

STATE ALZHEIMER'S DISEASE PLANS: CAREGIVERS

Recommendations to assist unpaid Alzheimer's caregivers

Arkansas	
California	<ul style="list-style-type: none"> • Support, fund, and expand the availability of professional guidance to help family caregivers navigate and manage myriad safety and behavioral issues through an array of services such as caregiver assessment, care consultation, counseling, care management, respite care, support groups, assistive technologies, and other effective interventions. • Empower family caregivers to register for, participate in, and complete training in established educational programs offered by reliable public and nonprofit organizations with specialized expertise in Alzheimer's disease. • Increase participation in educational programs among diverse caregivers through culturally and linguistically appropriate offerings. • Encourage businesses and other workplace sites to offer family caregiver support services; for example, flexible work hours, referrals and counseling through Employee Assistance Programs, and other employee initiatives. • Secure foundation, corporate, and nonprofit funding for effective statewide family caregiver training programs. • Invest in the future of the Caregiver Resource Centers, Alzheimer's Day Care Resource Centers, California Alzheimer's Disease Centers, and other programs tailored to the unique needs of family caregivers. • Increase the availability of and referral to face-to-face and web-based support groups for family caregivers and persons in the early stage of the disease. Encourage referral by physicians, health professionals, and community-based organizations. • Educate and enlist the faith community as community resources that can help reach out to and support family caregivers. • Recognize and address the financial burden of caregiving and work to protect spouses from impoverishment at all levels of care. • Recognize caregiving as a health risk factor that warrants public health attention to encourage health professionals to acknowledge and address the issue.
Colorado	<ul style="list-style-type: none"> • Educate employers about the issues facing family caregivers and encourage them to establish policies such as flextime, telecommuting, referral services, and on-site support programs. • Ensure that local Area Agencies on Aging are aware of and promote existing training materials available to family caregivers, especially those located in rural areas. • Increase funding for and expand the reach of the Savvy Caregiver program and equivalent training programs for all stages of dementia.
Connecticut	<ul style="list-style-type: none"> • Amend the state tax code to include a Dependent Care Credit where the tax filer can receive a credit for care expenses incurred so the caregiver is able to work.
Delaware	<ul style="list-style-type: none"> • Explore the use of volunteer respite providers through a variety of sources including nursing programs, volunteer organizations, community organizations, and faith-based groups. • Explore options for the provision of emergency respite services. • Educate employers about the issues facing caregivers and encourage them to establish workplace policies such as flextime, telecommuting, referral services, and on-site support programs. • Perform an environmental scan of all caregiver training and resources currently available. • Create a robust online "toolkit" for placement on the Delaware Aging and Disability Resource Center (ADRC) and Division of Services for Aging and Adults with Physical Disabilities (DSAAPD) websites containing practical tips, educational materials, and links to educational programs for use by caregivers, ADRC call center staff, and others – and include "toolkit" information in DSAAPD's <i>Guide to Services for Older Delawareans and Persons with Disabilities</i>.

