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2024

NAVIGATING DEMENTIA

Empowering Caregivers:

Essential Resources and

Supports in Maryland

RESOURCE BOOK

FOR AGING SERVICES
PROFESSIONALS
& CAREGIVERS

Funded by a generous grant from the Maryland Department of Aging





WEBINAR & IN-PERSON* SESSIONS

MARCH 1 1-3 PM
CHANGES IN MEMORY

MARCH 8 1-3 PM
THE DEMENTIAS

* MARCH 22 9-4 PM COMMUNICATION

APRIL 19 1-3 PM INTERVENTIONS

APRIL 24 8:30-2:30 PM SERVICES & SUPPORTS

* MAY 10 9-4 PM
ASSESSMENT & REFERRALS

MAY 24 1-3 PM

MARYLAND RESOURCES

CEUS ARE AVAILABLE FOR MANY SPECIALTIES. *The Meeting House, Columbia, MD APPLY NOW FOR THE UMB AGE-FRIENDLY SPECIALIST CERTIFICATION!
SERIES HOURS COUNT TOWARDS COMPLETION. VISIT: TINYURL.COM/4EXD8WX7

Spring 2024 "Navigating Dementia" Education Series

Description: The Geriatrics & Gerontology Education and Research (GGEAR) program at University of Maryland, Baltimore, with generous support from the Maryland Department of Aging, is pleased to announce our new professional development and community education program entitled "Navigating Dementia." Alzheimer's disease and related dementias (ADRD) represent a growing public health crisis. Across Maryland, there are an estimated 110,000 individuals aged 65 and older living with ADRD and nearly 240,000 unpaid family members providing care to these individuals. Recognizing the unique needs of these groups, GGEAR is hosting a series of five webinars and two in-person conferences that are FREE and open to the public.

The "Navigating Dementia" educational series is intended for Aging Services professionals, caregivers of persons living with ADRD, and anyone with an interest in matters concerning older adults. The series will provide valuable knowledge, resources, and support on topics related to aging, cognitive health, dementia care, and caregiving in Maryland.

Overall objectives:

- 1. Advance personal understanding of dementia;
- 2. Formulate realistic expectations based on effects of dementia on persons living with ADRD and their caregivers;
- 3. Demonstrate confidence in interactions which reflects evidence-based, unbiased, culturally sensitive approaches to care; and
- 4. Create meaningful living opportunities for adults living with Alzheimer's disease or a related dementia in Maryland.

Webinar: Friday, May 24, 2024 (1:00-3:00pm; check-in begins at 12:30pm)

Title: Empowering Caregivers: Essential Resources and Supports in Maryland

Description: This live interactive webinar will provide information about the wide range of caregiver resources, including how to access, available throughout the state of Maryland.

Objectives:

- Identify Maryland supports and services designed to promote optimal health outcomes along with greater independence, better quality of life, choice, and autonomy.
- Evaluate and access useful features of The GUIDE Model, a comprehensive package of care coordination and care management, caregiver education and support, and respite services.





TODAY'S PRESENTERS



Amanda DiStefano, MSW

Director, Long-Term Care Services Division Maryland Department of Aging

Amanda Distefano is the Long-Term Services Division Director at the Maryland Department of Aging, where she works to change the trajectory

of aging by helping Maryland residents live healthy, active, and independent lives in the community as long as possible. Amanda is a certified Community Resource Specialist, specializing in aging and disabilities resources. She has 22 years of experience in education, public health, injury prevention, and aging and disability resources. Her passion for improving the quality of life for older Marylanders led Amanda to her current role. When not at work, Amanda can be found most nights at a ball field in Washington County, Maryland with her husband cheering on her favorite players--her two boys!



Sage Hart

Health Insurance Specialist, Division of Healthcare Payment Models

Sage C. Hart is a GUIDE Model Co-Lead within the Patient Care Models Group at the Centers for Medicare & Medicaid Services' Center for Medicare and Medicaid Innovation (CMMI). Prior to joining CMMI, Sage worked as an attorney in private practice focusing on elder law and special needs planning. As a practicing attorney, she was a Certified Elder Law Attorney (CELA) and served as an affiliate member of the Special Needs Alliance and a member of the National Academy of Elder Law Attorneys. Sage has a J.D., cum laude, with a certificate in health law, from the University of Maryland Francis King Carey School of Law.



LET'S TALK ABOUT CARE PARTNERING

It is time to debunk common myths or misconceptions about this relationship.

Get ready to become an expert!

MYTH: There's no time for self- careit's selfish.	THE OPPOSITE IS TRUE! It's actually easier to take care of others if you've taken care of yourself first. You may put your loved one's needs ahead of yours at times, but don't let this turn into a habit of self-neglect.
MYTH: Self-care takes time and costs money.	MAKE IT SIMPLE - You don't need to leave town, or even the house. Take five minutes to journal, have a cup of coffee, or take a hot shower. With 10 minutes you can get outside for fresh air, listen to some favorite songs, have a snack, call a friend, meditate, read, or do some exercises. These simple breaks will make the day more enjoyable.
MYTH: I have to know everything.	LEARN AS YOU GO Knowledge is power and helps a person feel in control, but no one knows everything, even the professionals. Do the best you can in the moment, trust your instincts, and learn from others' experiences.
MYTH: I'm not the one who deserves to complain.	OPEN UP: Share your feelings- it's OK to talk with your care partner, too, about what is challenging for you. If you pretend everything is fine, the anxiety and stress could become overwhelming and eventually affect your own health.
MYTH: Care partnering is such a lonely job.	IT CAN BE, BUT HELP IS AVAILABLE! Many people have been there, understand what you're going through, and are eager to offer advice and encouragement. Join an in-person or virtual support group, reach out to your faith community, or call a 24/7 helpline (800-272-3900). Build a care team of family, friends, and care providers to achieve a balance in your responsibilities. No one needs to go it alone.

Adapted from 7 myths about caregiving you shouldn't believe | MD Anderson Cancer Center

FACTS ABOUT MARYLAND ADRD & CAREGIVING

Key points from the Maryland State Plan to Address Alzheimer's Disease and Related Dementias: 2022-2026 FINAL_2021.ADRD.state.plan.docx (maryland.gov)

- ADRD is very common and the prevalence in Maryland will increase substantially over the next several decades.
- Risk reduction or prevention of ADRD in later life may be possible by taking a life course approach to public health and by addressing modifiable risk factors.
- Dementia is a highly stigmatized group of conditions and continues to be under-detected and under-diagnosed.
- ADRD is strongly associated with high health care and long-term care costs and with high burden for individuals and families.
- People belonging to minority groups, women, and those living in poverty are disproportionately affected by ADRD and have significantly more health care disparities and worse outcomes.
- Currently there are no pharmacological treatments available to slow or stop the progression of most dementias, which makes these conditions fatal.
- Effective care management and symptom treatment options exist, however most PLWD and their family caregivers have care needs that go unevaluated and unmet. Many of these are non-medical needs.
- The provision and coordination of dementia care is inadequate, although effective care and treatment strategies have been developed.

In addition, Alzheimer's Association county-level data found the highest prevalence of Alzheimer's in the east and southeastern regions of the country -- with the highest in **Maryland** (12.9%), New York (12.7%), Mississippi (12.5%), and Florida (12.5%). For counties with a population of 10,000 or more individuals age 65 or older, the highest estimated prevalence rates are in:

- Miami-Dade County, Florida (16.6%)
- Baltimore City, Maryland (16.6%)
- Bronx County, New York (16.6%)
- Prince George's County, Maryland (16.1%)
- Hinds County, Mississippi (15.5%)
- Orleans Parish, Louisiana (15.4%)
- Dougherty County, Georgia (15.3%)

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Take a moment to color throughout the program book. We know this is a lot to absorb!



Maryland State Plan to Address Alzheimer's Disease and Related Dementias: 2022-2026

Pursuant to Health-General Article, §13-3207, Annotated Code of Maryland, and Chapters 410 and 411 of the Acts of 2019 (The Virginia I. Jones Alzheimer's Disease and Related Disorders Council, May 2022)

The plan is available here: FINAL_2021.ADRD.state.plan.docx (maryland.gov)

THE 2022-2026 STATE ADRD PLAN

Overview

The 2022-2026 State Plan builds on the 2012 Maryland ADRD State Plan and contains a variety of new recommendations for policy and actions suggested to achieve five major goals:

- Goal 1: Expand efforts to support public awareness, prevention, and early detection of ADRD;
- Goal 2: Enhance quality, access, and coordination of ADRD care;
- Goal 3: Enhance and expand supports for family caregivers;
- Goal 4: Advance ADRD research and encourage evidence-based practices; and
- Goal 5: Enhance data capabilities related to dementia and dementia impact and effects of interventions.

The Council and its partners envision a dementia-capable Maryland which supports the health and well-being of its at-risk citizens and provides care, services, and resources through a whole-person, coordinated approach to meet the needs of Marylanders living with dementia and their caregivers across the disease continuum, care settings, and from diagnosis to end of life.

INTRODUCTION TO THE 2022-2026 STATE PLAN

In 2012, the ADRD Commission published Maryland's first ADRD State Plan which documented issues related to ADRD in Maryland and made a set of recommendations to serve as a blueprint to address the needs of people living with dementia, their families and caregivers.

In 2013, the Virginia I. Jones Alzheimer's Disease and Related Disorders Council (the Council) was authorized to continue the work of the Commission. Named in the honor of Virginia I. Jones, a dedicated public servant and Marylander who lived with Alzheimer's Disease for more than two decades, the Council was charged with developing and monitoring the State Plan and reviewing, promoting, and expanding statutes, policies, and programs to improve or enhance the lives of people living with dementia and their families. In 2019, pursuant to Health-General Article, §13-3207, Annotated Code of Maryland, and Chapters 410 and 411 of the Acts of 2019, the Council was re-seated and was directed as part of its charge to update the State Plan and advocate for the State Plan.

Throughout 2020 and 2021, the Council undertook a collaborative process to update and enhance the 2012 State Plan. The Council's revision process included an environmental scan of national, state, and local initiatives, policies, and programs relevant to Alzheimer's disease and healthy brain aging, a systematic review of 18 recently-updated Dementia State Plans, a series of open Council workgroup meetings, a series of listening sessions for oral public comment, the solicitation of public comment via email, and iterative revisions of the State Plan's proposed goals, actions and strategies.

Through this review process the Council found that much has been accomplished in Maryland over the past 10 years to support brain health and improve care and outcomes for Marylanders living with dementia. This includes, but is not limited to, programs/initiatives/resources/policies such as:

- · Maryland Total Cost of Care Program and the Total Cost of Care All-Payer Model,
- Baltimore City Healthy Brain Initiative,
- · Age-Friendly and Dementia Friendly Community Initiatives,
- AARPs Staying Sharp Program,
- Maryland Access Point (expansion and enhancement),
- · Dementia Capable Community Connections,
- Johns Hopkins Geriatric Workforce Enhancement Program (GWEP),
- Community for LifeSM (CFL),
- · State Health Information Exchange (CRISP), and
- Alzheimer's Association Health Systems and Clinicians Initiative to Enhance Care and Improve Outcomes.

The 2022-2026 State Plan aims to build on, enhance, and extend these ongoing efforts in Maryland and to align with and leverage important new policies and opportunities happening across the country, such as:

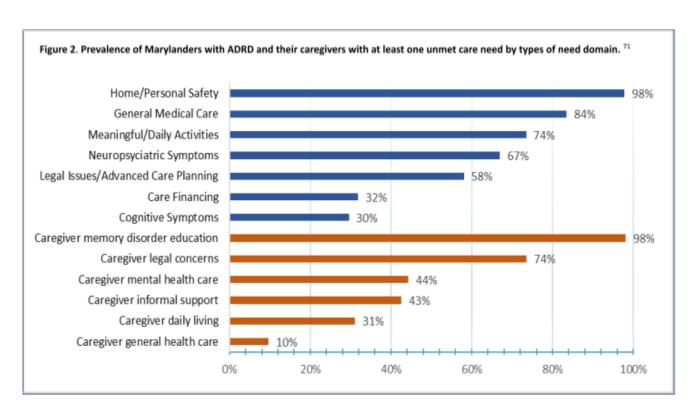
- The Centers for Disease Control and Prevention (CDC) Healthy Brain Initiative,
- The Affordable Care Act,
- Building Our Largest Dementia Infrastructure for Alzheimer's (BOLD) Act Funding,
- The National Alzheimer's Project Act (NAPA),
- Younger-Onset Alzheimer's Disease Act as part of the Older Americans Act,
- Centers for Medicare and Medicaid Services Health Care Innovation Center (CMMI),
- RAISE Family Caregivers Act,
- · Dementia Friendly America, and
- American Rescue Plan Act.

This 2022-2026 State Plan builds on these positive changes, takes advantage of opportunities for improvement, and most importantly, offers hope to Marylanders now and in the future through the promotion of healthy brain aging and brain health, early detection and diagnosis, a better and more holistic approach to ADRD treatment and management.

