NEBRASKA

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DEPT. OF HEALTH AND HUMAN SERVICES

Jim Pillen, Governor

March 31, 2025

The Honorable Jim Pillen
Governor of Nebraska
P.O. Box 94848
Lincoln, NE 68509

Mr. Brandon Metzler
Clerk of the Legislature
P.O. Box 94604
Lincoln, NE 68509

Subject: State Alzheimer's Plan

Dear Governor Pillen and Mr. Metzler:

On behalf of the Alzheimer's Disease and Other Dementias Advisory Council, I am pleased to submit the comprehensive State Alzheimer's Plan. Since December 2023, the Advisory Council has worked diligently to assess the needs of Nebraskans impacted by Alzheimer's disease and other dementias and develop thoughtful, data-informed recommendations to enhance services, supports, and care for individuals, families, and caregivers across the state.

This plan reflects extensive collaboration among stakeholders, including the State Unit on Aging and partners across the Nebraska Department of Health and Human Services. We look forward to working with the Legislature and other key partners to evaluate these recommendations and implement strategies that strengthen Nebraska's response to the growing challenges posed by Alzheimer's and other dementias.

Sincerely,

Tony Green
Director, Division of Developmental Disabilities

The Nebraska Alzheimer's State Plan

Presented March 31, 2025

by

The Alzheimer's Disease and
Other Dementia Advisory Council

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Executive Summary

In December 2022, Governor Pete Ricketts signed into law the Alzheimer's Disease and Other Dementia Support Act (Neb Rev. Stat. § 71-561 to 71-567). This important piece of legislation acknowledged that Alzheimer's Disease and other forms of dementia are of "significant concern" to the state of Nebraska, and that "the state would benefit from a more coordinated approach to addressing Alzheimer's Disease and other dementia." (While the title of the statute and many discussions use "Alzheimer's Disease" as an umbrella term and "other dementia" as a catch-all for other types, the advisory council has chosen to use "dementia" as an umbrella term encompassing all forms of dementia, including Alzheimer's.)

As the population of people over 65 increases, so will the prevalence of dementia. The population of Americans aged sixty-five and older is projected to grow from 58 million in 2022 to 82 million by 2050. There are approximately 293,000 people in Nebraska over the age of 65, 17.2% of the state's population. Eight thousand Nebraskans retire every year, and one in ten of them will suffer dementia. Currently, there are approximately 35,000 Nebraskans suffering from dementia. In 2021, the most recent year for which data have been collected, there were 768 deaths dementia-related causes in Nebraska (Facts and Figures 38).

The prevalence of dementia is not evenly distributed across the state. Smaller communities tend to have a higher average age, which means a larger portion of the population will have dementia. There are currently seventeen counties in Nebraska where 12% or more of the population is living with dementia. The situation is exacerbated by what is happening at the other end of the demographic spectrum. People are having fewer children. Just as more people are experiencing dementia and require individualized care, there will be fewer adult children to take care of them. The "brain drain" that has resulted in so many capable young people leaving the state exacerbates the problem.

This plan builds on the work of the first Nebraska State Plan for Alzheimer's Disease and Other Dementia that was presented to the legislature and governor in June 2016 by the Aging Nebraskans Task Force. In preparing this report, a subcommittee of task force members held four town hall meetings (in Alliance, Kearney, Pender, and Omaha) from August to September 2015. Subsequent input from stakeholders and state agencies led to the finalization of the 2016 plan, which served as the roadmap for the state's efforts in the fight against dementia until now.

It is appropriate that, in 2025, our state develop a new state plan that builds on the lessons of the last eight years. The landscape of diagnosis, treatment, and supports available to caregivers has changed. There are needs for infrastructure, capacity, and workforce development that were not addressed previously, however, because these needs were not yet fully recognized or as extreme as they are now.

The statute establishing the advisory council requires that periodic status reports on the implementation of the plan be submitted to the legislature and the governor every year, and that the plan be revised every four years. It is the hope of the advisory council that when it comes time to submit the first implementation report at the end of 2025, the plan will have served as a helpful road map in addressing the various complicated issues in the fight against dementia.

Part I: Increase Support for Caregivers

One aspect of dementia that increases the burden on families is that unlike many other diseases, most of the care for individuals with dementia is provided by family members, especially spouses, or other informal and generally unpaid caregivers. Nearly half of all caregivers providing help to adults over 65 are doing so for someone with dementia (Working Caregiver Survey Report).

There are approximately 40,000 people in Nebraska providing unpaid care to someone with dementia (Facts and Figures 2024, p. 47). These caregivers provide a staggering 62 million hours of care with a value of $1,188,000,000. Research has yielded a profile of the typical caregiver/care partner in Nebraska. The average Nebraska caregiver is a female age 40-59 who has a job in addition to being an informal caregiver. She provides at least twenty hours of care per week outside of working hours and serves in this role for three to five years. The person with dementia often lives in the caregiver's home.