<p>Delaware (cont.)</p>	<ul style="list-style-type: none"> • Coordinate with the Alzheimer’s Association and other public and private community partners to link caregivers to community-based and online educational programs for caregivers through the Delaware ADRC and DSAAPD websites, Caregiver Resource Centers, pamphlets, brochures, and other promotional outreach. • Increase participation in educational programs among diverse caregivers through culturally and linguistically appropriate offerings, including programs offered in Spanish. • Identify caregiving as a health risk factor and promote self-care and frequent breaks for caregivers. • Promote and link caregivers to the Delaware ADRC, local Caregiver Resource Centers, and the Alzheimer’s Association for help in understanding Alzheimer’s disease, navigating the long-term care system, sorting through service options, and accessing relevant supports, including caregiver assessments, care consultation, counseling, care management, respite care, support groups, assistive technologies, future care needs, and other effective interventions. • Explore options to increase support for diverse caregivers, including those caring for persons with early-onset Alzheimer’s disease. • Promote and encourage referrals to the Delaware ADRC by physicians, health care and service providers, faith-based organizations, and other community partners. • Explore options to enlist the faith-based community as a key resource that can reach out to and support caregivers, including promoting partnerships in developing programs to train volunteers. • Build strong partnerships with the health care community and develop avenues to promote caregiving as a health risk factor, and encourage health care professionals to acknowledge and address the issue. • Establish a legislative agenda to address caregiver issues.
<p>District of Columbia</p>	<ul style="list-style-type: none"> • Collaborate with responsible parties to provide person-centered support services for caregivers and persons with Alzheimer’s disease and other dementias.
<p>Florida</p>	<ul style="list-style-type: none"> • Conduct a survey of family caregivers affected by Alzheimer’s disease and other dementias. • Create a statewide buying cooperative for family caregivers affected by Alzheimer’s disease and other dementias to make services for caregivers more affordable. • Pass legislation to provide a tax credit to businesses that provide financial benefit assistance to employees using adult day care services for family members affected by Alzheimer’s. • Create an annual statewide Alzheimer’s disease and other dementias family caregiver week. • Ensure all family caregivers have access to respite services if needed. • Provide respite care vouchers for family caregivers of persons with Alzheimer’s disease and other dementias. • Create regulations for respite programs that service people with Alzheimer’s disease and other dementias. • Increase funding for respite care.
<p>Georgia</p>	<ul style="list-style-type: none"> • Ensure that local Aging and Disability Resource Centers as well as Area Agencies on Aging are aware of and promote existing training and informational materials available to family caregivers, especially those located in rural areas. • Evaluate the cost and feasibility of developing state and/or federally-funded caregiver support programs for caregivers who do not currently qualify for Medicaid services. • Offer accessible training for the family caregiver, including an understanding of the disease, its progression, and how it affects thinking and behavior; strategies for effective communication and behavior guidance; information about available resources and services; treatment; strategies for self-care; and the management of caregiver stress. • Provide funding and implement innovative models to increase caregivers’ access to respite that is provided through in-home respite providers, adult day service organizations, volunteer-based respite programs, and other sources. • Develop an ongoing repository of culturally sensitive resources for use by partners. Engage organizations as repositories that are currently serving in this capacity (such as the Rosalynn Carter Institute).

Georgia (cont.)	<ul style="list-style-type: none"> • Create funding mechanisms to support family caregivers to keep their family member with dementia at home longer by providing reimbursement for personal care services, specialized medical supplies, and respite care, for example. • Use assistive technology to provide services and training in care and safety to help both persons with dementia and their caregivers. Research current and upcoming technology options being utilized for dementia. Create a Resource Guide for Adaptive Technology. Provide increased access to safety monitoring and support for caregivers.
Hawaii	<ul style="list-style-type: none"> • Ensure that Hawaii care partners and families receive culturally sensitive education, training, and support materials. • Enable Hawaii's caregivers and families to continue to provide care while maintaining their own health and well-being, including through the use of peer mentors, more access to caregiver support groups, affordable transportation options (especially in rural areas), and respite services.
Idaho	<ul style="list-style-type: none"> • Link current Alzheimer's disease and other dementias support groups and respite care services into a vetted caregiver support network and provide viable options for areas of the state not presently served (i.e. rural areas).
Illinois	<ul style="list-style-type: none"> • Provide physical, emotional, and financial assistance to unpaid caregivers of persons with Alzheimer's disease and other dementias, including accessible, available, and affordable adult day services, respite services, support services for caregivers, and financial assistance, taking into account the type and amount of services provided by currently unpaid caregivers. • Seek any necessary waivers to allow a family member, including a spouse, to receive some form of financial incentives for their services and for the additional costs incurred in order to care for a person with Alzheimer's disease at home. • Create incentives (such as cash benefits and income tax credits) for caregivers to permit them to continue to provide services to persons with Alzheimer's disease and other dementias, such as necessary training, support, and financial assistance, if needed, to allow these persons to remain in the most homelike setting for as long as possible.
Indiana	<ul style="list-style-type: none"> • Provide training and support for caregivers. • Encourage employers to include family caregiver support services as part of their benefit packages and policies.
Iowa	<ul style="list-style-type: none"> • Correlate the stages of Alzheimer's disease and other dementias with interventions to assist caregivers and service providers in making care decisions and in navigating the delivery system by identifying interventions, service needs, safety needs (including home environments), and caregiver needs. • Compile an analysis of Iowa's population by county and age to determine current utilization and future service needs of caregivers and persons with Alzheimer's disease and other dementias to support development of programs and services.
Kentucky	<ul style="list-style-type: none"> • Support legislation for a caregiver tax credit for providing in-home care for dependent relatives who have little to no income, and have been diagnosed with Alzheimer's and other dementias. • Develop incentives beyond tax incentives for caregivers.
Louisiana	<ul style="list-style-type: none"> • Develop and implement, building upon existing resources, a public awareness campaign to increase knowledge about, and use of, existing federal and state tax exemptions, deductions, and credits for caregivers of persons with Alzheimer's disease and other dementias. • Encourage development of services that support caregivers remaining in the workforce through efforts such as: (1) partnering with stakeholders such as the Chamber of Commerce, Society of Human Resource Managers, small business owners and others, and caregivers to explore employer implementation of a "cafeteria plan" state income tax benefit for caregivers of persons with Alzheimer's disease and other dementias; and (2) partnering with the state Society of Human Resource Managers and caregivers to develop and implement employee assistance programs for employees who are caregivers for persons with Alzheimer's disease and other dementias. • Explore opportunities to increase funding for the National Family Caregiver Support Program.