Care Needs Among People Living with Dementia (PLWD) and Their Caregivers

Despite the high spending, PLWD still experience significant disparities in care and excesses in adverse outcomes and higher costs. ^{55,56} Primary care, the hub of care for most PLWD, faces significant time and resource challenges, making it difficult to assess and respond to the complex and multidimensional care needs of both PLWD and caregivers including non-medical, supportive care needs. ^{57,58} Unfortunately, dementia care needs commonly go unevaluated and unmet. ⁵⁷⁻⁶⁴ Common, modifiable, dementia-related needs including lack of dementia recognition and diagnostic evaluation, safety (e.g., home safety, wander risk management, driving, fall-risk), medical care and multimorbidity management, management of behavioral symptoms, medication management, and social and supportive care in daily living (e.g., meaningful activities, activities of daily living [ADL] assistance). ^{57-61,64-67} Family caregivers have a number of needs as well, including education about memory disorders and what to expect, knowledge of and access to medical and community-based resources, self-care, social support, and emotional health. ^{62,63,68}

Two recent Maryland-based studies from Johns Hopkins University between 2014 and 2019 provide detailed data on care needs for Marylanders with ADRD who are living at home and with their caregivers. ^{62,69,70} The studies included 646 community-residing PLWD (n=646) and informal caregivers (n=637) in the greater Baltimore and Maryland suburban District of Columbia region (Anne Arundel, Baltimore, Carroll, Harford, Howard, Montgomery, and Prince George's Counties, and Baltimore City). The study utilized the Johns Hopkins Dementia Care Needs Assessment (JHDCNA), and found that unmet needs for community-living PLWD and their caregivers are extremely common, modifiable, and often non-medical, ⁷¹ validating an earlier Maryland-based ADRD needs study. ^{63,67,68,72} Marylanders living with dementia had high prevalence rates of non-medical needs such as home and personal safety (98%), meaningful/daily activities (74%), and caregiver informal support (43%). Other common needs were for neuropsychiatric behavior management (67%), medical condition management (84%) and caregiver mental health (44%) (Figure 2). Unmet JHDCNA needs are related to poor outcomes like caregiver burden. ^{67,71}

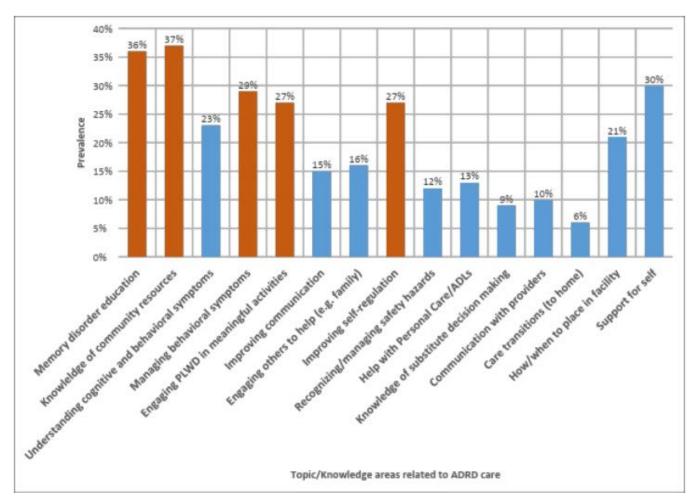


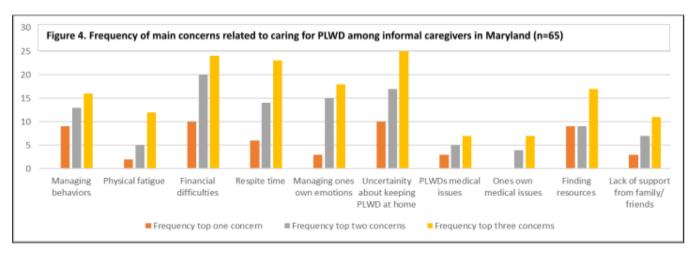
Caregivers of PLWD in these studies (n=641) reported a number of areas where they desired more support. The most prevalent priority areas were knowledge of and access to community resources for memory problems (37%), education

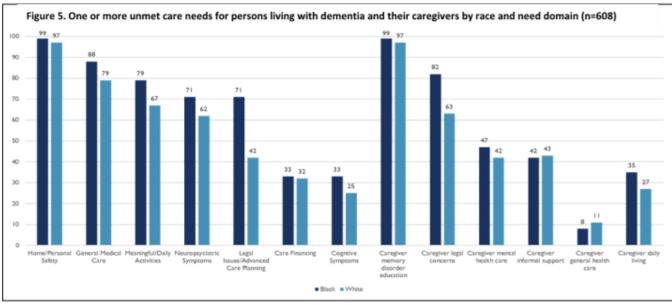
about memory disorders (36%), support for themselves (30%), and how to manage dementia-related problem behaviors (29%) (Figure 3). A supplemental survey (n=65) asked caregivers to rank their top three concerns related to caregiving and found that uncertainty about being able to keep the PLWD at home, financial difficulties, and respite time were consistently ranked as the most common top three concerns (Figure 4).⁶²

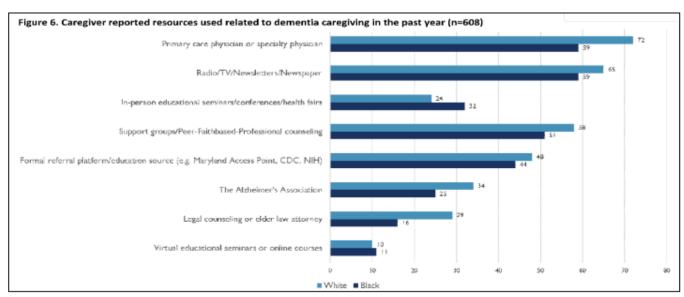
These two studies also examined whether there are disparities in care by race. 64,73 Data suggest Black Marylanders with ADRD had greater overall percentages of unmet needs (27%) compared to Whites (22%) (p<0.001), as did Black ADRD caregivers compared to their White counterparts. The largest gaps by race were in unmet needs related to advance care planning and other legal issues (71% vs. 42%), caregiver-related legal issues (82% vs. 63%), meaningful/daily living activities for the PLWD (79% vs. 67%), and management of the PLWD's neuropsychiatric symptoms (71% vs. 62%) (Figure 5). Black ADRD caregivers also tended to use fewer community resources for dementia care, with the exception of in-person conferences/health fairs (Figure 6). 64,73

Figure 3. Survey of self-report areas related to ADRD care that Maryland informal caregivers (n=641)









Goal 3: Enhance and expand supports for family caregivers.

Introduction: Marylanders living with dementia require a range of cognitive, functional, behavioral, psychosocial, and environmental supports over the course of the illness, much of which is provided through millions of hours of unpaid care provided by informal caregivers in Maryland every year. Informal caregivers include family, extended family, and friends who assist with the multidimensional and changing needs of persons living with dementia. These individuals often themselves need access to a variety of supports and resources by nature of serving as a caregiver. Unfortunately, the health care system is not currently set up to provide family-centered ADRD care that purposefully involves supporting the caregiver both in services and education, as well as in ways to maintain their own medical and mental wellbeing along the way. As such, many ADRD caregivers find themselves thrust into the unfamiliar territory of dementia, having to learn on their own what it means for them and their loved one, and how to navigate a complex and disjointed network of health care services and LTSS. Common needs of ADRD caregivers and families may include education about dementia and what to expect; how to plan for the future; skill-building and training for how to communicate effectively; personal care or how to best manage behavioral health needs (neuropsychiatric symptoms associated with dementia); education about care financing options; and information on how to find and access resources (e.g., appropriate services, education, guidance, and tools). Because dementia caregiving is associated with increasing intensity over a prolonged period of time, it can be very physically and emotionally taxing. Caregivers must also be provided with support to reduce stress, avoid burnout, and to maintain physical and mental well-being.

Goal 3 is focused on enhancing caregiver support to directly address needs that exist among Maryland dementia caregivers. Our vision is that every Marylander who finds themselves as a dementia caregiver can be provided with a roadmap and a coordinated network of support that helps them take care of both their loved ones living with dementia and themselves in the process. Five strategies are recommended to enable the enhancement and expansion of supports for family caregivers: (A) Identify unmet needs for family caregivers; (B) Assist families in planning for ADRD care needs; (C) Promote and expand family caregiver supports across care settings; (D) Address caregiver health and wellness; and (E) Address the COVID-19 pandemic and other emergency/natural disaster events.

Strategy	Actions (Recommendations for needed policies or responses)	Short	Mid	Long
A. Identify unmet needs for family caregivers	1. Conduct a comprehensive needs assessment that includes diverse, under-represented, and under-resourced groups of PLWD, their family caregivers, and the multi-disciplinary providers who serve them to identify unmet service and supportive care needs (e.g., health and wellness programs, health care and medical LTSS, respite/daily living/social/palliative care service needs, and residential and long-term care). This needs assessment could use focus groups, interviews, and surveys to evaluate the impacts of COVID-19 on ADRD family caregivers. Partners including the State Commission on Caregiving, the State Commission on Aging, and experts on diversity and health care inequities could be engaged to assist in designing and conducting this assessment.	Х		
	 Use data gained from the needs assessment to identify barriers, guide services planning, and identify existing resources, with a focus on bridging services and support gaps and enhancing availability and accessibility, particularly among ADRD family caregivers who are under-represented and under-served. Share 			х

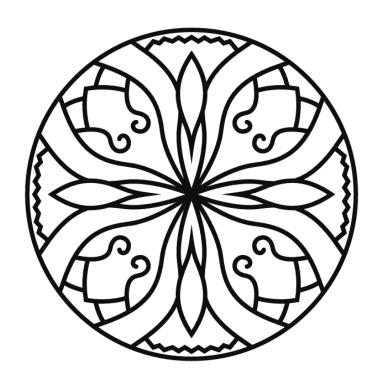
Strategy	trategy Actions (Recommendations for needed policies or response		Mid	Long
	assessment findings with partners and the public in a manner that is easily understood by a general audience.			
B. Assist families in planning for ADRD care needs	 Increase the utilization of MAP as a referral source for community services and a resource for persons with ADRD and their caregivers through curated content and expanded listings within the MAP/ 211 Maryland provider directory (including the Alzheimer's Association, Alzheimer's Foundation of America, Family Caregiver Alliance, respite care, overnight care, drop-in daycare, volunteer programs, crisis/emergency respite, support groups, and wellness promotion programs such as memory care and wellness services). Promote the resource through an annual social media consumer education campaign. 	х		
	 Further develop MAP self-guided assessment and resource tools embedded within the MAP website, to include tools specific to ADRD care needs for Marylanders with an existing diagnosis, with consideration for the range of needs that a family and/or caregivers may have over time, including financial support, respite, caregiver skills training, legal supports, access to health care, and support for their psychological and emotional needs. 			х
	 Encourage the use of validated non-clinical ADRD screening tools among MAP sites and a process for referral to a health care provider for evaluation for ADRD. 		x	
	4. Increase the inclusion of family caregivers for people with ADRD in all aspects of care planning for PLWD during health care visits (e.g., understanding prognosis, health care, LTSS, social, and financial, legal, and advance care implications). Provide educational, referral, and supportive resources at the time of diagnosis (and at regular intervals afterward) to ensure family caregivers receive information and support from providers regarding diagnosis, treatment at different illness stages, long-term care, community supports, and caregiver wellness.		x	
	 Disseminate information from the CDC educational series on topics including care planning tools, help for PLWD and their caregivers to stay physically active, heart and brain health, and facts about aging and ADRD. 	х		
	 Promote dissemination of information to caregivers and persons living with ADRD about the Family and Medical Leave Act (FMLA), long-term care insurance, the benefits of advanced legal and financial planning, and support programs through agency websites, educational forums, service networks, and media. 		x	

GOAL 3: ENHANCE AND EXPAND SUPPORTS FOR FAMILY CAREGIVERS					
Strategy Acti		tions (Recommendations for needed policies or responses)	Short	Mid	Long
	7.	Educate family caregivers on long-term care and support needs and options, what services are provided in different settings of care, costs, and how to select long-term care options based on personal preferences and circumstances.		х	
	8.	Enhance financial literacy and preparedness through statewide dissemination channels focusing on potential short and long-term ADRD-related costs (medical, services, out-of-pocket).		x	
	9.	Provide information to families about non-statutory and statutory authority of caregivers for individuals needing LTSS.		X	
C. Promote and expand family caregiver supports across care settings	1.	Promote adoption and use of evidence-informed programs and interventions among Maryland State agencies, aging services partners, and home and community-based services (e.g., AAAs, local health departments, and nonprofits). Focus on and prioritize programs/interventions addressing known and emerging areas of needs among Marylanders living with dementia and their families and caregivers such as caregiver memory disorder education and knowledge of/access to resources, respite care (e.g., facility-based, in-home), home and personal safety issues including home hazard, fall-risk and wander risk prevention, caregiver skills (dementia communication skills, dementia-related neuropsychiatric behavior management, home care activities such as managing medications and using effective approaches for managing personal care and oral health needs, addressing sensory deficits and incorporating meaningful activity into the day), social support, maintaining caregiver wellness and stress management, and financial assistance to cover LTSS. Examples of evidence-informed programs identified by Maryland State agencies and national agencies can be found in the Administration for Community Living's National Alzheimer's and Dementia Resource Center (NADRC) and include Building Better Caregivers, Powerful Tools for Caregivers, REACH, Savvy Caregiver, STAR-C, DICE, SKILLS2CareWeCareAdvisor™.		X	
	2.	Disseminate information on effective caregiver interventions to family caregivers and the public through ADRD-capable systems and diverse channels (including MAP, social networking websites, government and community websites, colleges and universities, nonprofit organizations, religious institutions, and conferences).			x
	3.	Expand the delivery and accessibility of free statewide ADRD-capable caregiver workshops and training in the			х