Twenty percent of caregivers are over 65 themselves and many of them are dealing with health issues of their own, including conditions such as depression that are directly linked to the burdens of caregiving. The relationship between caregiver and person with dementia has been the subject of much recent research, which has shown that what affects caregivers negatively often has negative ramifications for the people they are caring for.

In addition to informal, unpaid caregivers, caregiving services are frequently provided on a private pay basis or by Medicaid. The average family caregiver in the U.S. spends roughly $7,200 a year on caregiving activities, including hiring home care aides. As we address home health and home care, it is important to clarify the difference between the two services. "Home health" refers to skilled medical services, prescribed by a physician and typically comprising skilled nursing, therapy, often provided to individuals who are homebound during recovery following hospitalization or a change in medical condition. "Home care" refers to nonmedical services such as companionship, meals, laundry, and household chores.

In addition to providing health-related services such as medication management and transporting loved ones to doctors' appointments, home care includes assistance with "activities of daily living" such as bathing, dressing, feeding, toileting, getting in and out of bed, and ambulating around the home, as well as "instrumental activities of daily living," including financial management, shopping, and other activities.

Due to the range of services and the different skills and training required for each, finding the right combination of services can vary from individual to individual. While it is largely agreed that remaining in the home setting for as long as possible, i.e., "aging in place," is optimal in many circumstances, this often places the caregiving burden on family members, who as a result can easily experience burnout, loneliness, stress and health conditions of their own. Additionally, the income lost when caregivers miss work or leave the workforce entirely makes the real economic impact of dementia clearer. Home health providers are required under Medicare regulations to be licensed. In Nebraska, there are 129 licensed home health agencies, which employ licensed health professionals. In contrast, home care providers are not required to be licensed, and this lack of regulation makes it difficult to determine how many home care providers operate in Nebraska.

Another important support for caregivers is respite and adult day care. Adult day and respite services offer critical additional support for caregivers. These services provide structured, supervised care to loved ones with dementia. This gives caregivers time they can spend stepping back from the daily grind of caregiving, taking care of tasks and errands unrelated to dementia care, spending time with friends, and rejuvenating themselves.

When an unrelated emergency occurs and the primary caregiver must leave the person with dementia in the home alone, this creates the risk of unsafe living situations. There should be an evaluation of the current regulations to make a modification for respite stays including both private-pay or Medicaid source, many Nebraskans could benefit.

Resources for respite care are limited and often come with time or payor source restrictions. Nebraska's eight Area Agencies on Aging (AAAs) provide in-home respite and adult day services. Low-income Nebraskans are eligible to receive adult day services under the Social Services to the Aged and Disabled fund. The reimbursement rates for these services are low, and do not provide an incentive for privately owned facilities to accept this funding, thereby excluding many individuals from necessary services.

There are also web-based caregiver support platforms such as Trualta (trualta.com). Trualta offers caregivers support through various resources including educational programming, and one-on-one care coaching in addition to support groups. Bi-lingual materials are also available. It is possible to offer programming statewide. As an example, the state of Iowa recently entered a partnership with Trualta and now offers free access for all Iowa residents to all Trualta's resources. For persons living with dementia under the age of 60, the League of Human Dignity is an option. The League offers information about housing options and other resources in the community. Another on-line support platform is the Empowered Caregiver program available through the Alzheimer's Association (https://www.alz/org/help-support/resources).

AARP offers a wide range of resources for caregivers and their families through the AARP Caregiving Resource Center (www.aarp.org/caregiving). Some of the key areas include family caregiving basics, specialized care for caring for loved ones with specific conditions like dementia, coping strategies, legal and financial advice as well as local resources; state specific guides to help with finding local caregiving assistance and services. AARP has created tools and resources for family caregivers that are caring for a loved one. A dedicated, toll-free family Caregiving Resource Line is also available (1-877-333-5885), providing resources on a variety of topics.

The question of who will provide care is even more pressing in the case of older persons who lack family support, an increasingly common situation. According to AARP, about a third of people aged 50 and older now live alone and do not have children, are estranged from their children or can't depend on them or other family members for help. These solo agers face many of the same planning issues as older adults with children—figuring out how they will manage their future care, where they should live and how to make their money last. But their different circumstances often warrant different solutions. And when it comes to older persons who do have children, they are having fewer of them. Just as more people are experiencing dementia and require individualized care, there will be fewer adult children to take care of them. A drop in the number of children people are having will contribute to the availability of support in the future. The "brain drain" that has resulted in so many capable young people leaving the state exacerbates the problem.