Maine	<ul style="list-style-type: none"> • Conduct a gap analysis to identify new and existing opportunities to enhance and adequately fund – and then fund – state policies and programs regarding benefits and subsidies to family caregivers that promote active involvement of families in dementia care. • Develop, enhance, and improve the variety and supply of formal and informal supports for caregivers of persons with Alzheimer’s, including supports appropriate for elders and their caregivers in ethnic, immigrant, and tribal communities. • Identify and expand the availability of professional guidance options to help family caregivers navigate and manage the myriad of safety and behavioral issues through an array of services such as caregiver assessment, care consultation, counseling, care management, respite care, support groups, assistive technologies, and other effective interventions. • Identify and expand the reach of public and not-for-profit training programs run by organizations and agencies with expertise in Alzheimer’s disease to inform, educate, and offer care giving strategies and interventions to empower family members and/or friends of those living with individuals with Alzheimer’s at home. • Increase participation in educational programs among diverse caregivers through culturally and linguistically appropriate trainings and materials. Customize outreach tailored to immigrant and other diverse communities and where possible, recruit participation of native language speakers to deliver programs. • Educate and enlist the faith community as community resources that can help reach out to and support family caregivers. Invite faith leaders to applicable trainings and also utilize them as a resource to disseminate information and materials. • Encourage businesses and other workplace sites to offer family caregiver support services, such as flexible work hours, referrals, and counseling through Employee Assistance Programs and other employee initiatives. Invite employers to applicable trainings and also utilize them as a resource to disseminate information and materials. • Establish and support consumer and family involvement in public advocacy through advocacy training and financial supports such as travel reimbursement and funding for respite care. • Enhance the state 2-1-1 information line’s ability to be an effective channel for people seeking access to resources related to Alzheimer’s disease and other dementias by ensuring the system has access to up-to-date contact information for resources in each county. • Educate family caregivers and individuals to recognize and choose quality dementia care. • Enhance and expand the reach of dementia-specific family caregiving trainings, including guidance on available resources and support and navigating systems of care. • Educate family members about best practices in home care. • Educate family members about how to work with facility staff to ensure the needs of their loved ones are met, including anticipated guidance regarding the intake and admissions process, assessment, care plan development and conferences, resident and/or family councils as well as ongoing more informal interaction during visits. It should also include anticipatory guidance on how family caregivers can help support their loved ones to prepare for the change of setting, as well as guidance on how to prepare themselves.
Maryland	
Massachusetts	<ul style="list-style-type: none"> • Assess barriers to families living with younger-onset Alzheimer’s and develop strategies to enhance support for these families. • Coordinate widespread dissemination of multilingual information about the disease process, living with Alzheimer’s, and caregiving strategies. • Assess state and private sector ability to offer enhanced financial incentives, including tax credits or paid time off, for those who give up their income to be full-time caregivers for family members with Alzheimer’s and other dementias. • Collaborate with community partners to recruit support group leaders and maintain support groups in their communities. • Diversify the support group models to include in-person, telephone, and online support groups. • Work with the Alzheimer’s Association and other community partners to deliver community-based and online educational programs for caregivers.