Strategy	Actions (Recommendations for needed policies or responses)	Short	Mid	Long
	community to better equip family caregivers to deliver quality care at home through education and skills training offered by existing national organizations (e.g., Administration on Aging through the Administration for Community Living, Family Caregiver Alliance, the Alzheimer's Association, and the Alzheimer's Foundation of America) and local partnerships (e.g., Dementia Friendly Communities, AAAs, Community for Life SM , and MDPCP). Education topics could include memory disorder education, what to expect after a diagnosis, ADRD-capable communication, neuropsychiatric behavior management, problem solving and behavior management skills, provision of daily living assistance skills, patient advocacy, and legal and advanced care planning issues			
	 Identify and engage leaders of faith communities to explore ways in which these entities may serve as resources for ADRD family caregivers. Provide educational materials, resources, and supports to faith community partners to implement ADRD-focused education and support programs. 	х		
	5. Facilitate distribution of equitable and culturally-sensitive education, training, and support materials for family caregivers to better serve under-resourced areas and increase the number of racially, culturally, and linguistically diverse caregivers receiving such education and support programs. Utilize appropriate existing federal and State-developed educational materials. Ensure materials are available in non-English languages to reflect the prevalence of Maryland's non-English speaking population (e.g., Spanish, Indo-European languages, Korean, and other Asian and Pacific Island languages).		x	
	 Identify and engage leaders of diverse communities to explore ways in which these communities may serve as resources for ADRD family caregivers. Provide educational materials, resources, and supports to community partners to implement ADRD-focused education and support programs. 	х		
	 Work to develop dementia friendly public spaces and Dementia Friends initiatives. Distribute information on such initiatives through State and partner-based communications and convene stakeholders to develop, plan, and implement initiatives. 		x	
	 Continue to promote use of the National Alzheimer's Association Call Center (1-800-272-3900) to provide reflective listening, problem solving, education, action planning, and crisis intervention to people with ADRD or their caregivers. 	x		

GOAL 3: ENHANCE AND EXPAND SUPPORTS FOR FAMILY CAREGIVERS						
Strategy	Actions (Recommendations for needed policies or responses)			Mid	Long	
	9.	Expand and promote implementation of early-stage memory loss groups for people with cognitive impairment and/or ADRD and their care partners.		х		
	10.	Expand programs that focus on collaborative models of social engagement that include both the person living with dementia and their family caregivers, such as Alzheimer's Cafés, Sibley Memorial Club Memory, dementia friendly recreation programs, intergenerational programs, and civic engagement initiatives that encourage engagement of multiple generations and/or volunteerism throughout the State.			х	
	11.	Promote the expansion and reimbursement for telehealth, telemedicine, and web-based resources for family caregivers, including use in rural and under-resourced communities.		х		
	12.	Leverage financial/payment models and/or policy to incentivize hospitals to design and provide care models that include family caregiving in discharge planning and specific discharge instructions to the family.			х	
D. Address caregiver health and wellness	1.	Promote education and public awareness of caregiving as a behavioral and physical health risk factor that requires public health attention and include caregiving in public health campaigns and programs.	Х			
	2.	Increase availability and access to caregiver-focused wellness and support programs that include evidence-informed interventions and therapies, especially among under-served and under-resourced communities, family caregivers of persons with early-onset ADRD, and those from culturally and linguistically diverse backgrounds. These programs may include cognitive behavioral therapy or psychosocial programs (i.e., support groups and integrative health practices that promote self-care and/or trauma-informed practices to reduce stress and increase resilience, such as meditation, mindfulness, and acupuncture) combined with access to traditional medical support. Programs should be available across multiple mediums including in-person, virtual, and hybrid.		X		
	3.	Promote the expansion of coverage of behavioral health services targeting PLWD and family caregivers via employment-based health plans and health insurance.			х	

Strategy	Strategy Actions (Recommendations for needed policies or responses)		Mid	Long
E. Address COVID-19 pandemic and other emergency/ natural disaster events	 Assess the impact of COVID-19 on family caregivers and consider their experiences in the establishment of a Maryland Epidemic Action Network (see 2.C.5) to support communal living settings serving high concentrations of vulnerable PLWD and delivery of ADRD care in home-based settings. Facilitate the provision of free training and mentorship to nursing homes, assisted living communities, continuing care retirement communities (CCRC), communal living residences, and individual family caregivers to increase the uptake of evidence-based infection prevention and safety practices to protect PLWD, family caregivers and staff, while concurrently balancing quality of life issues such as social isolation and mental health impacts as recommended by the Agency for Health Care Research and Quality. 	х		





MOVING FORWARD AFTER A DIAGNOSIS

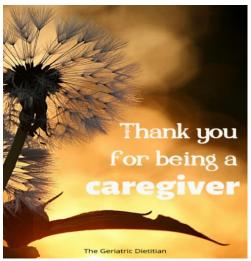
Consider these tips to help the person in the early stage of the disease come to terms with his or her diagnosis:

- Provide time for the individual to feel sad about how his or her identity is changing because of the diagnosis.
- Emphasize the roles and responsibilities that are still significant to the individual's identity, i.e. grandfather, mother, daughter, etc.
- Encourage the person to speak with a trusted friend, minister or even a professional counselor, to talk through difficult emotions.

Finding a new purpose can help confirm that dementia does not have to define a person; it only becomes a part of who they are. Help the person find meaning and purpose with these suggestions:

- Discuss what brings meaning and purpose to life.
- Encourage the person to stay involved in activities he or she enjoys.
- Consider activities you can do together.
- Work together to identify opportunities at home or in the community that can leverage his
 or her strengths and interests.
- Discuss what new activities the person may be interested in trying.
- Encourage the individual to get connected with others who are living with the disease to learn what they are doing to remain active and engaged in life.

Accepting the Diagnosis | Alzheimer's Association



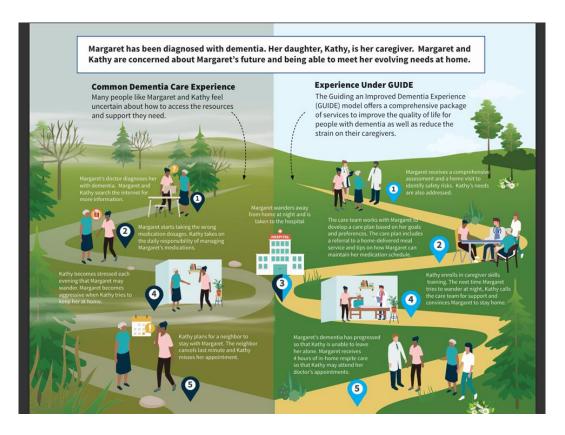
GUIDING AN IMPROVED DEMENTIA EXPERIENCE (GUIDE) MODEL | CMS

Dementia affects more than 6.7 million Americans in 2023, with 14 million projected cases by 2060.

People living with dementia often have multiple chronic conditions and receive fragmented care, leading to high rates of hospitalization and emergency department visits. They also may have behavioral health concerns, and some eventually use 24/7 care. The challenges of managing health care, providing constant support, and dealing with the behavioral and psychological symptoms of dementia can present a significant mental, physical, emotional, and financial burden for caregivers and disproportionately impact Black, Hispanic, and Asian Americans, Native Hawaiian, and Pacific Islander populations.

The GUIDE Model will offer a standard approach to care, including 24/7 access to a support line, as well as caregiver training, education, and support services. This standard approach will allow people living with dementia to remain safely in their homes for longer by preventing or delaying nursing home placement and improve quality of life for both people living with dementia and their unpaid caregivers.

To reduce disparities in access to dementia care services, the GUIDE Model incorporates policies to enhance health equity by ensuring that underserved communities have equal access to the model intervention.



PAID FOR CARE: PROGRAMS THAT COMPENSATE FAMILY MEMBERS TO CARE FOR LOVED ONES WITH ALZHEIMER'S OR DEMENTIA

Paying Family Caregivers to Provide Alzheimer's Care (dementiacarecentral.com)

Caring for a loved one with dementia or Alzheimer's disease can be difficult. Often this task falls to a family member, and as the disease progresses, the amount of care needed becomes more significant, requiring more caregiving hours. The caregiver might need to cut back on their work hours or quit their job altogether to provide the care their loved one requires. Fortunately, in the US, one can be paid to care for a loved one suffering from dementia. There are a variety of different programs that can support you and your loved one.

Medicaid Programs that Pay Family Members

Medicaid is a nationwide program but its benefits, eligibility requirements, and other rules are state specific. In most states, Medicaid offers at least one program that can be used to pay family members for caregiving. There are several different types of Medicaid programs through which a family member might be compensated. Be aware that compensation might not always refer to cash compensation.

- 1. Medicaid Waivers
- 2. Medicaid state Plans/ Regular Medicaid
- 3. Adult Foster Care
- 4. The Caregiver Child Exemption

Depending on the financial situation of the individual with Alzheimer's or related dementia, they may qualify for Medicaid. As of 2023, an individual with income under \$2,742 and liquid assets valued under \$2,000 (not including their home), will likely qualify for Medicaid. Though many states are similar, each has different financial rules, care need rules, and spousal protections. Furthermore, each of the programs described above may have different eligibility criteria.

Maryland

The state's Attendant Care Program was created to help disabled persons live at home. Not all persons diagnosed with Alzheimer's or dementia are officially designated as disabled by Social Security. Those persons whose dementia is severe enough to be disabled, may be able to hire family members to provide them with care. Learn more from the Maryland Department of Disabilities.

Programs for Veterans to Care for their Loved Ones

1) Veteran Directed Care Program

For seniors with dementia who are veterans, there are veteran-specific programs that assist in paying for care. As part of the VA Medical Benefits package, Veteran Directed Care Program (formerly called Veteran-Directed Home and Community-Based Services) is available. Rather than requiring nursing home care, this allows seniors with dementia to receive care in their homes and community via funds from a flexible budget. Since the services are veteran-directed, they can choose their caregiver. This means a family member can be paid to provide the care that is needed for their loved one. More information is available here.

2) A&A Pension

Another option for veterans, and their spouses, who served during a period of war is the Aid & Attendance Pension. This pension is intended to assist with the cost of long-term care and is ideal for those who are suffering from dementia. As the disease progresses, your loved one will need to be reminded to perform daily activities, such as brushing one's teeth or washing one's hands. One may need assistance with eating, dressing, moving from one location to another, using the bathroom, and so forth. The Aid & Attendance Pension is intended for those who require assistance with the above daily living activities and is an extremely desirable option since veterans can

choose their caregivers, including relatives. However, because the VA counts a spouse's income when considering eligibility, Aid & Attendance cannot be used to pay a spouse as a caregiver but can be used to pay adult children and other family members. Read more.

Long-term Care Insurance is another possibility for family members to be paid for providing care for a loved one with dementia. Each policy is different, so verify to determine if their specific policy will indeed pay relatives for providing care. Some policies that do allow relatives to be paid caregivers require that the caregiver be certified to provide care. However, this is a rather simple process, and one should not feel intimidated. Alternatively, if relatives are not permitted to be paid, one might consider forming a home care agency and hiring and paying the agency instead. In some states, this workaround approach may be adequate.

Applying tax deductions, while not technically a way to be paid for providing care, is a way to offset the cost of care. For example, say your mother who is suffering from Alzheimer's lives in your home and you are fully supporting her. As a result, you can deduct certain medical expenses from your taxes, such as the cost of doctors' visits, prescription drugs, and home modifications that are medically necessary, such as grab bars.

One may also apply a tax credit such as the child and dependent tax credit if they pay for a dependent person with dementia to be cared for while he or she is at work. Again, while it doesn't directly pay the family member for providing care, it does decrease the amount of taxes one will owe, in turn, saving the individual money.

There are several ways to get paid to provide care for a loved one suffering from Alzheimer's disease or another dementia. Since each situation is highly personal, all the circumstances should be carefully considered to find the best solution for you and your family.





Now What?

Next Steps After an Alzheimer's Diagnosis

A diagnosis of Alzheimer's disease can be difficult, but getting accurate information and support can help you know what to expect and what to do next. Use this checklist to help you get started.



Learn about Alzheimer's disease

Being informed will help you know what to expect as the disease progresses. Here are some resources:

- Alzheimer's and related Dementias Education and Referral (ADEAR) Center www.alzheimers.gov | 800-438-4380
- Alzheimer's Association www.alz.org | 800-272-3900

- Alzheimer's Foundation of America https://alzfdn.org | 866-232-8484
- ✓ Local hospitals and community centers may have educational programs about Alzheimer's disease and related dementias.

Get regular medical care

- Make regular appointments with your primary care doctor or specialist (neurologist, neuropsychiatrist, geriatric psychiatrist).
 - www.nia.nih.gov/health/doctor-patientcommunication/talking-with-your-doctor
- Consider going to a memory disorders clinic. Ask your doctor for a referral if desired.