Recommendations:

- Explore the feasibility of implementing Trualta or other on-line caregiver support platform and make access free to all Nebraska residents. The fiscal cost for this recommendation is $132,000 to $180,000 annually.

- Seek one time grant funding for long-term care and assisted living communities to establish adult day care programs. In rural areas consider including senior centers.

- Develop a respite admission program for long-term care communities to enable quick admissions for emergent respite stays.

Part II: Provide Care Navigation Through Area Agencies on Aging

Because the work of caregiving is constant and provided in the home, caregivers/care partners can feel isolated from the outside world and on their own when it comes to finding the information and support, they need to provide the best care possible. Caregivers/care partners often have difficulty locating providers and appropriate resources and support systems and need assistance with care navigation. And caregivers sometimes need assistance with such issues as nutrition and financial literacy.

Care navigation is one of the most important services that the state and organizations can provide. Effective care navigation depends on caregivers understanding all the different pieces to the dementia care puzzle and how to move seamlessly from one to the other as their loved one's needs shift. Responding to the dementia crisis will take a comprehensive, multi-pronged approach. Addressing issues one by one will not solve the problem.

One important source of information and support for caregivers/care partners is the Area Agencies on Aging (AAAs). AAAs provide services designed to help older adults live in their home as long as possible. They also fund senior centers that provide meals, activities, and respite for caregivers. Professional care managers work with older adults, identifying and coordinating available community resources and services. The eight AAAs serve the state of Nebraska based on region. A complete listing of Nebraska's AAAs is found in the appendix on resources. Also included is a link to the Aging Disability Resource Center (ADRC) for Nebraska, offering additional resource information.

Most AAAs have a Caregiver Support Program in which the caregiver rather than the person with dementia is the client. There are also case management, supplemental services as well as educational opportunities.

One recommendation of this plan is to establish care navigators in each of the eight AAAs across Nebraska. An initial pilot study is needed in order to determine the return on investment for the state and family caregivers. Another option is drawing from the work of national programs. For example, "Dementia Friendly America" offers a framework for updating community services to support individuals with dementia and their care partners. This model could be beneficial for Nebraska for future consideration.

The AAAs, along with the senior centers they support, are often the first resource accessed by family caregivers seeking information about what to do in managing the challenges of caregiving/care partnering. Senior center staff may also be the first to observe changes in someone who visits the center frequently, particularly centers in more rural areas and those serving diverse populations.

Many families lack the financial resources to pay for long-term care. Dementia exacerbates this problem, because dementia as a cognitive issue often does not require medical assistance and is not funded by original Medicaid, but by waiver. In April 2024, Governor Pillen signed into law the Caregiver Tax Credit Act, which offers Nebraska family caregivers who meet income requirements to apply for a nonrefundable tax credit equal to half of their eligible caregiving expenses (see www.aarp.org/NEcaregiving). The maximum credit is $2,000 a year or $3,000 per year for caregivers of a veteran or someone with dementia. There are fiscal limits to the amount the

Department of Revenue can award each year with a build up to 2,500,000 in annual expenditure over the next 3 years.

The Medicaid Waiver program is extremely important for the families of persons with dementia, who can be generally healthy medically speaking even when their level of cognitive impairment is high. This population does not require a nursing-home level of care. With the extra supervision and security from being in a locked memory care unit, a person with dementia can often function well in an assisted living setting that would be covered under the waiver.

In order for an individual to qualify for Medicaid Long-Term Care Services, or Medicaid Waiver Services, the individual must be approved for Medicaid and be evaluated by either the League of Human Dignity or the Area Agency on Aging. This evaluation determines an individual's level of care and must occur before their stay at the facility (or services in the home) is funded. An individual must require assistance with at least three activities of daily living in order to be eligible for Medicaid/Medicaid Waiver coverage, and this can sometimes present a barrier to acceptance, as residents with dementia do not always report their care requirements accurately. After the level of care determination is completed, Medicaid Waiver provider will also develop a service plan that will address the individual's needs and determine how and which services are provided.

Recommendations:

- Create a two-year dementia care navigator pilot project within the Eastern Nebraska Office on Aging that serves both urban and rural caregivers/care partners. The projected fiscal expenditure for this recommendation is $100,000 per year.

- Engage with local hospitals, nonprofits, and support groups to create a comprehensive directory of services available for individuals with dementia.

- Educate the aging network on available programs and benefits such as the Caregiver Tax Credit.

Part III: Increase Availability and Quality of Facility-Based Care

One of the most difficult questions caregivers and family members have to determine is at what point it becomes necessary to move someone into a facility, whether it be assisted living, a nursing home, or memory care within an assisted living or nursing home. The level of care varies based on the setting—assisted living facilities, which can provide assistance to individuals within a fairly independent home environment, and skilled nursing facilities, which provide continuous medical care and supervision to residents.