Michigan	<ul style="list-style-type: none"> • Identify and promote use of best community caregiver assessment tools and practices. • Promote existing tools and resource materials, including Effective Caregiver Interventions, in-home and community-based respite care best practices, technology lexicon/assistive technology, and other selected resources. • Provide input in development and implementation of home- and community-based caregiver support services provided through the Alzheimer's Disease Supportive Services Program.
Minnesota	<ul style="list-style-type: none"> • Develop, enhance, and improve the variety and supply of informal and formal supports for caregivers of persons with Alzheimer's, including supports appropriate for elders and their caregivers in ethnic, immigrant, and tribal communities. • Support expansion of programs that use the New York University caregiver counseling model proven to increase the duration of family caregiving and delay nursing home placement.
Missouri	
Nevada	<ul style="list-style-type: none"> • Explore the use of volunteers to provide support to family caregivers by collaborating with community organizations and faith-based groups. • Collaborate with the business community to create employee assistance programs that include education and training for caregivers.
New Mexico	<ul style="list-style-type: none"> • Expand access to culturally appropriate resources and supports for family caregivers and all populations and entities dealing with the care and treatment of individuals with Alzheimer's disease and other dementias. • Increase access to culturally competent support services, including respite, care coordination, and case management services in a time, manner, and location that meets family needs. • Expand evidence-based caregiver training in a manner that is effective across New Mexico cultures and locations.
New York	<ul style="list-style-type: none"> • Educate caregivers and patients about the Family and Medical Leave Act, long-term care insurance, the benefits of advanced legal and financial planning, and existing support programs through agency websites, educational forums, service networks, and the media. • Educate employers about caregiving responsibilities and how they can be responsive to these employees through partnerships with trade organizations. • Gradually expand Alzheimer's Disease Community Service Programs that provide multiple activities such as support groups and caregiver help lines until they are available statewide over the next three years. • Provide in-person, phone, and web-based support for caregivers through existing mechanisms (for example, the Alzheimer's Disease Community Service Programs). • Gradually expand Alzheimer's Disease Community Service Programs that provide multiple support and training activities until they are available statewide. • Educate caregivers on the importance of home modifications to prevent injury. • Offer caregivers help on how to keep records and present information to medical providers. • Partner with community-based organizations such as the Alzheimer's Association to train volunteers and educate caregivers about appropriate strategies to deal with ongoing legal, financial, medical, behavioral, and emotional challenges.
North Dakota	
Oklahoma	<ul style="list-style-type: none"> • Evaluate the ability for the state to provide a financial incentive such as, but not limited to, a tax credit for those caregivers who give up their income to care for someone with Alzheimer's disease and other dementias. • Address the needs of employees who are caregivers to persons with Alzheimer's disease through the use of on-site support groups, case management, and other initiatives.
Oregon	
Pennsylvania	<ul style="list-style-type: none"> • Ensure that a statewide comprehensive central clearinghouse for family members and caregivers on treatment and risk reduction options is developed and maintained. • Identify and/or develop culturally and linguistically appropriate educational and training tools for families and caregivers, with the goal of ensuring that all understand the implications of Alzheimer's and other dementias; disseminate these tools throughout the community.