Find local services and support

- Find local services by contacting Eldercare Locator https://eldercare.acl.gov | 800-677-1116
- Contact your local Alzheimer's Disease Research Center www.nia.nih.gov/health/alzheimersdisease-research-centers
- Find local chapters, organizations, and support groups:
 - Alzheimer's Association www.alz.org | 800-272-3900
 - Alzheimer's Foundation of America https://alzfdn.org | 866-232-8484

Do some legal, financial, and long-term care planning

- Get information to help you plan. www.nia.nih.gov/health/legal-and-financialplanning-people-alzheimers
- Prepare or update your will, living will, health care power of attorney, and financial power of attorney. To find a lawyer, contact your local bar association or the National Academy of Elder Law Attorneys. www.naela.org
- Learn about care you may need in the future and how to pay for it. https://longtermcare.acl.gov
- Explore getting help to pay for medicines, housing, transportation, and more. www.benefitscheckup.org

Get help as needed with day-to-day tasks

- ✓ Use simple memory aids like a notepad or sticky notes to jot down reminders, a pillbox to keep medications organized, and a calendar to record appointments.
- Ask family members or friends or find local services to help with routine tasks, such as cooking, paying bills, transportation, or shopping.
- Onsider using technology solutions for medication management, safety (e.g., emergency response, door alarms), and other care.
- See tips about coping daily, changes in relationships, and more.

www.nia.nih.gov/health/alzheimers/caregiving

Page 1 of 2

next-steps-after-alzheimers-diagnosis.pdf (nih.gov)

Be safe at home

- Ask your doctor to order a home-safety evaluation and recommend a home health care agency to conduct it. Medicare may cover the cost.
- Consider wearing a medical ID bracelet or necklace in case you get lost or need help, or joining the MedicAlert and Alzheimer's Association's Wandering Support program. www.medicalert.org/alz

Stay safe on the road

- Talk with your doctor if you become confused, get lost, or need lots of help with directions, or if others worry about your driving.
- Get a driving evaluation. Ask your doctor for names of driving evaluators, or visit the American Occupational Therapy Association. https://myaota.aota.org/driver_search
- Learn about driving safety. www.nia.nih.gov/health/driving-safety-andalzheimers-disease

Consider participating in a clinical trial

- Ask your doctor about trials or studies.
- Contact an Alzheimer's Disease Research Center for assessment and potential research opportunities.
- Search for a clinical trial or study near you or that you could participate in remotely:
 - NIA Clinical Trials Finder www.nia.nih.gov/alzheimers/clinical-trials
- Learn more about clinical trials:
 - NIA Clinical Trials Information www.nia.nih.gov/health/clinical-trials
 - National Institutes of Health www.nih.gov/health-information/ nih-clinical-research-trials-you

Stay healthy

- Be active! Getting exercise helps people with
 Alzheimer's feel better and helps keep their muscles,
 joints, and heart in good shape.
 www.nia.nih.gov/health/exercise-physical-activity
- Eat a well-balanced diet that includes fruits, vegetables, and whole grains. www.nia.nih.gov/health/healthy-eating
- Continue to enjoy visits with family and friends, hobbies, and outings.

If you live alone

- Identify someone who can visit you regularly and be an emergency contact.
- If you are at risk of falling, order an emergency response system. A special pendant or bracelet lets you summon help if you fall and can't reach the phone.
- Consider working with an occupational therapist. This person can teach you ways to stay independent. Ask your doctor for more information.
- Stick with familiar places, people, and routines. Simplify your life.
- Get tips about self-care, safety, staying connected, and more. www.nia.nih.gov/health/tips-living-alone-earlystage-dementia

If you are working

- If you have problems performing your job, consider reducing your hours or switching to a less demanding position.
- Consider consulting your employer's HR department or employee assistance program about family leave, disability benefits, and other employee benefits.
- Find out if you qualify for Social Security disability benefits through "compassionate allowances."

www.ssa.gov/compassionateallowances 800-772-1213



Alzheimer's and related Dementias Education and Referral Center | June 2020

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NIH Publication No. 20-AG-8126

MARYLAND DEPARTMENT OF AGING PROGRAMS & SERVICES









Maryland Community for LifeSM Overview:

Maryland Community for LifeSM is an innovative program developed by the Maryland Department of Aging to support older adults as they age at home. The Community for LifeSM program provides a package of services that make it comfortable and convenient to age at home to Marylanders over the age of 60. The program's services are designed to prevent the predictable challenges of aging that can require admittance into a high level of care facility, such as a nursing home or assisted living facility.

Join Maryland Community for LifeSM today to enjoy your independence for many tomorrows to come.

Three core services define the Community for LifeSM program: **home maintenance**, **service navigation**, and **transportation**. Please note actual services offered may vary from jurisdiction to jurisdiction. <u>Maryland Community for Life</u>

Maryland Durable Medical Equipment Re-Use The Maryland Department of Aging is providing durable medical equipment (DME) to Marylanders with any illness, injury, or disability, regardless of age, at no cost. All equipment is collected via donation and is sanitized, repaired, and redistributed to Marylanders in need.

State Health Insurance Assistance Program (maryland.gov) SHIP is your local State Health Insurance Assistance program. We provide free, unbiased help to Medicare-eligible beneficiaries, their families, and caregivers. Whether you are new to Medicare, reviewing Medicare plan options, or have questions about how to use your Medicare, SHIP can help. Trained staff and volunteer counselors are available in all 23 counties and Baltimore City for one-on-one assistance and community education.





Senior Care (maryland.gov)

The Senior Care System provides case management and funds for services for people 65 or older who may be at risk of nursing home placement. Senior Care allows seniors to live with dignity and in the comfort of their own homes and at a lower cost than nursing facility care. Senior Care provides a comprehensive assessment of an individual's needs, a case manager to secure and coordinate services, and a pool of gap

filling funds to purchase services for individuals who meet program eligibility requirements. Services may include personal care, chore service, medications, medical supplies, adult day care, respite care, home delivered meals, transportation, and emergency response systems.



Senior Centers (maryland.gov) Senior Centers provide a vital link for older adults looking to take charge of their health and remain independent and active in the community. Find a range of programs including meal

service, arts and crafts, continuing education, health promotion and disease prevention services, and transportation opportunities.

Ombudsman Program (maryland.gov) Protecting the Rights and Promoting the Well-Being of Residents of Long-Term Care Facilities - Long-Term Care (LTC) Ombudsmen are advocates for residents of nursing homes and assisted living facilities. They work to resolve problems of individual residents and to bring about changes at the local, state, and national levels that will improve residents' care and quality of life. The term ombudsman (om-budz-man) is Scandinavian in origin. In the United States, it has come to mean "advocate".

Public Guardianship (maryland.gov) The Maryland Department of Aging Public Guardianship Program serves individuals 65 years of age and older, who have been deemed by a court of law to lack the capacity to make or communicate responsible decisions concerning their daily living needs. The law authorizes, as a last resort, appointing the Secretary of the State Department of Aging or the Director of a local Area Agency on Aging (AAA) as a "guardian of person" when there is no other person or organization willing and appropriate to be named. Public Guardianship is a relationship created by state law in which a court gives one person or entity (the guardian) the duty and power to make personal and/or property decisions for another person (the ward). The court determines if a person's ability to make health and safety decisions for themselves is significantly impaired by disease, accident, or disability. If so, the court will appoint a guardian to act as a surrogate decision-maker on behalf of that disabled adult.

<u>Senior Legal Assistance (maryland.gov)</u> The Senior Legal Assistance Program was created to be the hallmark and champion for justice by empowering, defending, and protecting vulnerable older adults with direct resources. Seniors and their families often face an array of challenges and need help weighing all of the options to make the best decisions possible.

ElderAbuseTaskForce (maryland.gov)

5 THINGS EVERYONE CAN DO TO PREVENT ELDER ABUSE

- Listen to older people and caregivers to understand their challenges and provide support
- Educate one another about the signs of abuse and how to get help
- Report suspected abuse or neglect as soon as possible
- 4 Build a community that fosters social connections and supports
- 5 Reach out to professional services for support where available



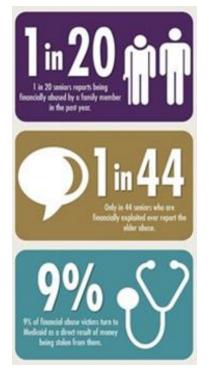








Multiple forms of abuse can occur at once.



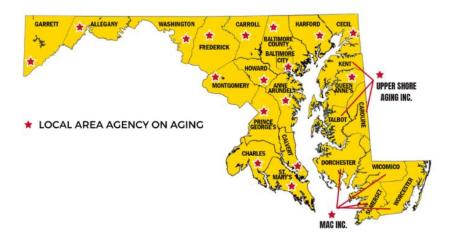
Elder Financial Exploitation - Scams (maryland.gov) Financial exploitation is defined as someone illegally or improperly using a person's money or belongings for their own personal use. One in ten Americans aged 60 or older has experienced abuse, and one of the most frequent forms of abuse is financial exploitation. It can be devastating, both emotionally and financially, and can take many forms, including scams, abuse by trusted individuals such as family members or friends, and predatory products and services marketed specifically to older people.



Nutrition and Meal Services (maryland.gov) The Maryland Department of Aging provides leadership for nutrition programs serving healthy meals or supplemental food to older adults throughout the state. To ensure that older adults achieve and maintain optimal nutritional status, services offered by our community partners may include:

- Home Delivered Meals and Group Dining (Congregate Nutrition)
- Nutrition Screening, Counseling, and Education
- My Groceries to Go! (Commodity Supplemental Food Program)
- Senior Farmers' Market Nutrition Program

Area Agencies on Aging (maryland.gov) In Maryland's twenty-three counties and Baltimore City, each local governing body designates an Area Agency on Aging or AAA. The agency may be a unit of local government or a private, nonprofit corporation. In some counties, it is the office on aging. In others, it may be named differently. In Baltimore City, it is called the Division on Aging and Care Services. Local agencies on aging provide a variety of adult services, incorporating assisted living, protective services, and temporary disability programs. Transportation services for seniors and people with disabilities are also provided at the county level through either a division of the aging department or by a separate transportation department.



National Family Caregiver Support (maryland.gov) The Maryland Family Caregiver Support Program is administered by the Maryland Department of Aging and is part of a national network of caregiver programs funded by the federal Administration for Community Living. The program helps family and informal caregivers care for their loved ones at home for as long as possible. Family caregivers are the major source of unpaid help for older and disabled adults living in communities across the state. These caregivers typically include spouses, adult children, relatives, and friends.



Maryland's Family Caregiver Support Program works in conjunction with a host of State and community-based services to create a coordinated array of supports for individuals who need them. Studies show that these services can reduce caregiver depression, anxiety, and stress and enable them to provide care longer, thereby avoiding or delaying the need for costly institutional care. The program offers five types of Caregiver Services:

Information
Assistance with accessing services
Counseling, education, and the establishment of support groups
Respite
Supplemental Services

National Family Caregivers Month Celebrated every November, National Family Caregivers Month is a time to recognize and honor family caregivers, including spouses, adult children, relatives, and friends, who provide invaluable support to older adults and people with disabilities.



National Family Caregiver Support Program

ABOUT THE PROGRAM

Maryland's Family Caregiver Support Program is administered by the Maryland Department of Aging and is part of a national network of caregiver programs funded by the federal Administration for Community Living. The program helps family and informal caregivers care for their loved ones at home for as long as possible. Family caregivers are the major source of unpaid help for older and disabled adults living in communities across the state. These caregivers typically include spouses, adult children, relatives, and friends.

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5 TYPES OF SERVICE:

- · Information to caregivers about available services
- Assistance to caregivers in gaining access to services
- Individual counseling, organization of support groups, and caregiver training
- Respite care
- Supplemental services (on a limited basis)

FAMILY CAREGIVERS WHO ARE ELIGIBLE INCLUDE:

- Adult family members or other informal caregivers age 18 and older providing care to individuals 60 years of age and older
- Adult family members or other informal caregivers age 18 and older providing care to individuals of any age with Alzheimer's disease and related disorders
- Grandparents and other relatives (not parents) 55 years of age and older providing care to children under the age of 18
- Grandparents and other relatives (not parents) 55 years of age and older providing care to adults age 18-59 with disabilities.

To learn more visit, www.aging.maryland.gov or www.marylandaccesspoint.info Call 410.767.1100 or 1.800.243.3425



1-800-243-3425 aging.maryland.gov

Maryland Department of Human Services

Adult Services - Maryland Department of Human Services

Office of Adult Services Mission Statement

To serve vulnerable adults who have functional limitations due to a disability or advanced age, and their informal family caregivers, through a home and community-based service delivery system.

This system protects vulnerable persons, promotes self-sufficiency and avoids or delays unnecessary institutional care or other out-of-home placements.

ADULT PROTECTIVE SERVICES (APS)

The purpose of this program is to investigate, prevent, and/or remedy concerns of abuse, neglect, self-neglect, and exploitation of adults who are unable to protect their own interests and are at risk of immediate harm.

Adult Protective Services offers:

- Vulnerable adults protection from abuse, neglect and exploitation;
- The right to self-determination; including the right to refuse services.
- Linkage to the least restrictive available alternative in living situation and treatment;
- Assistance and guidance in having the provision of services, safety, and well being rest with the vulnerable adult, family, and the total professional community and service systems; not solely with the Local Department.

WHO IS A VULNERABLE ADULT?

Someone who lacks the physical or mental capacity to provide for their own daily needs



Local Department of Social Services Adult Services Programs

Allegany County	301-784-7050
Anne Arundel County	410-421-8400
Baltimore City	410-361-5000
Baltimore County	410-853-3000
Calvert County	443-550-6969
Caroline County	
Carroll County	410-386-3434
Cecil County	410-996-0100
Charles County	301-392-6400
Dorchester County	410-901-4100
Frederick County	301-600-2635
Garrett County	301-533-3000
Harford County	410-836-4717
Howard County	410-872-8823
Kent County	. 410-810-7600
Montgomery County	240-777-3000
Prince George's County	. 301-909-2228
Queen Anne County	. 410-758-8000
Somerset County	410-677-4200
St. Mary's County	240-895-7000
Talbot County	410-770-4848
Washington County	240-420-2155
Wicomico County	410-713-3900
Worcester County	410-677-6800



SOCIAL SERVICES TO ADULTS (SSTA)

The Department of Huam Services core program of social work services is for adults 18 years old and older.