In addition to skilled therapy for individuals wishing to rehabilitate and return to other living environments, skilled nursing facilities also provide custodial care for individuals requiring long-term care, such as residents with dementia. Skilled nursing facilities experienced a Medicaid reimbursement increase in the last several years and this has had a positive impact on skilled nursing facilities' ability to accept Medicaid. However, skilled nursing rates could be increased for individuals with dementia, as they typically require a higher level of physical assistance that raises the care rate.

Current reimbursement for Medicaid Waiver in assisted living is $3,116 per month (this rate includes residents' room and board portion). This often does not cover the total cost of care, and there can be loss of revenue, which can be between $500-$900 per month for each Medicaid Waiver resident, depending on the level of care. The loss of revenue is even greater for residents with memory care needs.

Current Medicaid Waiver reimbursement in assisted living does not take these memory support needs into account, and the state should strongly consider an enhanced reimbursement rate for memory care residents to possibly increase the number of assisted living facilities that will accept individuals on Medicaid waiver needing a memory support level of care. Currently, many Nebraskans with dementia are living in long-term care facilities instead of assisted living solely because of their payor source. This phenomenon affects members of underserved communities even more heavily.

One issue of increasing concern is caring for older adults with co-occurring disorders such as mental illness, intellectual and developmental disabilities, and substance abuse. Many facilities will not accept these individuals out of fear that they would create disruptions for other residents and the financial implications involved in their care. The types and severity of dementia-related behaviors can vary based on the individual, the stage of dementia, and any underlying medical conditions or environmental factors. Some types of dementia such as Parkinson's or Lewy-Body, can have symptoms such as delusions and paranoia that resemble mental illness, which delays diagnosis. Training staff in de-escalation and communication techniques is vital. More training in managing resident behavior would enable healthcare professionals to accommodate residents more effectively with serious needs.

The Medicaid Waiver program in assisted living is extremely important for the families of persons with dementia, who can be generally healthy medically speaking even when their level of cognitive impairment is high. This population does not require a nursing-home level of care. With the extra supervision and security from being in a locked memory care unit, a person with dementia can often function well in an assisted living setting that would be covered under the waiver.

In order for an individual to qualify for Medicaid Long-Term Care Services, or Medicaid Waiver Services in assisted livings, the individual must be evaluated by either the League of Human Dignity or the Area Agency on Aging. This evaluation determines an individual's level of care and must occur before their stay at the facility (or services in the home) is funded. An individual must require assistance with at least three activities of daily living in order to be eligible for Medicaid/Medicaid Waiver coverage. After the level of care determination is completed, the service worker from League of Human Dignity or the Area Agency on Aging will also develop a service plan that will address the individual's needs and determine how and which services are provided. Continued touchpoints from the service worker in person and over the phone connections that occur monthly. The service worker acts as an advocate for needed services for a Medicaid Waiver participant. The Medicaid Waiver Resource Developer also conducts an annual renewal of continued services at the provider level to ensure that all requirements are met by the provider. These requirements of the program ensure quality services are being received by the person on HCBS and the contracted provider is providing quality services.

Some people with dementia have other medical conditions such as diabetes and COPD, while others may only need assistance with activities of daily living—bathing, eating, dressing, toileting, and transferring out of bed.

Memory care units can be found in assisted living or skilled nursing. There are also facilities that are 100% memory care. What differentiates memory care from other levels of care is primarily that it is a secure space, where residents cannot exit the facility without family or staff assistance. For memory care provided in the assisted living and skilled nursing levels of care, facility staff members are required to receive four hours of dementia-specific training on an annual basis, meal service that is adjusted to support nutritional needs, activity programing that promotes engagement and independence, and strong coordination with family/caregivers to provide a safe outcome for the resident that is no longer able to make their own wishes known.

In all types of facilities, there are severe staffing shortages. While the number of healthcare providers has decreased, especially in nursing professions, in 2023 the Center for Medicare and Medicaid Services has imposed unfunded minimum staffing requirements on skilled nursing facilities. This will present further inequities in income versus cost, and this is further compounded by increasing rates of staff turnover and potential facility closure.

Eighty-six assisted living facilities (30% of the 283 assisted living facilities in the state) report that they have a dementia or special care unit. There are currently 193 licensed nursing homes in Nebraska. The total number of licensed beds is 14, 916. Forty-five nursing homes (29% of SNFs in the state) report that they have dementia or special care units. However, not all these facilities are licensed to accept Medicare/Medicaid, and some exist in a hospital-based setting. The lack of memory care beds means that many people who have dementia and need special care live with the general resident population and are cared for by staff who may not have dementia-specific training. Facilities that offer a dementia or special care unit, must license their facility with DHHS to include that specialty. The facility will be checked for compliance with all rules and regulations during their unannounced routine inspection from DHHS.