<p>Pennsylvania (cont.)</p>	<ul style="list-style-type: none"> • Utilize and strengthen linkages between medical care team and informal caregivers. • Conduct an assessment of caregiver needs, including, but not limited to, legal and financial guidance, respite care, psychological counseling, and stress management. • Disseminate information about currently available web- and paper-based tools for family and long-distance caregivers. • Partner with organizations to develop caregiver materials that are understandable and appropriate across varied population groups. • Inventory and make available a listing of caregiver support groups. • Encourage the establishment of additional caregiver support groups in geographical areas currently lacking such groups. • Encourage the use of Health Insurance Portability and Accountability Act-compliant, web-based health tracking tools that facilitate communication between informal caregivers and health care providers. • Explore legislation to provide financial support to caregivers.
<p>Rhode Island</p>	<ul style="list-style-type: none"> • Encourage the development of social media networks as resources for caregivers. • Build upon existing caregiver newsletters to pool resources and extend outreach to caregivers interested in learning about Rhode Island-specific services and supports. • Formalize a peer mentor network to connect families and caregivers that are new to the disease with those who have more experience. • Partner with geriatric mental and behavioral health experts to provide services for caregivers who screen positive for depression, anxiety, and burnout – and develop the capacity to offer education and consultation to community providers who work with families and caregivers. • Support and build upon ongoing public outreach efforts through the Providence Catholic Diocese, the Division of Elderly Affairs, and the Rhode Island Alzheimer’s Disease website to increase public awareness of the CareBreaks program (respite services), with a goal of improving the rate of utilization of respite care among family caregivers. • Encourage the development of a comprehensive network of respite options across the state, including short- and mid-term respite care. • Explore potential to incorporate mid- to long-term in-home respite services into the overall network of options. • Survey national models akin to the Shared Living program that address the prohibition on spouses, parents, or other persons financially responsible for the care recipient from serving as the paid caregiver. • Enhance provision of respite care services to include emergency or short-term immediate access, including by exploring the possibility of (1) shortening the average required stay at nursing homes for emergency or short-term respite; (2) simplifying the application process for nursing home respite care; and (3) alternative providers of care who could be more readily available to step into a respite need on an immediate basis. • Seek to develop long-term respite care services modeled around best practices for people with Alzheimer’s disease, including keeping the person at home and developing long-term relationships. • Expand respite care worker education and training opportunities across the state. • Establish ongoing links with Employee Assistance Programs (EAP) and provide educational and informational resources on support for families dealing with Alzheimer’s disease. • Strengthen existing EAP resources for Alzheimer’s at large companies currently offering EAPs to employees; include outreach about the State Plan for Alzheimer’s disease and awareness of the Rhode Island Alzheimer’s Disease website. • Work to ensure that all EAPs receive information about referral resources for employees requiring more intensive or long-term mental health services, such as geriatric mental health programs that include services for caregivers. • Enhance awareness of the Rhode Island State EAP and make efforts to improve outreach to employees dealing with Alzheimer’s disease caregiving responsibilities.

Rhode Island (cont.)	<ul style="list-style-type: none"> • Support expansion of EAPs across large, mid-size, and small employers in Rhode Island. Explore possible partnerships across smaller sized companies by building shared resources through, for example, Chambers of Commerce. • Develop additional partnerships for the provision of workplace-sponsored support groups and educational series focused on Alzheimer's disease. • Create a peer mentorship program to pair new caregivers with more experienced caregivers; explore the potential to connect peer mentors through the online chat function as part of the Rhode Island Alzheimer's disease website. • Incorporate real-time employee-focused supports and resources to the Rhode Island Alzheimer's disease website. • Identify best practices and future improvements for the support of remote caregivers and caregivers with extensive external demands such as family and job-related responsibilities. • Research grant opportunities to implement telehealth demonstration programs for families caring for persons with Alzheimer's or other dementias in home situations. • Explore a partnership between state colleges and universities and the Alzheimer's Association to develop a series of Rhode Island-specific online videos with two targets: (1) a focus on introducing families and caregivers to Alzheimer's disease and Alzheimer's disease resources across the state; and (2) a series of short training modules for anyone interested in learning the basics of caring for someone with Alzheimer's. • Develop a two-week certification program, offered by a local university or organization with input from the Alzheimer's Association, for family members caring for individuals with dementia. Incorporate ways to address the needs of other family members (in particular young children) in training and education modules to help them better understand the disease. • Develop training and education opportunities for friends and family members who will be caregivers and for those who will provide respite to the primary caregiver.
South Carolina	<ul style="list-style-type: none"> • Promote and support private and public sector businesses in addressing the needs of employees who are caregivers to persons with Alzheimer's disease and other dementias through the use of on-site respite care, support groups, or other initiatives.
Tennessee	<ul style="list-style-type: none"> • Educate caregivers through the Alzheimer's Association and other agencies, and provide support and possible referral to mental health services, paying attention to caregiver's mental state during office visits. • Increase and improve support, counseling, and education for family and informal caregivers to provide information on available support services and the importance of maintaining their own health, including by (1) providing an efficient method of identifying and tracking resources across Tennessee; and (2) examining linkages with existing options, such as the National Family Caregiver Support Program, inpatient respite care, and the Alzheimer's Innovation Grant.
Texas	<ul style="list-style-type: none"> • Assess caregivers on their experiences in obtaining access to needed information and services. • Partner with at least one Texas health care system or group of primary care physicians to pilot test an evidence-based approach to identification, assessment, and support of Alzheimer's disease caregivers within health care settings. • Establish a translational research workgroup to explore opportunities for implementing an evidence-based caregiver support program into a large health care system or within a group of primary care physicians in Texas. • Promote integration of Alzheimer's disease caregiver support services into Texas health care system(s), providers, and other health care-related organizations. • Encourage partnerships between Alzheimer's disease support service organizations, such as the Alzheimer's Association and local Area Agencies on Aging, and health care systems to facilitate caregiver access to support services. • Identify potential sources of financial support for health care systems or physicians who provide support services to Alzheimer's disease caregivers; for example, Centers for Medicare and Medicaid Services (CMS) demonstration projects, CMS waivers, and Medicaid Waiver programs.