The purpose of the program is to provide services to enable and assist adults to:

- Achieve or maintain self-sufficiency;
- Prevent or avoid abuse, neglect, or exploitation; prevent or reduce unnecessary or inappropriate institutionalization; and
- Secure necessary and appropriate institutional care services.

SSTA Program offers Case Management services that can assist with linkage to community resources, development of a service plan to reach agreed upon goals, monitoring of goal progress and face to face contact on a regular basis.

The program seeks to build, sustain and augment, rather than to replace the adult's family and community support systems.

IF YOU SUSPECT A VULNERABLE
ADULT IS BEING ABUSED, NEGLECTED,
OR EXPLOITED CONTACT THE
APPROPRIATE LOCAL DEPARTMENT
LISTED ON BACK OF THIS PAMPHLET

IF YOU ARE INTERESTED IN BECOMING A PROVIDER FOR PROJECT HOME CONTACT (410) 767-7422

DHS Office of Adult Services

Adult Services Programs

- Adult Protective Services (APS)
 And Public Guardianship
- Social Services to Adults (SSTA)
- In-Home Aide Services (IHAS)
- Project Home
- Respite Care



IN HOME AIDE SERVICES (IHAS)

The purpose of the IHAS Program is to complement other social services programs by providing personal care and chore services to individuals with functional disabilities in the community to enable them to live independently in the least restrictive setting possible.

Services offered include assistance with:

- · bathing/hygiene, dressing
- light chores
- laundry
 light meal planning and preparation
- transferring

PROJECT HOME

The Project Home Program provides supportive, family centered housing to meet a range of needs presented by adults living with a disability.

The purpose of the program is to:

- Link adults living with a disability with families who want to help support their success while sharing their homes
- Provide case management services to residents in the program.



DEPARTAMENTOS LOCALES DE SERVICIOS SOCIALES

Allegany County DSS	(301) 784-7000
Anne Arundel County DSS	(410) 269-4500
Baltimore City DSS	(410) 361-4700
Baltimore County DSS	410) 887-2800
Calvert County DSS	(443) 550-6900
Caroline County DSS	(410) 479-5900
Carroll County DSS	(410) 876-2190
Cecil County DSS	(410) 996-0100
Charles County DSS	(301) 392-6400
Dorchester County DSS	301) 901-4100
Frederick County DSS	(301) 694-4555
Garrett County DSS	(301) 533-3000
Harford County DSS	(410) 836-4949
Howard County DSS	(410) 872-8700
Kent County DSS	(410) 810-7600
Montgomery County DSS	(240) 777-1245
Prince George's County DSS	(301) 909-7000
Queen Anne's County DSS	(410) 758-8000
St. Mary's County DSS	(240) 895-7000
Somerset County DSS	(410) 677-4200
Talbot County DSS	(410) 770-4848
Washington County DSS	(240) 420-2100
Wicomico County DSS	(410) 713-3900
Worcester County DSS	(410) 677-6800

Para información acerca de los programas de servicio comuníquese a:

Oficina de Servicios para Adultos.
Administración de Servicios Comunitarios
Departamento de Recursos Humanos de Maryland
311 W. Saratoga Street, #259
Baltimore 21201-3521
(410) 767-7384
visite nuestra Página Web
www.dhr.state.md.us/oas

La oficina de los programas de Servicios para Adultos es patrocinada por el estado de Maryland y el Gobierno Federal.



Departamento de Recursos Humanos

Empresa de Igualdad de Oportunidades

DHR Pub/CSA 1558sp

OFICINA DE SERVICIOS PARA ADULTOS

La oficina de servicios para adultos (Servicios de Protección para Adultos, Servicios de Ayuda En el Hogar, Proyecto Hogar y los Servicios Sociales para los Adultos) se enfoca en las necesidades de los ancianos, incapacitados y adultos vulnerables. La Oficina de Servicios para los Adultos supervisa un grupo de programas dentro de la Administración de Servicios Comunitarios del Departamento de Recursos Humanos del estado de Maryland. Esta unido con los objetivos del departamento de cuidado, prevención y protección. La oficina de Servicios para los adultos en conjunto con los departamentos locales de servicios sociales y las organizaciones comunitarias coordinan los servicios para la población adulta vulnerable en todo el estado de Maryland.

MISION

La misión de la oficina de servicios para adultos es servir a los ancianos, incapacitados, personas vulnerables y a miembros de la familia a través de un sistema de proceso de servicios hogareño y comunitario. Este sistema protege a las personas vulnerables y promueve la autosuficiencia y evita o demora el cuidado institucional innecesario u otras colocaciones fuera del hogar. La Oficina de Servicios para Adultos está comprometida a entregar servicios en una manera que aumenta laposibilidad de que una persona funcione independientemente dada a sus limitaciones fisicas. Los servicios incorporan los principios de dignidad personal, calidad de vida, privacidad y el derecho de selección.

SERVICIOS DE PROTECCION PARA ADULTOS

El programa de los servicios de protección para adultos sirve a las personas mayores de 18 años de edad, que carecen de la capacidad física o mental para proveerse sus necesidades diarias. El propósito de este programa es prevenir o remediar el descuido, autodescuido, abuso o explotación de los adultos que no pueden proteger sus propios intereses y están en riesgo de hacerse daño inmediato a sí mismos o a otros. Este programa provee servicios

Este programa provee servicios profesionales para proteger la salud, la seguridad y bienestar de los adultos vulnerables.

SERVICIOS SOCIALES PARA LOS ADULTOS

El Programa de los servicios sociales para los adultos es un programa de manejo de cas diseñado para avudar a los ancianos incapacitados y adultos vulnerables, mayores de 18 años a obtener servicios necesarios en el hogar y servicios ccomunitarios de cuidado a largo plazo, equipo y programas. Es targo piaco, equipo y programas. Es considerado el programa modelo de la Oficina de Servicios para Adultos en servicios sociales para adultos. El propósito de éste programa es habilitar y asistir a los clientes en su mantenimiento de autosuficiencia, ayuda autoeconómica y prevención de abuso, negligencia o explotación. Este programa reduce el número de adultos colocados en cuidado institucional y asegura el cuidado institucional cuando es apropiado. El modelo de entrega de servicios en el manejo de casos utiliza evaluaciones, planes de desarrollo individualizados, coordinación de servicios y vinculación. Supervisión y defensa en representación de los clientes son otras funciones.



Agencia de Servicios Humanos de Maryland

DEPARTAMENTO DE RECURSOS HUMANOS DE MARYLAND

> ADMINISTRACION DE SERVICIOS COMUNITARIOS

> > OFICINA DE SERVICIOS PARA ADULTOS

Servicios de Protección para Adultos

Servicios de Ayuda en el Hogar Proyecto HOGAR

Servicios Sociales para Adultos

PROYECTO HOGAR (PROJECT HOME)

El Proyecto "HOGAR" provee hogares residenciales certificados ambientados (CARE) donde personas incapacitadas mayores de 18 años son aceptadas, cuidadas y supervisadas. Un hogar "CARE" provee ambiente hogareño en una vivienda protectiva para adultos incapacitados que no pueden vivir solos a causa de los problemas de salud mental o física. Los servicios que se proveen a los residentes en los hogares de CARE incluyen: cuarto, hospedaje, asistencia con la higiene personal y otras actividades de uso diario. Además, los proveedores brindan entendimiento y apoyo emocional, animan a los residentes a hacer lo que puedan por ellos mismos, y tienen oportunidades para las actividades sociales y recreativas.

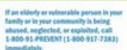
SERVICIOS DE AYUDA EN EL HOGAR (IN-HOME AIDE SERVICES)

El Programa de los Servicios de Ayuda en el Hogar asiste a los adultos funcionalmente incapacitados con actividades de uso diario en su hogar.

Los servicios que se proveen incluyen el quehacer de la casa, cuidado personal, transportación/acompañamiento, entrenamiento en autocuidado y destreza para cuidarse a sí mismo. Orientación y apoyo estan disponibles para los padres de familia bajo tensión y los cuidadores de incapacitados, ancianos y adultos vulnerables.

Otros servicios incluyen el Programa "Respite Care" (cuidado a corto plazo para los incapacitados con el desenvolvimiento o funcionalmente y sus familias) y "Attendant Care" (reembolso financiero a los individuos con incapacidades fisicas severas).

Be on the lookout for abuse of the vulnerable and elderly





Have you seen Physical signs of abuse, such as:

- Curs, wounds, black and blue mades, braines, or wells
- · Borne
- . Donal injuries
- * Appearing shery, oncharen, nearly
- · Didenosided, debylated
- Untrained moderal condition

DHS



Adult Protective Services

Have you seen **Bohavioral** signs of abuse, such as:

- · Confusion, Segrifulness
- * Aspe
- · Depression
- * Fear, Jelplemen, show

Have you seen Sucial signs of abuse, such as:

- · Isoland, little medde contact
- · Violence or drug abuse
- * Usable to speak freely

Have you seen Financial signs of abuse, such as:

- . Usual back account activity
- · Change in spending balins
- . Signatum on checks do not much
- . Uspeid bills

If you notice any of theses signs, call 1-800-91-PREVENT (1-800-917-7383) immediately. Adult Protective Services - Maryland Department of Human Services

All suspected cases of Adult Abuse and Neglect should be reported to your local DSS Office or by calling \$\cdot\$ 1-800-91Prevent (1-800-917-7383).

Marifold Superior of Marien Services (122 N. Servicia St., Selfreye, MR (120))



Do you need help to maintain your independence?





For additional information, contact your local department of social service at 1-800-332-6347 or visit our website at http://dhr.maryland.gov/in-home-services.

ome-services.



In-Home Aides Services

In-Home Aides

In-Home Aides serve adults 18 or older with functional disabilities who need assistance with activities of daily living in their home, vulnerable adults with no caregiver, those at risk of institutional placement, and those at risk of abuse or neglect. In-Tome Aides provide help with personal care, transportation/escort, training in self-care and care-giving skills, and also perform minor household chores.

Application Process

Individuals or their caregivers should call the local department of social services in the county or city where the applicant lives. The local department representative will arrange a home visit to conduct an interview with the applicant to determine their specific needs. The availability of funding for the program determines the number of individuals who can be served statewide. To ensure that those with the greatest need are served first, local departments use a ranking scale.

Sliding Scale Fee

Depending on the income and family size of the applicant, the applicant may be required to contribute toward the hourly cost of the aide service. The amount is determined by a slidingscale and the fee is paid to the local department of social services.



<u>In-Home Aides Services - Maryland Department of Human Services</u>

Help for people with disabilities

Social Services to Adults provides assistance to adults with functional disabilities seeking to remain or become self-sufficient; it seeks to prevent abuse, neglect or exploitation; it reduces unnecessary institutionalization, or secures appropriate institutional care when necessary.



Who is eligible?

Services are available to adults with functional disabilities including second or physical challenges where the individual does not have dependent children in their home.



Social Services to Adults

Cost

Services are provided without regard to income.

What services are provided?

This program provides an assessment of needs and develops an individual plan of service. The service plan focuses on the adult's long and short-term goals and component the adult to make informed decisions about their future.

Services may include:

- Case management the facilitation and coordination of services at the community level
- Crisis Intervention up to 60 days of intersection emergent intervention.
- Information and Referral identification of other community services and measure

How to access services

For additional information contact year local department of social service at 1-800-332-6347 or visit our website at http://dls.maryland.adubs. Social Services to Adults - Maryland Department of Human Services

Rangiand Department of Numer Processes 211 W. Sanatego St., Bullimers, MD 21281



Do you need help making a safety decision?

Adult Public Guardianship is a legal procedure in which the court determines if a person's ability to make health and safety decisions for themselves is significantly impaired. If so, the court will then appoint a guardian to act as a substitute decision-maker.



Who needs a guardian?

A person mentally incapable of making decisions regarding their safety and well-being because of disease, accident or disability might benefit by having a guardian.

Why would someone need a public guardian?

The court may decide to appoint an Adult Public Guardian if there are no family members to help.

Types of guardianships

There are two types of adult public guardianships. The guardian of the person makes decisions about health care, shelter, and other daily needs. This responsibility may be granted to an individual or an agency. The guardian of the property manages assets and finances. A public agency may not become a guardian of the property.



Adult Public Guardianship

Steps for implementing guardianship

Hospital agencies, long-term care facilities, Adult Protective Services (APS) programs, Social Services agencies, and other public or private agencies petition a court to have guardianship established on a person's behalf.

What oversight is available?

Each local jurisdiction has an Adult Public Guardianship Review Board that acts as a consultant to the guardian. Every six months the board reviews cases and makes recommendation to the court to continue, modify, or terminate guardianship.

The Board consists of a representative from the local department of social services, one physician, one psychiatrist, a representative from the aging agency, a representative from a nonprofit social services agency, an attorney, two citizen representatives, a public health nurse and a professional in the field of disability. The board does not have oversight of private guardianship cases.

For additional information, contact your local department of social service at 1-800-332-6347 or visit our website at https://dhs.maryland.gov/office-of-adult-services/adult-public-guardianship.

MARYLAND DHE

Department of Human Services

Adult Public Guardianship - Maryland

Maryland Department of Human Resources - 311 W. Saratoga St., Baltimore, MD 21201

Respite Care Program - Maryland Department of Human Services

Are you a caregiver?

