing and Health Professions at Drexel University.

## PROFESSIONAL

Dr. Gitlin is the author of more than 300 scientific publications including authoring or co-authoring seven books, the most recent ones published in 2016 on behavioral intervention research and in 2018 on *Better Living with Dementia: Implications for*

*Individuals, Families, Communities, and Society*. She has also published books with tips for family caregivers and for older adults with functional challenges.

Dr. Gitlin has received numerous academic distinctions, including a Fellow of the American Academy of Nursing, a Fellow of The Gerontological Society of America, and a Fellow of the College of Physicians of Philadelphia.

She is a member of the American Academy of Nursing, the American Occupational Therapy Association, the Gerontological Society of America, the New York Academy of Sciences, and the International Lancet Commission on dementia care.

In 2016 Dr. Gitlin was appointed to the Health and Human Services (HHS) Advisory Council for the National Alzheimer’s Project Act. She served as its chair from 2017 to 2019. The 22-member Council recommends actions for the National Plan to assist persons diagnosed with Alzheimer’s disease and related dementias (AD/ADRS) and their caregivers.

## AWARDS:

- 2009 Eastern Pennsylvania Geriatric Society, Carles Ewing Presidential Award for outstanding contribution to geriatric care
- 2010 United Way Champion Impact Award for Healthy Aging at Home
- 2010 National Institute of Senior Centers Award with Center in the Park
- 2010 MetLife Award for translating the Skills2Care Program, a dementia caregiver intervention program, with home healthcare agency Fox Rehabilitation
- 2011 John Mackey Award for Excellence in

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- Dementia Care, from Johns Hopkins University
- 2014 M. Powell Lawton Award from the Gerontological Society of America
- 2015 Honorary Fellow, American Academy of Nursing (FAAN)
- 2016 Johns Hopkins University School of Nursing SONie award for Best Media Presence
- 2016 Co-organizer of symposium, “Whose responsibility is it? Balancing Family and Societal Supports in Caring for Older Adults” selected as the Ollie Randall Symposium of the Gerontological Society of America, New Orleans.
- 2017 Leadership Service Commendation, American Occupational Therapy Foundation (AOTF)
- 2017 Sr. Genevieve Cummings Lecture Speaker, nominated by students/faculty, St. Catherine University, St. Paul, MN
- 2017 First Isabel Hampton Robb Distinguished Scholar, Johns Hopkins University School of Nursing
- 2017 Honorary Member, Sigma Theta Tau, Honorary Society of Nursing
- 2019 Michael M. Ossoff Visiting Lectureship (May 14), Johns Hopkins Memory and Alzheimer’s Treatment Center.
- 2021 Fulbright Specialist Fellow (through 2023)

## CONCLUSION

Dr. Gitlin has not followed a traditional course for her career. While some researchers spend their entire career on one intervention, she has developed close to 20 multi-component interventions that address complex health challenges of people as they age.

She has examined the psychosocial and physical

benefits of exercise for older adults, the impact of housing and home adaptations on daily functioning, the role of active engagement to address mood disorders, the role of families in the care of relatives, and the impact of social determinants (including place, race/ethnicity, and financial strain) on wellbeing.

There are surprises that come from study results, whether positive or negative. But she said that her interventions share certain characteristics: They are theory-based, involve community engagement and partnerships, are person-family-centered and strength-based, and result in important benefits for their intended population.

“Being an intervention scientist is exciting as you are always learning new methodologies and strategies,” Dr. Gitlin said. “This form of research is action oriented to help make life better for others.”

[READ MORE ABOUT WeCareAdvisor](#)

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