Alzheimer’s disease is a progressive neurodegenerative condition, and people living with this disease can become unreliable participants in their own care. As a result, the primary caregiver – often a family member – may also bear the emotional, physical, and financial burden of Alzheimer’s care.

In 2018, an estimated 16.1 million Americans provided 18.4 billion hours of unpaid supportive care for people with Alzheimer’s disease and related disorders, including household chores, preparing meals, organizing medications, and managing behavioral symptoms. Approximately 60% of informal caregivers for people with ADRDs report substantial emotional stress and depression.
Given the complexity of Alzheimer’s disease, patients often require multidisciplinary care that may involve physicians, nurses, social workers, informal caregivers, among others. Effectively coordinating this care, including referrals to supportive community services, can improve patient and caregiver outcomes and overall quality of life. Care coordination models, tailored to the distinctive needs of people living with Alzheimer’s and their caregivers, also show promise in reducing disparities in care.

THE VALUE OF CARE COORDINATION

SUPPORTING ALZHEIMER’S PATIENTS AND CAREGIVERS

The MSD Foundation has committed $5 million through 2021 to support programs that aim to improve the health and wellbeing of vulnerable individuals living with Alzheimer’s and their caregivers in the United States. These programs focus on strengthening care coordination and navigation to help:

- Increase access to needed care and provide support for people living with Alzheimer’s disease and their caregivers
- Foster collaboration across the health and social service sectors to address the medical and social needs of patients and their caregivers
- Improve patient and caregiver outcomes, including quality of life
The Alzheimer’s Association, Massachusetts/New Hampshire Chapter is expanding its Dementia Care Coordination program in Massachusetts and taking it to Maine, New Hampshire, and Rhode Island. The program increases access to care and support for people who are living with Alzheimer’s disease and their caregivers in underserved urban and rural areas.

As part of this evidence-informed model, a health care provider or payer refers the caregiver for a consultation with a Memory Specialist who develops an individualized care plan. The plan is designed to help manage the patient’s symptoms and behaviors, connect caregivers to needed resources in the community, and overcome barriers to care and support.

The Alzheimer’s Association’s health system and insurance partners, recognizing the potential financial savings of coordinating patient care, assume a portion, or all, of the cost associated with their participation in the program, helping to ensure sustainability.

HealthPartners Center for Memory and Aging: The Care Ecosystem

HealthPartners (HP) Center for Memory and Aging, in partnership with the University of California, San Francisco (UCSF), is implementing UCSF’s Care Ecosystem program in Minnesota to coordinate care for people with dementia and their caregivers living in rural areas with limited access to specialty care.

The Care Ecosystem expands the ability of dementia specialists to address the unmet needs of patients and their caregivers by providing support, education, care coordination, and linkages to community-based resources. As part of adopting this model, which has demonstrated strong results in California, UCSF will provide ongoing training to the HP clinical team and care team navigators.

UCSF will evaluate the impact of the program on patient access to dementia care services as well as the projected value of the program in reducing emergency-related health care costs and the potential to increase reimbursement for dementia care services.

North Carolina A&T State University Center for Outreach in Alzheimer’s, Aging, and Community Health (COAACH)

COAACH educates and raises awareness about Alzheimer’s disease among vulnerable populations in rural communities in North Carolina. COAACH aims to create a sustainable model for community-based support for people living with Alzheimer’s and their caregivers.

The organization’s programs include a Caregiver College that trains Lay Health Advisors from local faith-based institutions to help underserved patients and caregivers with care management and coping strategies. COAACH also offers a web-based Family Navigation Program to help families affected by Alzheimer’s disease overcome barriers to timely screening, diagnosis, treatment, and supportive care.
By investing in these innovative programs, the Foundation hopes to identify effective models that demonstrate strong potential for replication.

We also aim to disseminate best practices to help advance Alzheimer’s care and support for vulnerable patients and their caregivers.

REFERENCES