An informal family caregiver is an individual who routinely cares for an individual with a developmental or functional disability and is not compensated for the care.

What is respite?

Respite is the short-term periodic and temporary care of individuals with developmental or functional disabilities in order to temporarily relieve the family or informal caregiver.

The Respite Care program offers financial reimbursement for short-term temporary care to provide a period of rest and renewal to family caregivers by temporarily relieving them of the demands and stresses of caregiving responsibilities. Respite care is provided at planned intervals, in a time of crisis, or on an asneeded basis. We serve children and adults with developmental disabilities and adults with functional disabilities and their families.

Marylanders may call their <u>local Department of Social Services</u> to speak with a caseworker today, who will assist them (unique needs, next steps, assist).

AARP Resources for Caregivers and their Families

ARP is the nation's largest nonprofit, nonpartisan organization dedicated to empowering Americans 50 and older to choose how they live as they age.

Helping a Loved One Live Independently at Home (aarp.org)

Dementia Caregivers Guide: Tips for Unique Challenges (aarp.org)

RESOURCES FOR CARE PARTNERS





What Caregivers Should Know About Memory Care: Finding the right facility can improve your loved one's quality of life

<u>Create a Respite Care Plan to Give Caregivers a Break</u>: Learn what services and programs are available to help

<u>Care Tips to Keep Dementia Patients Safe at Home</u>: Follow these tips to ensure the safety of your loved ones with dementia and Alzheimer's

<u>How to Manage 8 Dementia-Related Behaviors</u>: Finding the right solution requires steady sleuthing, calm compassion

How Therapeutic Fibbing and Diversion Can Help Dementia: Tactics to comfort, alleviate stress and meet individuals in 'their reality'

<u>Family Caregivers Wonder: What Is My Loved One With Dementia Feeling?</u>: Employing different strategies to help communicate may ease some worries

ALZHEIMER'S \(\frac{1}{2} \) ASSOCIATION°

The Alzheimer's Association leads the way to end Alzheimer's and all other dementia — by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support.

<u>Greater Maryland Chapter Alzheimer's Association</u> The Greater Maryland Chapter provides information on caregiving, education and living with Alzheimer's disease.

What we offer

Our **24/7 Helpline**, **800.272.3900**, offers support in more than 200 languages. Our staff is highly trained and knowledgeable about all aspects of Alzheimer's disease. Get answers to your questions about:

- Alzheimer's disease or memory loss, medication and treatment options, brain health and care
 options.
- How the Association can help you
- Caregiving tips and respite care options
- Services that are available in your community and referrals

You can also call us at our Helpline, 800.272.3900, for emotional support as often as you need — at any time day or night. We know that living with Alzheimer's is challenging.

National Capital Area Chapter (alz.org)

WE'VE MOVED!

Please send all correspondence, deliveries, and donations to: 3550 S. Clark St., Suite 203 Arlington, VA 22202

Serving the District of Columbia, suburban and Southern Maryland and Northern Virginia

Alzheimer's National chapter Local News 2024

Alzheimer's Disease: Caregivers

The Daily Drum, WHUR 96.3, Apr. 2, 2024

New Alzheimer's Association Report Reveals Top Stressors for Caregivers and Lack of Care Navigation Support and Resources (p. A4)

Prince George's Post, Apr. 4, 2024

New report shows Alzheimer's stress on caregivers

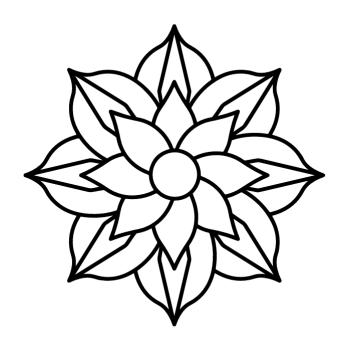
NBC4 Washington, Mar. 29, 2024

Alzheimer's Association reveals increase in cases and care costs in 2024 report

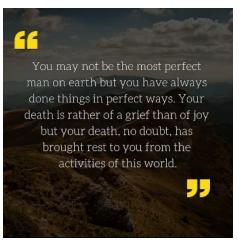
ABC7 DC, Mar. 20, 2024

Six in Ten People With Alzheimer's, Dementia Will Wander (p. A3)

Prince George's Post, Feb. 22, 2024



FINAL FAREWELL PREPARATION



If you're caring for someone with dementia, there are some signs to help you know when they are nearing the end of their life. And preparation can help alleviate some of the stress and grief that naturally occurs during this time.

How do you know when someone is in the final stages of dementia? Dementia is a progressive condition. This means it steadily gets worse with time. Everyone follows a different path through the stages of dementia. But there are some common signs that someone with dementia is in the final stages and nearing the end of their life. You will notice they:

• **Need more day-to-day help:** They will need assistance with nearly all activities of daily living, like getting dressed and

bathing.

- Eat and drink less: It's normal for a person who is nearing death to lose interest in food and drink.
- **Have trouble swallowing:** It will get harder for them to swallow their saliva. Because of this, they may have noisy breathing or increased coughing.
- Talk less: They may become less interactive and be able to communicate with only single words.
- **Have difficulty walking:** They will have less energy and strength to move around. This decline in mobility and balance might also mean they fall more often.
- **Sleep more:** As someone moves around less, this usually means they spend more time in bed. Even if someone is in the late stages of dementia, it doesn't necessarily mean that death is near. For some, their condition can decline quickly. For others, it happens over the course of several weeks or months. But there are some additional signs that can signal someone is likely in their final days.

The end-of-life journey looks different for everyone. But there are seven signs that suggest someone is likely in the final days or hours before death:

- 1. **They have changes in behavior.** You will likely notice a decline in their mental status. This may mean they're more sleepy and less responsive. Or it may look like confusion, restlessness, and emotional outbursts.
- 2. **They stop speaking.** A decline in their responsiveness may mean they may stop speaking or responding to you.
- 3. **They stop eating or drinking.** A complete loss of interest in food or drink is common in the final stage before death.
- 4. **They have difficulty breathing.** People who are close to dying may breathe quickly, slowly, or they may gasp for air. They may also have moments when they stop breathing completely for a few seconds before starting again.
- 5. **Their body temperature drops.** You may notice their skin, especially in their hands and feet, feels cooler to the touch.
- 6. **Their heart rate changes.** Their pulse may speed up or slow down. But in the final minutes or hours, the heart rate typically slows down.

7. **They have moments of clarity.** This is also called "paradoxical" or "terminal lucidity." It refers to the way someone with dementia may suddenly be able to recall memories and recognize family members moments before dying.

Keep in mind that not every person with dementia will show these signs before death. And not all of these signs necessarily mean that death is near. Someone with signs of advanced dementia may live with these symptoms for several months. For most, it is a gradual decline. Someone with dementia is less likely to die suddenly, unless from another underlying health condition.

Caregiver advice: Preparing for the death of someone with dementia

If you're caring for someone with dementia, an end-of-life care plan can help take away a lot of the stress and fear around death. Even though it can be hard to talk about these topics, it's never too soon to discuss future care. This is especially true for people with dementia, since the condition can affect a person's ability to make decisions for themselves in the final stages.

Talk to the person about what they want

It's important to discuss advance care planning with your loved one. This way, you know what types of treatment they want — or don't want — when they are nearing the end of their life. And if they're at a stage when they can no longer decide this for themselves, don't hesitate to reach out to their healthcare provider. They can help guide you through what makes sense with their current health status.

Make legal and financial plans

There are many resources to help with the financial burden of caring for someone with dementia. And there are important legal documents to have in place that outline things like guardianship and power of attorney.

Provide comfort when you can

There are simple ways to provide comfort to someone with dementia who is dying. You can read to them, play music, brush their hair, or hold their hand. You can also use a scent that they like or give them something soft to hold. You can share a memory box with them. And just simply being present with the person may provide comfort for both of you.

Give yourself grace

Caregiving is a hard job. Many caregivers feel some sense of relief after a loved one with dementia dies. If you are caring for someone with dementia, it's OK to take breaks when you need it. Taking time for yourself can help you better prepare and cope with their death.

Mental health resources and support

While caring for someone with dementia, it's important to also take care of yourself and get help with caregiving. You can do this in several ways:

- **Join a support group.** Search online for groups near you that arrange events in-person or virtually.
- **Use relaxation techniques.** There are many different breathing exercises you can try. A simple one is to close your eyes, picture a place that is calm, and focus on taking slow and deep breaths. This simple exercise can lower your stress level.
- Tap into community resources. The Alzheimer's Association has an online community resource
 center for easy access to services like social engagement groups, education programs, and tools
 for self-care.

- Connect with friends and family. Create a calendar so that loved ones, friends, and others know when you need their support. And reach out to your support group when you need some company and time to unwind.
- **Find professional help.** Mental health professionals can guide you through understanding and managing your feelings. Together, you can build a plan that helps you process the stress and grief you may feel before and after the death of a loved one.

7 Signs That Death May Be Near in Someone With Dementia
Advance Care Planning: Advance Directives for Health Care | National Institute on Aging (nih.gov)

acp-resources-public.pdf (cdc.gov)

My Journey: A Care Partner's Journal Space						



PERSONAL DOCUMENTS CHECKLIST

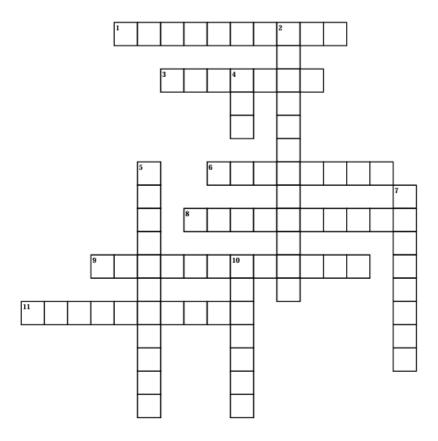
Personal and Spouse's Information
Insurance Policies
Contact List of Family Members and Friends
Family Advisors
Attorney
Estate Attorney
Physician
Accountant
Financial Information
Assets
Income
Investments
Liabilities
Banking Information
Hospital Preferences
Physician
Copy of
Driver's license or State Identification
Birth Certificate
Social Security Verification Letter
Marriage Certificate (if applicable)
Divorce Decree (if applicable)
DD214 (Veterans; if applicable)
Deed(s) (if applicable)
Title(s) (if applicable)
Funeral Arrangements
Funeral Home information
Obituary and Service
 Your Name (Including first, last, middle, maiden, nickname, title)
 Dates of Birth and Death
 List of Loved Ones (Spouses, romantic partners, children, grandchildren, parents
siblings, long-time friends, even beloved pets)
 Your Story (Education and Career Highlights, Military Service and Rank,
Memberships in Organizations)
 Hobbies or Special Lesson(s) Learned
o Order of service
 Ending (Memorial Funds, Thank you, Quote or poem)

Executor/Executrix of Esta	ate:	
Name:		
Address:		
City, State		
Zip:		
Phone:		
Relationship:		
Funeral Home:		
Name:		
Address:		
City, State		
Zip:		
Phone:		
Fax:		
Prearranged?		
Yes	_ No	
Disposition Request?		
Cremation		
Earth Burial		
Mausoleum		
Other		
Insurance Assignment		
Yes	No	

Password Keeper

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Caregiver terms

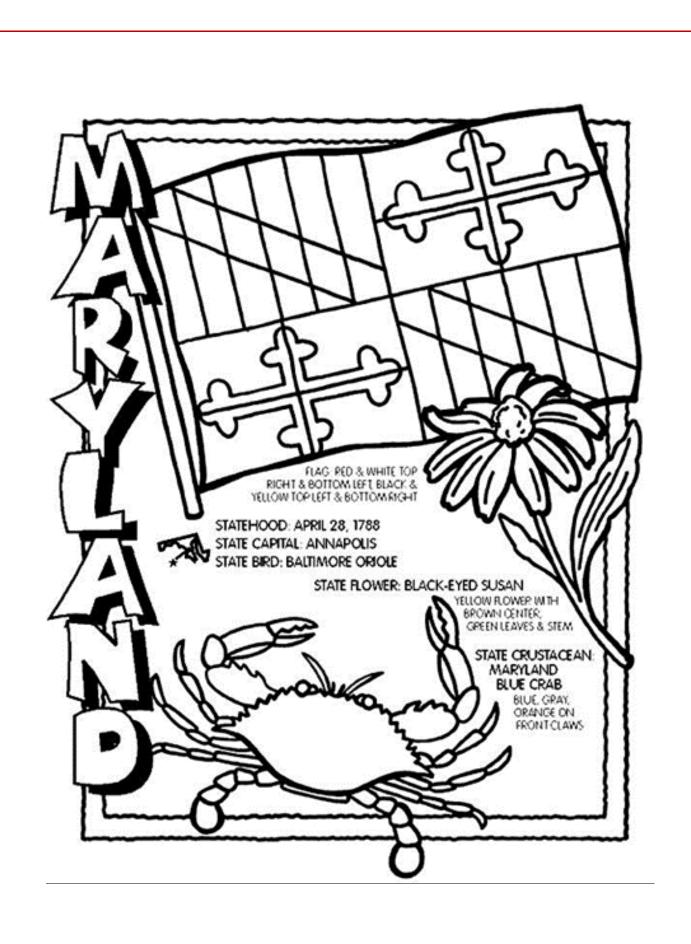


Across

- [1] A state of confusion that occurs later in the afternoon and into the night.
- [3] A treatment regime for people who have an advanced, life-limiting, often incurable illnesses.
- [6] Short-term confused thinking and disrupted attention usually accompanied by disordered speech and hallucinations.
- [8] A person's ability to understand information, make a choice based on that information and communicate that decision in an understandable way.
- [9] A medical doctor who has completed a residency in either family medicine or internal medicine and focuses on older adults.
- [11] A type of progressive mental deterioration, affecting memory and the ability to process thoughts, that is one form of dementia.

