The Care Ecosystem: Navigating Patients and Families through Stages of Care

Southern CA Alzheimer’s Disease Research Conference

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It took nearly 4 years for us to get a diagnosis. The doctor told us it was Alzheimer’s, that there was nothing he could do, and to come back in a year. We were first devastated, then angry. I also have diabetes, and I got medication, education and care management for that. Now I have a fatal brain disease, and I got ‘diagnose and adios.’

We have to do better.

-Julie, a person living with early-stage AD
Dementia care is too often crisis-oriented and fragmented

- Frequent emergency department visits and hospitalizations (Hunt, Coombs, et al., 2018; Zhu, Cosentino et al., 2015)
- Multiple care transitions (Callahan, Tu, et al., 2015)
- Inappropriate and potentially harmful medication use (Maust, Kim, et al., 2015)
- Aggressive end of life care that is often inconsistent with the patient’s values (Mitchell, Teno, Kiely et al., 2009)
- Informal caregivers shoulder substantial burdens with minimal support from our patient-centric healthcare models
  - When caregivers are depressed, PWLD use the ED more (Guterman, Allen, et al., 2019)
- The COVID-19 pandemic has disproportionately disrupted the lives of people living with dementia and their caregivers (Ibáñez, Pina-Escudero et al., 2021)
Dementia Caregivers Report High Emotional and Physical Stress Due to Caregiving

Alzheimer's Association Facts and Figures 2019
The Care Ecosystem Model

The Care Team Navigator (CTN) is at the Center

- Community Resources
- Health Care Providers
- Patient/Caregiver Dyad
- CTN
- Pharmacist
- Nurse
- Social Worker

Care Ecosystem Dementia Specialist Team
Who is a Care Team Navigator or “CTN”?

- A friendly, empathic, and organized person who loves working with people
- Health care background not required
- CTN is trained, supervised, and supported by a clinical team
- CTN provides telephone-based care coordination, education, and support
Care Modules

Medications
Review and monitor patient medicines to make sure they are safe and effective

Caregiver Support
Offer suggestions and advice about caring for the patient and provide customized caregiver education, support, and community resources

Behavior
Coach and advise caregivers on strategies to manage behaviors while promoting safety and quality of life

Decision-Making
Provide support and resource links for medical, legal, and financial care planning

UCSF
Agile Development of the Care Model

- 132 caregiver satisfaction surveys
- 3 waves of clinical staff interviews and input from weekly clinical debriefings
  June 2015 – July 2016
- 6 Family Advisory Council meetings
  April 2015 – July 2016
- 9 primary care focus groups
  Feb – June 2015

Program designed by multidisciplinary team of dementia specialists

Care Model Release 1.0
March 2015

Care Model Release 2.0
Sept 2016

Possin et al., 2017, PLOS Medicine
Randomized Trial: Locations of patients enrolled

Possin et al., JAMA Internal Medicine, 2019
Randomized Trial: Design & Results

N=512 dyads

N=268 dyads

- Improved caregiver well-being
- Improved patient quality of life
- Reduced emergency room visits
- Reduced potentially inappropriate medication use

Possin et al., JAMA Internal Medicine, 2019
Scientists have a critical role in bridging the science-practice gap

- Scientists too often expect that the implementation and dissemination of their interventions will be taken up by other parties, which is often not the case (Callahan, Bateman, et al., 2018)

- As scientists, we need to understand the barriers to the dissemination of effective dementia care, and trial implementation methods to bridge the gap. (Boustani, Unützer, Leykum, 2021; National Academies of Sciences, Engineering, and Medicine Report, 2021)
The AHRQ’s systematic review, and the National Academies of Science’s consensus study report, summarize the evidence on effective dementia care models. Evidence is sufficient to justify implementation of collaborative care models, including the Care Ecosystem and the UCLA program, in a broad spectrum of community settings, with evaluation conducted to continue expanding the evidence base.
Find the Care Ecosystem Toolkit, care protocols, and CTN training program at: memory.ucsf.edu/care-ecosystem

Sarah Dulaney, CNS
Care Ecosystem
Clinical Director

Care Ecosystem
The Care Ecosystem model was designed to help address the unmet needs of persons with dementia and their caregivers.

What is the Care Ecosystem?
The Care Ecosystem is a model of dementia care designed to provide personalized, cost-efficient care for persons with dementia (PVD) and their caregivers. This telephone and web-based intervention was developed and studied across California, Nebraska, and Iowa via an award from the Center for Medicare and Medicaid Innovation (CMHI grant number 1CTCMS331346) from 2014–2018 and continues to be studied with funding from the National Institute for Health (NIH grant number R01 AG056715) from 2018–2022.
CURRENT RESEARCH: Implementation and Effectiveness of the Care Ecosystem in 6 Health Systems

Providence
UCSF
LA County
U Colorado Denver
HealthPartners
Ochsner
The Future of Dementia Care

PLWD & caregivers are navigated by a care team that personalizes care goals to their needs and prioritizes their quality of life.
“These treatments and care practices will neither prevent nor cure Alzheimer’s or other dementias, but they will help to change the experience of people with the conditions and their family caregivers – helping them to manage and cope with the difficult situations caused by the conditions and live as well as possible despite them.”

Katie Maslow, MSW
Translating Innovation to Impact
Institute of Medicine Report 2012
UCSF:
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Sarah Hooper
Winston Chiong
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Nick Olney (Providence)
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Katie Ward (DHS LA County)

Want to learn more?
memory.ucsf.edu/care-ecosystem
The UCSF Memory and Aging Center

The mission of the UCSF Memory and Aging Center is to provide the highest quality of care for individuals with cognitive problems, to conduct research on causes and cures for degenerative brain diseases, and to educate health professionals, patients and their families.