Numerous assisted living facilities are limited in their ability to accept many people on Medicaid Waiver because they would then not be able to meet and sustain operating costs. The state should strongly consider increasing the reimbursement rate for memory care residents. The

net effect of this action would allow more facilities to take Medicaid, the action could decrease the amount of facility closures and allow facilities to hire and retain staff.

Approximately 60% of Nebraskans living in nursing home residents rely on Medicaid. Facility operating costs have experienced inflation due to supply chain demands, as well as every other factor that largely increases facility costs across the board. In addition, staffing challenges before and after the pandemic have necessitated an increased reliance on staffing companies, which leads to higher labor costs than facilities have previously experienced.

Recommendations:

- The state should strongly consider increasing the reimbursement rate for memory care, which would increase availability for ADRD individuals as identified in the "Rate Study for AD Waiver, TBI Waiver and PAS Services (updated September 2023).
- Analyze previous efforts to have long term care facilities and hospitals develop centralized system for locating available beds in facilities across the state to simplify referral system.
- Investigate how Medicaid Waiver, Home and Community-Based Services can include all areas of need. This could include adult day service level of engagement within the home.

Part IV: Increase Access for Rural and Underserved Communities

The total population of Nebraska as of 2024 is 1,978,379 [ACS, 2023) ADD]. Of these, 928,998 live in one of the state's five largest cities (Omaha, Lincoln, Bellevue, Grand Island and Kearney). That means 1,049,381, 52% of the population, live in rural areas or one of the 523 smaller towns in the state. Thirty-five percent of Nebraskans over the age of 65 live in rural areas.

One major factor affecting availability of facility beds is increasing numbers of facility closures. Facility-based care has taken a major hit in the last seven years with over thirty-nine nursing home closures and thirty-two assisted living closures since 2017. Many of these closures were facilities in rural portions of the state. There are currently twenty-two counties with zero nursing homes within county lines. Seventeen of these counties also lack assisted living facility. There are an additional twenty-seven counties that only have one nursing home within the county lines. Six of the seven counties with the highest population of people aged 65 or older per capita in the state—Sioux, Hooker, Keya Paha, Hayes, Wheeler, Greeley—have zero nursing homes; the exception is Pawnee, which has one nursing home. (Nebraska Health Care Association and Nebraska Hospital Association.) The size of the aging population and the lack of family caregivers has increased the need for paid caregivers, home health, home care, and above all facility beds. Currently the open facilities are usually full or at capacity. If the facility is not full it is a result of not having enough workforce in the area to support the staffing requirements to serve the residents in the facility.

Home care agencies are scarce in western Nebraska. Distance between locations is the main detriment along with travel time and costs for travel. Single rural adults living far from families have more difficulty finding full-time caregivers. The cost of travel time affects the cost per hour. Paid caregivers in metro areas may serve two to three times as many clients as those in rural communities. Incentives to provide services in rural areas may be supplemented by grants to home care businesses. Spouses or children are more likely to keep their loved ones at home longer in rural areas simply because the closest care facility may be an hour's drive away, which would make visitation more difficult.

Unfortunately, many older persons in rural areas face challenges due to limited access to home health and home care providers, further complicating aging in place. Nationwide, there is a growing shortage of direct care workers, and this is only expected to grow. Another challenge for persons living with dementia is the 24/7 nature of the care and assistance that enable them to live safely at home. For this reason, the cost of home care services for these individuals can become prohibitive. However, home care for short periods of time allows caregivers respite or a way to supplement care provided by family members. In order for the person living with dementia to remain safely at home, home care alone may be insufficient and other supports (e.g., home modifications, security, and monitoring) may become necessary.

Broadband and internet availability in rural areas is important for many reasons. Being able to communicate with distant families is important to prevent isolation or depression for aging loved ones. It provides the option for webinars and podcasts for education of dementia and training of caregivers. All education and training should be offered at no cost. Telehealth is an important service for those in rural areas. This may be the only direct line or help they may access or receive quickly on a 24/7 basis. It is imperative to make fiber optics or satellite internet accessibility

available for all rural areas. This may not be possible due to the cost of installation, and financial need of the individual.

When it comes to overall physical health, there are significant disparities among the care and services available to older adults in different communities across the state. Having dementia makes it more challenging, because even where there are health care resources available, there may not be anyone with specialized training in dementia. It is crucial to provide more dementia resources because members of underserved communities are more likely to develop dementia. National data from the CHAP study indicates that 19% of African American and 14% of Hispanic adults aged 65 or older have Alzheimer's dementia compared with 10% of older white adults. CHAD is a regularly used database as part of a wide variety of human exposure and health studies and has been cited in hundreds of articles on human exposure science.