Down

- [2] Inability of a person's body to control bowel or bladder functions.
- [4] Power of attorney; A legal document that gives someone you choose the authority to act on your behalf, usually on financial matters.
- [5] The presence, or coexistence, of more than one disorder in the same person.
- [7] A federal government program that provides medical insurance if you are 65 or older, under 65 and receiving Social Security Disability Insurance, or under 65 and diagnosed with end-stage renal disease (ESRD)
- [10] Short-term or temporary care of a sick, disabled or older person for a few hours, days or weeks, designed to provide relief to the regular caregiver.



CAREGIVER GLOSSARY: DEFINITIONS FOR THE MOST CONFUSING ACRONYMS AND TERMS (AARP.ORG)

Activities of daily living (ADLs) Actions a person must do by themselves to engage independently in everyday life, such as bathing, dressing, eating, being mobile, moving from bed to a chair and using the toilet.

Acute care Medical care given for a short time to treat a specific illness or condition. This can include doctor visits, short hospital stays or surgery.

Adult care home, also called an adult family-care home (AFCH) or group home. A small assisted living residence where employees provide for disabled adults or seniors who need help with certain tasks but want to remain as independent as possible. They are an alternative to more restrictive, institutional settings, such as nursing homes, which provide 24-hour nursing care.

Adult day care Centers that provide companionship and help to older adults who need supervision during the day. The programs can help give a break to a round-the-clock caregiver.

Advance directives Written statements that communicate individuals' medical preferences if they become unable to make their own health care decisions. Two types are possible:

- 1. A living will spelling out the types of medical treatment they want at the end of life if they are unable to speak for themselves.
- 2. A health care proxy, which identifies a health care agent or attorney-in-fact to serve as spokesperson on medical decisions for an individual who has lost the ability to communicate.

Alzheimer's disease A type of progressive mental deterioration, affecting memory and the ability to process thoughts, that is one form of dementia.

Assisted living facility (ALF). Housing for those who may need help living independently but do not need skilled nursing care. The level of assistance varies among residences and may include help with bathing, dressing, meals and housekeeping.

Assistive technology devices Products that improve a person's ability to live and function independently. Low-tech assistive devices include canes and pill organizers; high-tech items include electric wheelchairs, hearing aids and smartphones.

Cardiologist A medical doctor who specializes in heart disorders.

Chronic disease A condition that lasts one year or more and either requires ongoing medical attention or limits a person's ability to bathe, care for themselves, dress, eat or walk.

Cohousing A small planned community in which single-family homes, townhouses or rental units are clustered around amenities such as a community kitchen and dining room, common areas for sitting, craft and meeting rooms, gardens and potentially adult and child day care. The goal is to design a neighborhood where people of all ages and family statuses can rely on the informal, mutual support of neighbors to help out.

Comorbidity The presence, or coexistence, of more than one disorder in the same person. They can occur at the same time or one after the other. Interactions between the illnesses can worsen the course of both.

Competence In a legal sense, a person's ability to understand information, make a choice based on that information and communicate that decision in an understandable way.

Conservator A person whom a court appoints to handle someone's affairs when that person cannot do the job. Usually, a conservator handles only finances.

Consumer-directed personal assistance program A Medicaid program available in several states that permits chronically ill and physically disabled people to choose, train and supervise workers who help them with activities of daily living such as bathing, light housework and meal preparation so they can remain in their homes. Some relatives and friends of participants can qualify to be paid through this program.

Continence The ability to control bowel and bladder function.

Continuing care retirement community (CCRC) Housing that offers a variety of living options and services — including independent living, assisted living and skilled care, often all on the same campus — and is designed to meet a person's changing needs.

Copayment, sometimes called copays A fixed amount — \$20, for example — that one pays for a health care service covered by insurance after payment of the deductible. Let's say your health plan's allowable cost for a doctor's office visit is \$100. If you haven't yet met your deductible for the year, you'll pay the full \$100. If you have met the deductible, you pay the \$20 copay, usually at the time of the visit.

Custodial care Nonmedical care that helps individuals with bathing, dressing and other basic care that most people do themselves, such as using eye drops. It can occur in a range of environments including adult day care, assisted living centers and residential care facilities.

Delirium Short-term confused thinking and disrupted attention usually accompanied by disordered speech and hallucinations.

Dementia A general term for a decline in mental ability severe enough to interfere with daily life. Memory loss is an example. Alzheimer's disease is the most common cause of dementia, but not all dementia comes from Alzheimer's.

Dermatologist A medical doctor who specializes in skin disorders.

Discharge planner A professional who assists patients and their families in developing a method of care for a patient following a hospital or nursing home stay.

Do not resuscitate (DNR) order A type of advance directive in which a person states that health care providers should not attempt to restart the heart through cardiopulmonary resuscitation if the heart or breathing stops.

Durable power of attorney A legal document that gives someone you choose the authority to act financially, legally and medically in your place if you become incapacitated and unable to handle matters on your own. It remains in effect until the person who grants it either cancels it or dies.

End-of-life doula also known as a death doula. An individual who provides nonmedical comfort and support to a dying person and their family. This may include education and guidance as well as emotional, spiritual or practical care.

Endocrinologist A medical doctor who specializes in hormonal and metabolic disorders, including diabetes.

Extended care Short-term or temporary care in a rehabilitation hospital or nursing home with the goal of returning a patient home.

Family and Medical Leave Act (FMLA) A federal labor law that provides certain employees with up to 12 weeks per year of unpaid, job-protected leave to accommodate some family and medical situations. The law also requires that employees' group health benefits be maintained during the leave.

Family or informal caregiver Any relative, partner, friend or neighbor who has a significant personal relationship with and provides a broad range of assistance for an adult with a chronic or disabling condition.

Gastroenterologist A medical doctor who specializes in digestive disorders.

Geriatric care manager, also called an aging life care professional. A specialist who assesses a person's mental, physical, environmental and financial conditions to create a care plan to assist in arranging housing, medical, social and other services.

Geriatrician A medical doctor who has completed a residency in either family medicine or internal medicine and focuses on older adults.

Guardianship A court-sanctioned legal relationship in which a person is given legal authority over another when that other person is unable to make safe and sound decisions regarding his or her person or property.

Health care proxy A type of durable power of attorney in which people appoint another person to make health care decisions for them if they become unable to do so.

Hematologist A medical doctor who specializes in blood disorders.

Home health agency A company or nonprofit, often certified by Medicare, that provides health-related services such as nursing, personal care, social work, or occupational, physical or speech therapy in a client's home.

Home health aide (HHA) A trained and certified health care worker who assists a patient in the home. Duties typically include help with hygiene and exercise, light household work such as meal preparation, and monitoring the patient's condition.

Homemaker services Light housekeeping, meal preparation, washing clothes, shopping and other tasks workers from state-certified agencies perform for people who need assistance in their homes. Medicare does not cover these services, but some states' Medicaid programs help qualified low-income adults pay for them.

Hospice care A treatment plan for people who have an advanced, life-limiting, often incurable illnesses. Considered a type of palliative care, hospice focuses on the patient's psychological well-being and on managing symptoms of a disease rather than the disease itself, so they can spend their last days with dignity and quality, surrounded by loved ones.

Incontinence Inability of a person's body to control bowel or bladder functions.

Independent living An age-restricted option for a house, condominium or apartment — sometimes offered as part of a continuing care retirement community — that has few services as part of the basic rate. Those that are included are more often related to convenience, such as grass cutting or a clubhouse.

Informed consent The process of making decisions about medical care or medical experimentation based on open and honest communication among the health care provider, the patient and the patient's family.

Licensed practical nurse (LPN) A person who has completed nursing or vocational training and obtained a state license that authorizes the person to take care of basic duties in settings such as hospitals, nursing homes and long-term care facilities.

Living will A legal document in which the signer requests to be allowed to die rather than be kept alive by artificial means if disabled beyond a reasonable expectation of recovery.

Long-term care insurance Coverage that helps policyholders pay for long-term care in their home or at a nursing home or assisted living facility, or for other designated services, depending on the policy.

Long-term care ombudsman An advocate for residents of nursing homes, residential care homes and assisted living facilities. Ombudsmen are trained to resolve problems; they provide information on how to find a facility and what to do to get high-quality care.

Meals on Wheels A service that delivers daily hot meals to the homes of elderly or disabled people.

Medicaid Government-provided health care coverage for eligible low-income adults, children, pregnant women, elderly adults and people with disabilities. States and the U.S. government share the cost of Medicaid, with states administering the program according to federal requirements. As of May 2021, nearly 76 million people were covered in Medicaid, and enrollment has grown by more than 18 percent during the COVID-19 pandemic.

Medical doctor (M.D.) A health care professional who has graduated from an approved medical school, received additional training in a hospital, passed a federal medical licensing exam and qualified for a state license. Specialists must complete an additional three to nine years of postgraduate work in their practice area.

Medicare A federal government program that provides medical insurance if you are 65 or older, under 65 and receiving Social Security Disability Insurance, or under 65 and diagnosed with end-stage renal disease (ESRD). Medicare Part A is hospital insurance, and Medicare Part B covers certain doctors' services, outpatient care, medical supplies and preventive services. In 2020, 62.6 million people were enrolled in Medicare, 54.1 million of them on the basis of age.

Medicare Advantage, also called Medicare Part C. Private health plans that offer all benefits covered by "original" Medicare (parts A and B) but may also provide non-Medicare-covered benefits such as prescription drug coverage, dental and vision coverage, and even gym memberships, usually for an additional premium.

Medicare Savings Program (MSP) A federally funded, state-administered program that helps people with limited income and resources pay some or all of their Medicare premiums, deductibles, copayments and coinsurance. Four types of MSP are available:

- 1. Qualified Medicare Beneficiary (QMB) for people also enrolled in Medicaid.
- 2. Specified Low-Income Medicare Beneficiary (SLMB), which helps pay for Part B premiums only.
- 3. Qualifying Individual programs (QI and QI-1), which have slightly higher income limits but still help pay for Part B only,
- 4. Qualified Disabled & Working Individuals (QDWI), which helps pay for Part A premiums.

Medicare telehealth services Medicare-covered visits with health care professionals conducted via phone or video chat. Initially offered on a limited basis to people in rural areas, these services have expanded considerably during the COVID-19 pandemic, with telehealth now available to all Medicare enrollees and for a greater variety of visits and services at least until the end of the federally declared public health emergency.

Medigap, also called Medicare Supplemental Insurance. Private policies designed to pay costs not covered using original Medicare. For example, Medigap plans might cover your Medicare copayments, coinsurance and deductibles, or services original Medicare doesn't cover, such as care when you travel outside the United States.

Memory cafe A gathering place that provides a safe and supportive environment where individuals with dementia or other brain disorders and their caregivers can socialize, provide mutual support and exchange information.

Memory care communities Separate facilities or specialized units of an assisted living center that focus on helping people with Alzheimer's disease and other forms of dementia, where the staff is specifically trained to deal with recall problems and other impairments.

National Family Caregiver Support Program (NFCSP). A federal program that provides grants to states and territories for efforts to provide respite care, training, counseling and other supports that help caregivers to care for loved ones at home for as long as possible.

Nephrologist A medical doctor who specializes in kidney disorders.

Neurologist A medical doctor who specializes in nervous system disorders.

Nurse practitioner (NP), also known as advanced practice registered nurse (APRN). A primary-care provider with graduate training in advanced practice nursing who has the authority to order tests, write referrals and prescribe medicines.

Nursing home A public or private residential facility providing a high level of long-term personal or medical care for chronically ill, disabled and older people who are unable to care for themselves properly.

Oncologist A medical doctor who specializes in cancer treatment.

Ophthalmology A medical doctor who specializes in eye disorders and surgery.

Orthopedic surgeon or orthopedist A medical doctor who specializes in bone and connective tissue disorders.

Osteopath (DO), also called a Doctor of Osteopathic Medicine. A physician who has completed four years of medical school and has had 300 to 500 additional hours in the study of hands-on manual medicine and the body's musculoskeletal system. These doctors are state licensed and may have completed a two- to six-year residency and passed state examinations to become board certified.

Otolaryngologist or otorhinolaryngologist. A medical doctor who specializes in ear, nose, and throat (ENT) problems.

Outpatient care, also called ambulatory care. Health care procedures and treatment that do not require overnight hospitalization.

Palliative care Specialized medical care that focuses on providing relief from the symptoms and stress of a serious illness. The goal is to improve the quality of life for both the patient and the family. Unlike hospice care, which is typically given to people with terminal conditions who are nearing the end of life, palliative care can coincide with treatments to arrest or cure a disease.

Patient advocate A professional who can resolve concerns about someone's health care experience, particularly problems that cannot be taken care of immediately.

Personal care services (PCS) A broad term used to refer to help with personal hygiene and other self-care, such as bathing, dressing, eating, going to the bathroom, maintaining personal appearance and walking, provided by in-home personal care aides (PCAs). Some PCAs also help with meal preparation, grocery shopping and money management.

