MANAGING BEHAVIORS ASSOCIATED WITH DEMENTIA: RESOURCE GUIDE FOR CAREGIVERS

An estimated 10 to 11 percent of people age 65 and older have dementia; the prevalence among Medicare-Medicaid enrollees age 65 and older is as high as 23 percent.¹ According to an Alzheimer’s Association survey, “35 percent of caregivers for people with Alzheimer’s or another dementia report that their health has gotten worse due to care responsibilities” (as compared to 19 percent of caregivers for older individuals without dementia).² The ability of caregivers to support the health and well-being of enrollees with dementia may dramatically impact both the individual lives and the total cost of care for those enrollees. A number of resources are available for caregivers of people with dementia, and several recommendations are included below.

Please note that some of the resources listed below may have an associated cost.

INFORMATION HUBS

The national Alzheimer’s Association website has downloadable resources for patients and caregivers specific to each stage of dementia. These resources are available in English, Spanish, Chinese, Japanese, Korean, and Vietnamese.

🔗 http://www.alz.org/health-care-professionals/patient-information-education-care-resources.asp#patient_resources

The Caregiver Action Network (CAN) has an Alzheimer’s Video Resource Center with a library of videos and tip sheets on understanding symptoms and diagnosis, life as a caregiver, and finding support.

🔗 http://caregiveraction.org/resources/alzheimers-videos/

The Lewy Body Dementia Association provides outreach, education, and research to support those affected by Lewy body dementia, a common form of degenerative dementia. They offer information on understanding the associated behavior changes.

🔗 https://www.lbda.org/content/understanding-behavioral-changes-dementia

The National Institute on Aging website has an Alzheimer’s and related Dementias Education and Referral Center (ADEAR) with free publications and information for families, caregivers, and health professionals. ADEAR Center staff can provide referrals for local and national resources.

🔗 https://www.nia.nih.gov/health/alzheimers

¹ https://www.resourcesforintegratedcare.com/GeriatricCompetentCare/2017_GCC_Webinar_Series/Applying_Promising_Practices
COMMUNITIES & NEWSLETTERS

The national Alzheimer’s Association provides a search tool for local resources such as support groups and educational workshops in communities across the country.

http://www.alz.org/apps/findus.asp

The Association for Frontotemporal Degeneration offers seasonal newsletters that include first-person stories of challenges experienced by people living with frontotemporal degeneration.

http://www.theaftd.org/newsroom/newsletters/partners-in-ftd-care-newsletters

PUBLICATIONS & TRAININGS

Alzheimer’s Greater Los Angeles offers the Care Transitions Notebook: Caring for Someone with Memory Loss or Alzheimer’s After a Hospitalization. This publication helps caregivers better understand Alzheimer’s and other dementias and how to care for someone after a hospitalization. The notebook is available in English, Spanish, Korean, and Armenian.

http://www.alzgla.org/professionals/hospital-home-transitions/

Alzheimer’s Greater Los Angeles also publishes Plain Language Fact Sheets on Behavioral Symptoms and Care Challenges for staff or family caregivers. These fact sheets focus on understanding and managing common care challenges such as bathing, getting lost, paranoia, and mood changes and are available in English and Spanish.

http://www.alzgla.org/CaregiverTipSheets

The Family Caregiver Alliance hosts a Caregiver’s Guide to Understanding Dementia Behaviors with tips and strategies organized by types of behavior.

https://www.caregiver.org/caregivers-guide-understanding-dementia-behaviors

Home Instead Senior Care offers online interactive educational courses for families caring for persons with Alzheimer’s or other dementias.

http://www.helpforalzheimersfamilies.com/alzheimers-dementia-education/

Special thanks for contributions to this guide:

Debra Cherry, Ph.D.
Executive Vice President
Alzheimer’s Greater Los Angeles

Rebekah Wilson, MSW
Dementia Care Consultant
and Trainer

Teeshla Curtis
Program Manager
Healthy Connections Prime
South Carolina DHS

The Medicare-Medicaid Coordination Office (MMCO) in the Centers for Medicare & Medicaid Services (CMS) seeks to ensure that beneficiaries enrolled in both Medicare and Medicaid have access to seamless, high-quality health care that includes the full range of covered services in both programs. This brief is intended to support health plans and providers in integrating and coordinating care for Medicare-Medicaid enrollees. It does not convey current or anticipated health plan or provider requirements. For additional information, please go to www.resourcesforintegratedcare.com. Please submit any feedback on this brief or topic suggestions for other briefs to RIC@Lewin.com.