Few residential care facilities, adult day respite programs, home health, home care and hospice providers in Nebraska currently have the knowledge or resources to fully assist individuals from a wide variety of cultures and/or religions. Language barriers are also a significant issue.

Some members of underserved communities believe that treatments and therapies are unlikely to be effective for them because they are based on research that did not involve any members of underserved communities. The lack of diversity in clinical trials is an issue that dementia researchers have been struggling with in recent years. More than half of non-white Americans believe that cognitive impairment is a normal part of aging and thus not a problem needing to be investigated. Another factor in the lack of diversity is African Americans and Hispanics have been known that they would feel insulted if a health care provider asked them to undergo a cognitive assessment.

As the U.S. grows more diverse, the healthcare industry will also need to look at finding a way to build models of care that could serve a wider variety of cultures. As facilities, home care and home health agencies should employ a more diverse pool of employees—staff members, which may provide an understanding what would attract people of their culture to live in a facility and what would make them feel welcome. There is a need for interpreters and materials to be in multiple languages. The numbers of non-English speakers in need of services will increase. There is a need for education in sign language, Spanish, and other languages. Establishing relationships with churches or other faith-based communities is one way of providing information and education about dementia is one way to meet this objective.

Beyond the statistics, there are deep cultural habits that make dementia care more difficult. Many members of underserved communities report being less likely to seek dementia care because they believe they will be discriminated against. When asked how this discrimination manifests itself, the reason most frequently cited is feeling "not listened to" when they express concerns or ask questions of health care providers. This is a serious problem when it comes to caregivers confronting the complexities of care navigation.

High-speed internet is not a luxury. Expanding access to affordable, reliable, high-speed internet to everyone in the state, no matter where they live, or their circumstances is critical. It is a necessity for older Nebraskans. Better connectivity allows navigation to online government services, the ability to participate in virtual medical services, find and maintain employment for

potential work force in rural areas, secure caregiver and respite services, support of home security options for safety in the home, while also meeting daily needs and connecting socially. In short, expanding high speed internet will improve the quality of life and help adults 50+ safely age in place.

Specifically, affordable, dependable, and accessible high-speed internet is crucial for home health care and aging in place. High-speed internet enables telehealth, allowing patients and their caregivers to have virtual consultations with healthcare providers. Telehealth can be particularly helpful for older adults, who can benefit from the added convenience, reduced barriers to care, and increased independence. These benefits can be even more pronounced for members of underserved or rural communities, or older adults with disabilities or physical limitations – all of whom may experience additional barriers when seeking in-person care. Telehealth can support family caregivers' efforts to take care of their loved ones. This is particularly true for working or long-distance caregivers who may face additional challenges while balancing caregiving responsibilities with other obligations. Additionally, remote health monitoring allows healthcare providers the ability to monitor patients' health in real-time using devices that track vital signs and other health metrics, assisting in early detection or management of health issues.

The National Telecommunications and Information Administration (NTIA) recently approved Nebraska's digital opportunities plan. This approval is the first step in unlocking federal funding that can help underserved communities — including older Nebraskans, veterans, low-income families, tribal communities, people living in rural areas and others — to connect to the internet.

While the state has made significant strides in recent years to close digital gaps, it continues to face numerous challenges, especially in rural areas. 68% of rural locations are served with internet speeds that allow modern applications, compared to 87% of locations statewide. Through the $405 million allocation through the Federal Broadband Equity, Access, and Deployment (BEAD) program, Nebraska will pursue efforts to improve overall high-speed internet affordability, provide universal access, and promote digital skills. Expanding and promoting free public Wi-Fi at libraries, schools, and other publicly accessible locations are strategies that will assist in getting more Nebraskans connected.

Equally important to access is having the digital literacy skills necessary to use technology. This is especially important for older adults whose lack of digital skills threatens their ability to age in place. Nebraska must deliver on the state plan's promise of expanding digital literacy training and support. These programs should meet professional standards, ensure accessibility for people with special needs and be designed to meet the unique learning needs of all people, including older adults. Anchor institutions, such as libraries, community colleges and senior centers should play a key role in providing digital literacy training in conjunction with programs offering digital literacy curriculum.

Older Adults Technology Services (OATS), through its flagship program Senior Planet, provides digital literacy training and programs for older adults and caregivers. Senior Planet's mission is to help older adults stay connected, informed, and engaged through technology (www.seniorplanet.org). Senior Planet offers free classes and workshops on various technology topics, helping older adults and those caring for them how to use computers, smartphones, health monitoring devices, and the internet effectively.

Overall, high-speed internet is not just a convenience but a necessity for maintaining and improving the quality of life and health outcomes for older adults and their caregivers aging in place.