Personal emergency response system (PERS), also known as a medical alert system. An alarm system that lets someone experiencing a medical or personal emergency such as a fall summon help. Traditional systems are triggered by the user pressing a button on a wearable device like a bracelet, sending a radio signal to a console connected to a phone, which calls an emergency response center. In recent years, some smartphones and other connected devices like smartwatches have incorporated medical alert functions.

Physician assistant (PA) A health care professional with a master's degree who works in collaboration with a medical doctor or Doctor of Osteopathic Medicine, often in a primary care setting.

Podiatrist (DPM) A doctor with specialized training in treating foot and ankle problems.

Power of attorney (POA) A legal document that gives someone you choose the authority to act on your behalf, usually on financial matters.

Primary care physician (PCP) The doctor that you see first for checkups and health problems. Sometimes these health care professionals have family practices for all ages; others specialize in internal medicine for adults or pediatrics for children.

Psychiatrist A medical doctor who specializes in emotional and mental disorders.

Psychologist A specialist, but not a medical doctor, who can talk with patients and their families about emotional and personal matters and can help them make decisions.

Radiologist A medical doctor who specializes in X-rays and related procedures such as computed tomography (CT) scans, magnetic resonance imaging (MRI) and ultrasound tests.

Registered nurse (RN) A health professional who has graduated from a nursing program, passed a state board examination and has a state license.

Rehabilitation hospital A medical facility providing therapy and training for the restoration of physical function or cognitive skills following a serious injury, illness or medical event (such as a stroke).

Remote patient monitoring (RPM) A subcategory of telehealth services that allows patients to use mobile medical devices and technology to gather patient-generated health data, such as weight, blood pressure and heart rate, and send it to health care professionals.

Respite care Short-term or temporary care of a sick, disabled or older person for a few hours, days or weeks, designed to provide relief to the regular caregiver.

Rheumatologist A medical doctor who specializes in pain and other symptoms related to joints and other parts of the musculoskeletal system, such as bones, cartilage, ligaments, muscles and tendons.

Senior center A physical location providing opportunities for older adults to get active, enjoy various social activities and improve their overall quality of life.

Skilled care Nursing or rehabilitation services that a doctor orders and that licensed health professionals such as nurses and physical therapists provide.

Social Security The U.S. government's social insurance program, providing monthly benefit payments to retired workers age 62 and older; their spouses (or ex-spouses), children and survivors; and people with disabilities that prevent them from working for an extended period. The system is funded by payroll tax contributions workers make throughout their careers, with monthly benefit amounts determined primarily by their lifetime earnings history.

Social Security Disability Insurance (SSDI). Monthly benefit payments to people below retirement age with a significant illness or impairment that prevents them from working for at least a year or is expected to result in death. Eligibility is based on past work in which the person paid Social Security taxes and is reviewed periodically to make sure the disability continues to restrict them from working.

Sundown syndrome or sundowning. A state of confusion that occurs later in the afternoon and into the night. It is most often found in patients who have dementia or Alzheimer's disease and includes a range of behaviors such as increased confusion, anxiety, agitation and sleeplessness.

Supplemental Security Income (SSI) A program the Social Security Administration oversees that pays monthly benefits to people with limited income and resources who are disabled, blind, or age 65 or older.

Surrogate An individual appointed to act in place of another.

Urologist A medical doctor who specializes in disorders of the male reproductive system as well as the male and female urinary tract.

Vital signs Signs of life — specifically, a person's heart rate (pulse), breathing rate, body temperature and blood pressure. They show doctors how well a person's body is functioning.

TIPS TO MANAGE CAREGIVER STRESS

The emotional and physical demands of caregiving can strain even the strongest person. Many resources and tools can help you care for your loved one and yourself. Make use of them. If you don't take care of yourself, you won't be able to care for anyone else. Caregiver stress: Tips for taking care of yourself - Mayo Clinic

- Ask for and accept help. Make a list of ways in which others can help you. Then let them choose how to help. Ideas include taking regular walks with the person you care for, cooking a meal for you and helping with medical appointments.
- **Focus on what you can do.** At times, you might feel like you're not doing enough. But no one is a perfect caregiver. Believe that you're doing the best you can.
- **Set goals you can reach.** Break large tasks into smaller steps that you can do one at a time. Make lists of what's most important. Follow a daily routine. Say no to requests that are draining, such as hosting meals for holidays or other occasions.
- **Get connected.** Learn about caregiving resources in your area. There might be classes you can take. You might find caregiving services such as rides, meal delivery or house cleaning.
- **Join a support group.** People in support groups know what you're dealing with. They can cheer you on and help you solve problems. A support group also can be a place to make new friends.
- **Seek social support.** Stay connected to family and friends who support you. Make time each week to visit with someone, even if it's just a walk or a quick cup of coffee.
- **Take care of your health.** Find ways to sleep better. Move more on most days. Eat a healthy diet. Drink plenty of water.
- Many caregivers have trouble sleeping. Good sleep is important for health. If you have trouble getting a good night's sleep, talk to your health care professional.
- **See your health care professional.** Get the vaccines you need and regular health screenings. Tell your health care professional that you're a caregiver. Talk about worries or symptoms you have.

FOR MORE INFORMATION

AARPs Staying Sharp Program

Lifestyle Behavior and Brain Health - Staying Sharp (aarp.org)

Affordable Care Act, The

About the ACA | HHS.gov

Age-Friendly and Dementia Friendly Community Initiatives

Home Page - Dementia Friendly America (dfamerica.org)

Community Directory - Dementia Friendly America (dfamerica.org)

Alzheimer's Association Health Systems and Clinicians Initiative to Enhance Care and Improve Outcomes.

Health Systems & Clinicians | Alzheimer's Association

American Rescue Plan Act

American Rescue Plan | The White House H.R.1319 - 117th Congress (2021-2022): American Rescue Plan Act of 2021 | Congress.gov | Library of Congress

Baltimore City Healthy Brain Initiative

Road Map for State and Local Public Health | Alzheimer's Disease and Healthy Aging | CDC

Building Our Largest Dementia Infrastructure for Alzheimer's (BOLD) Act Funding BOLD Infrastructure for Alzheimer's Act | CDC

Centers for Disease Control and Prevention, the (CDC) Healthy Brain Initiative

Healthy Brain Initiative | Alzheimer's Disease and Healthy Aging | CDC

Centers for Medicare and Medicaid Services Health Care Innovation Center (CMMI)

About the CMS Innovation Center | CMS

Dementia Capable Community Connections

BH-Brief-Dementia-Capable-Basics.pdf (acl.gov)

Dementia Friendly America

Home Page - Dementia Friendly America (dfamerica.org)

Johns Hopkins Geriatric Workforce Enhancement Program (GWEP)

Welcome to the Geriatric Workforce Enhancement Program | Johns Hopkins Medicine

Maryland Access Point (expansion and enhancement)

Maryland Access Point

Maryland Total Cost of Care Program and the Total Cost of Care All-Payer Model

Maryland Total Cost of Care Model | CMS

National Alzheimer's Project Act, The (NAPA)

NAPA - National Alzheimer's Project Act | ASPE (hhs.gov)

❖ RAISE Family Caregivers Act

RAISE Family Caregivers Act | The National Alliance for Caregiving

<u>Text - H.R.3759 - 115th Congress (2017-2018): RAISE Family Caregivers Act | Congress.gov | Library of Congress</u>

State Health Information Exchange (CRISP)

<u>Home - Improve Outcomes and Enhance the Patient Experience | CRISP | Improve Outcomes and Enhance the Patient Experience | CRISP (crisphealth.org)</u>

University of Maryland, Baltimore

UM-MIND Institute

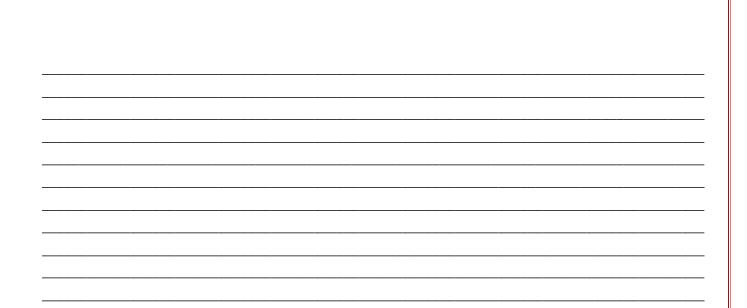
University of Maryland Medical Center

Division of Gerontology and Geriatric Medicine

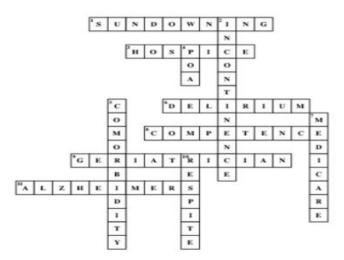
Younger-Onset Alzheimer's Disease Act as part of the Older Americans Act

Younger-Onset Alzheimer's Disease Act (alzimpact.org)

NOTES		



Caregiver terms



Across

- [1] A state of confusion that occurs later in the afternoon
- and into the night.

 [3] A treatment regime for people who have an advanced, [4] Power of attorney; A legal document that gives life-limiting, often incurable illnesses.

 [6] Short-term confused thinking and disrupted attention
- usually accompanied by disordered speech and hallucinations.
- [8] A person's ability to understand information, make a choice based on that information and communicate that decision in an understandable way.
- [9] A medical doctor who has completed a residency in either family medicine or internal medicine and focuses
- [11] A type of progressive mental deterioration, affecting provide relief to the regular caregiver, memory and the ability to process thoughts, that is one form of dementia.

Down

- [2] Inability of a person's body to control bowel or
- someone you choose the authority to act on your behalf, usually on financial matters.
- [5] The presence, or coexistence, of more than one disorder in the same person.
- [7] A federal government program that provides medical insurance if you are 65 or older, under 65 and receiving Social Security Disability Insurance, or under 65 and diagnosed with end-stage renal disease (ESRD)
- [10] Short-term or temporary care of a sick, disabled or older person for a few hours, days or weeks, designed to





MISSION

The Geriatrics & Gerontology Education and Research Program

is a University of Maryland, Baltimore-based program that facilitates interprofessional education and interdisciplinary research activities in the field of aging in partnership with campus affiliates and agencies and organizations serving Maryland's older adults and their caregivers.

VISION Optimize care provided to older adults to promote quality of life through education, research, and training.

CORE VALUES

Accountability Excellence
Civility Diversity
Leadership Knowledge

Collaboration

Whether you want to make an impact directly by working with older adults and their families or indirectly through research, changing policy, or developing innovative technology to tackle the complex health and social challenges associated with growing older, a graduate degree from UMB is a great place to start.

Programs such as our graduate certificate in <u>Aging & Applied Thanatology</u>, our <u>Master's in Gerontology</u>, and our <u>PhD in Gerontology</u> are designed to help you meet your career goals. Visit our <u>website</u> for a complete list of academic programs.

<u>Geriatrics and Gerontology Education and Research Program - UMB: An Age-Friendly University (umaryland.edu)</u>

The Graduate School is home to the Geriatrics & Gerontology Education and Research (GGEAR) program. Educational programs developed by GGEAR and its partners include online training modules through Geri-ED and interprofessional training opportunities such as the Geriatric Assessment Interdisciplinary Team (GAIT) program, in which students learn and work collaboratively in interprofessional settings.

For more information about the GGEAR Program or our offerings, please contact Diane Martin, Ph.D., Director, at diane.martin@umaryland.edu or 410-706-4327.





Spring 2024 "Navigating Dementia" Education Series Dates

Participant Registration Form

FOR WEBINARS, THE ZOOM LINK OPENS 30 MINUTES BEFORE THE START OF THE WEBINAR.

For example, webinar 1 opens at 12:30pm and begins promptly at 1:00pm.

Webinar 1: Friday, March 1, 2024 (12:30pm-3:00pm): Understanding Cognitive Aging: Differentiating Between Usual and Unusual Changes in Memory

Webinar 2: Friday, March 8, 2024 (12:30pm-3:00pm): Understanding Dementia: Differentiating Reversible and Irreversible Causes

In-Person Conference 1: Friday, March 22, 2024 (8:30am-4:00pm) The Meeting House, Columbia, MD: Health Literacy and Plain Language Communication in Alzheimer's and Related Dementia

Webinar 3: Friday, April 19, 2024 (12:30-3:00pm): Exploring Medical and Non-medical Interventions to Slow Cognitive Decline Associated with ADRD

Webinar 4: Wednesday, April 24, 2024 (tbd): Spectrum of Services & Supports in Maryland for Persons Living with Dementia (note: this webinar will be one of several offered during the annual caregiver's conference webinar hosted by Eastern Shore MAC, Inc. More information will be provided to individuals registering for this webinar held April 24 from 8:30am-3:00pm)

In-person Conference 2: Friday, May 10, 2024 (8:30am-4:00pm) The Meeting House, Columbia, MD: Assessment Tools Workshop: Tools & Referrals for Non-Clinicians

Webinar 5: Friday, May 24 (12:30pm-3:00pm): Empowering Caregivers: Essential Resources and Supports in Maryland

CEUs are available at no-cost for Certified Dementia Practitioners, Certified Senior Advisors, Maryland Social Workers, and Maryland Psychologists and Mental Health Professionals. A Certificate of Attendance will be provided to all participants.

Plus, you can earn your Age-Friendly Specialist Certificate by attending our series. Visit https://www.umaryland.edu/media/umb/geriatric-programs/GGEAR-AFU-Brochure.pdf for more details.