Utah	<ul style="list-style-type: none"> • Educate and enlist the faith-based community as a key resource that can reach out to and support family caregivers. • Recognize caregiving as a health risk factor that warrants public health attention to encourage health professionals to acknowledge and address the issue. • Ameliorate neuropsychiatric symptoms of persons with dementia cared for at home by enhanced training and support of family caregivers on effective behavioral interventions that are designed to modify such symptoms, reduce caregiver distress, and delay nursing home placement. • Support, fund, and expand the availability of professional guidance to help family caregivers navigate and manage myriad safety and behavioral issues through an array of services such as caregiver assessment, care consultation, counseling, care management, respite care, support groups, assistive technologies, and other effective communications. • Increase participation in educational programs among diverse caregivers through culturally and linguistically appropriate offerings. • Secure foundation, corporate, and nonprofit funding for effective statewide family caregiver training programs. • Provide health education to caregivers early in the disease through medical providers, voluntary agencies, and the Caregiver Support Program of the Area Agencies on Aging that includes information about disease course and services needed at different disease stages. • Recognize and address the financial burden of caregiving and work to protect spouses from impoverishment at all levels of care. • Encourage businesses and other workplace sites to offer family caregiver support services; for example, flexible work hours, referrals and counseling through Employee Assistance Programs, and other employee initiatives. • Advocate for state and federal tax credits, similar to the child care tax credit, for frail spousal and working adult offspring caregivers paying for direct care services to encourage the use of early intervention and support services, such as adult day and respite care. • Research, disseminate, and expand private insurance and cafeteria plans that cover supportive services (such as adult day care) for caregivers.
Vermont	<ul style="list-style-type: none"> • Provide training and orientation to consumers and family members of individuals newly diagnosed with dementia regarding the condition, the system of dementia care, and social supports. • Develop state policies regarding benefits and subsidies to family caregivers that promote active involvement of families in dementia care. These incentives can be in the form of monetary incentives, tax incentives, health care coverage, or deferred income incentives (retirement) as well as non-monetary incentives such as eligibility to obtain counseling and support for family caregivers through Choices for Care and other state or locally sponsored programs. • Develop employer-supported dementia caregiver training and other employer-supported programs.
Virginia	<ul style="list-style-type: none"> • Restore funding to maintain the Virginia Caregivers Grant. • Train and link family and informal caregivers to information and education about dementia and the caregiving process, including information about dementia as well as information on how caregivers can stay healthy, organize the various legal issues associated with a loved one's dementia diagnosis, and how caregivers can locate and make use of resources for respite care services.
West Virginia	<ul style="list-style-type: none"> • Establish a state-funded Alzheimer's disease training program for family and lay caregivers to be offered statewide.
Wisconsin	<ul style="list-style-type: none"> • Expand access to caregiver education and support programs. • Expand and update the Alzheimer's Family Caregiver Support Program, including by (1) revising the maximum per family allowance and income eligibility requirements; (2) increasing awareness of the program and the National Family Caregiver Support Program; (3) encouraging greater coordination between state and federal programs; (4) increasing funding; and (5) establishing a funding allocation for tribes.

Wisconsin (cont.)	<ul style="list-style-type: none">• Use volunteer programs to provide support for people with dementia and their family caregivers, including by (1) developing additional examples of volunteer-based programs for family caregivers of people with dementia; (2) developing a toolkit for replication of best practice programs; (3) awarding grants to pay a volunteer coordinator; and (4) monitoring implementation and progress.
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