Recommendations:

- Develop a program for building partnerships between individual facilities and the communities where they are located.
- Explore incentives to increase the workforce in home care and home health workers in rural areas.
- Implement targeted outreach by churches, doctor's offices, etc. to raise awareness about dementia within rural and ethnic communities.
- Create one-time grant opportunities for healthcare staff members to learn a new language or pursue cultural studies focused on the populations they serve.
- Establish programs encouraging more immigrants to enter health care professions generally but dementia care in particular.

Part V: Increase Public Awareness and Education

There needs to be more and better education at each point along the continuum of care: (i) educating health providers on the diagnosis and treatment of dementia, (ii) educating staff of care facilities and home care agencies, (iii) education of families and caregivers on the resources available to assist them; (iv) educating students at high schools, community colleges, universities, professional degree programs , and even K-12 educational institutions to promote dementia care as a vitally important field that requires at all levels, from certified medication aids at facilities up to administrators running the non-profits and other organizations that play a crucial role. This education will be provided by educational institutions, health care providers, non-profit organizations such as the Alzheimer's Association, and government or quasi-governmental agencies such as Area Agencies on Aging and the Eastern Nebraska Office on Aging.

Another area in which there needs to be education is the importance of brain health, its relationship to physical health, and its role in preventing dementia. Experts believe that in most cases, Alzheimer's disease, like other common chronic conditions, likely develops from complex interactions among various factors, including age, genetics, environment, lifestyle, and coexisting medical conditions. While certain risk factors, such as age and genetics, are beyond control, others, like high blood pressure and physical inactivity, can often be modified to lower the risk.

Brain health has long been a concern of the CDC. In 2005, Congress first appropriated funds for CDC to focus on brain health and dementia. This action led to the Healthy Brain Initiative (HBI). The overarching vision of the Healthy Brain Initiative (HBI) is that everyone deserves a life with the healthiest brain possible. Across the country, health departments are emerging as leaders and foundational partners in addressing the growing impact of Alzheimer's, cognitive decline, and dementia caregiving. In Nebraska, health departments should use innovative public health approaches to prioritize healthy aging across all communities.

Medical providers, educators, and local organizations across the state should collaborate to address the interconnected risks of dementia and vascular health. This entails public awareness campaigns that educate community members on the connectedness of heart health and brain health and state-wide programs that integrate brain and heart health education for individuals of all ages. Special attention should be paid to disseminating this information to populations with high prevalence rates of dementia, members of underserved communities, and students in our K-12 education system. This should also involve incorporating brain health messaging into any existing public health campaigns.

AARP has created a brain health assessment and program called Staying Sharp (https://stayingsharp.aarp.org), which works to educate Americans about how a well-rounded healthy living approach can improve brain health. Comprehensive tools are available for free, allowing public health departments and the State Unit on Aging to collaborate effectively.

The Alzheimer's Association - Nebraska Chapter offers a free brain health program as well, titled Healthy Living for Your Brain and Body. This program offers science-based recommendations about taking care of our brains and bodies and can be presented to all audiences.

As the number of people diagnosed with dementia increases, so will the need for information that the state and the health care system can use to understand the prevalence of dementia and how allocating resources to deal with it. One of the essential tools in gathering this

information is a dementia registry. While national surveys are helpful, state-level tracking offers a more granular understanding of regional variations and facilitates targeted interventions depending on the resources currently available or needing to be built in particular areas.

Nebraska already has models that would be useful in creating a dementia registry. One such model is the Parkinson's Registry, established pursuant to the Parkinson's Disease Registry Act pass by the legislature in 1996. This legislation requires physicians and pharmacists to report anyone diagnosed with Parkinson's or being provided with Parkinson's Disease medications.

The dementia registry would be voluntary and assure protection of the identity of anyone who wishes to be included. Those eligible to be placed on the registry would have the ability to opt out of the reporting. Data collected on the registry would be utilized to inform policy that will identify regional disparities, allocate resources based on prevalence, provide early intervention and prevention, enhance support to caregivers and make informed policy decisions.

The dementia registry would have numerous benefits. The expectation would be that any Nebraskan newly diagnosed with dementia would be entered into the database, with a responsible party listed in case an emergency situation arises. Certain demographic information would be collected, such as location, family size, demographic profile, and other factors. State-level tracking would enable Nebraska to identify regional disparities, allocate resources based on prevalence, provide early intervention and prevention, enhance support to caregivers and make informed policy decisions.

In addition to a central registry, another important means of gathering information is the Behavioral Risk Factor Surveillance System. BRFSS is the nation's leading system of health-related telephone surveys that collect data regarding health-related risk behaviors, chronic health conditions, use of preventive services and other issues. Nebraska currently participates in the BRFSS system by way of UNL's Bureau of Sociological Research, which has been conducting surveys annually since 1986. The system is based on a research design developed by the CDC and used in all fifty states. Questions are standardized to ensure comparability of data across states and over time.

BRFFS is comprised of a set of modules that are included for limited periods of time among the modules utilized by survey-takers at any given point in the ongoing survey. A module has to be funded in order to be included in the BRFSS survey. There are two existing modules related to dementia, one focused on cognitive decline and another on caregiving. These modules have been in Nebraska's annual BRFSS survey in the past—both in 2015, the cognitive decline module in 2019, and the caregiving module in 2021—when funded by a combination of CDC grant funding and private donor funding. The state should make necessary investments in the future to ensure that the cognitive decline and caregiving modules are permanently part of the annual survey.

Focused research is at the forefront of the University of Nebraska Medical Center (UNMC), As recently as July 2024, UNMC completed a research study where two UNMC neurologists help advance science on AI diagnosis of dementia. Daniel Murman, MD, and Olga Taraschenko, MD, PhD, of the UNMC Department of Neurological Sciences, were co-authors of the journal article "AI-based differential diagnosis of dementia etiologies on multimodal data."

The research, which was published in the journal Nature Medicine in July, developed a diagnostic computer model drawn from medical records from 51,269 participants in anonymous datasets that included exam findings, test results and magnetic resonance imaging scans. Those records were collected from nine medical databases covering both common and rare dementias, including Alzheimer's dementia and Lewy body dementia.

The goal of the project was to develop a diagnostic tool that could assist practitioners who are rarely exposed to dementia to triage the patient referrals to subspecialty clinics.

All Nebraskans—people living with dementia and their caregivers—should have access to timely screenings for dementia. A diagnosis of dementia should reflect a standard of practice that is evidence-based and draws on insights from family members and the primary care provider. Educating patients and carers of what disease progression looks like is critical.

One important reason for improving diagnosis, particularly in the preliminary stages of the disease, is because there are now treatments that can slow the progress of some types of dementia. In January 2023, the Food and Drug Administration gave full approval to Lecanemab (brand name "Leqembi"), a new drug that slows the progress of Alzheimer's. In July 2024, the FDA approved a second drug, Donanemab (brand name "Kisunla"). Both of these drugs are monoclonal antibodies that attack the proteins that cause Alzheimer's. They are only effective in slowing early-stage Alzheimer's and not for late-stage Alzheimer's or other forms of dementia.

Nebraska Medicine began offering infusion services for administering Lecanemab in February 2024 and currently has fifteen patients receiving treatment, which consists of infusions every two weeks. Donenemab is given as a monthly infusion. Both treatments require regular brain scans to detect brain bleeds. CHI Health does not currently offer treatments of either drug. A focus needs to be on making all area physicians, health professionals and hospitals equipped to be able to offer the treatments.

Recommendations:

- Establish partnerships with public health departments and the AAAs to develop awareness and education campaigns focused on brain health for individuals of all ages, with a specific focus on individuals in Nebraska's underserved communities.
- Create brain health curriculum that can be distributed to public school districts and taught to K-12 students.
- Ensure local health departments utilize the existing HBI Road Map tools.
- Explore establishing a state-wide tracking system for dementia overseen by DHHS or a contracted entity such as UNL's Bureau of Sociological Research.
- Consider reintroducing the dementia registry legislation introduced in 106th Congress, Second Session 2020 9 (LB 1138).

- Seek permanent funding for the inclusion of Cognitive Decline and Caregiving Modules in the annual BRFSS survey.
- Seek to increase research and federal funding to improve the lives of Nebraskans living with dementia.
- Investigate and seek to improve how Nebraska policy makers and state medical director evaluate and adopt policies to assist individuals diagnosed with Alzheimer's disease or other dementia and their families.

Part VI: Build the Dementia Care Workforce

Dementia is not treated with medications and procedures alone. Instead, it requires a continuum of care and services that are personalized. The agonizing, often months-long trajectory from the first appearance of symptoms to the correct diagnosis is partly the result of the lack of capacity in our health care system, such as the lack of specialists able to administer cognitive evaluations and the lack of geriatricians, neurologists, home health care workers, nurse practitioners and other providers. It can be difficult for any professional along the continuum of care to receive the best practices training in dementia care. This is a particular problem in less-populated, rural parts of the state, where the average age of a small community may be in the 50s or 60s, increasing the need for geriatric care and the likelihood of dementia in the community.

This is often simply a matter of access. Across the state and indeed the nation, there is a shortage of geriatricians. According to the Alzheimer's Association, there are currently 23 board-certified geriatricians in Nebraska. Even if we assumed that only 10% of people over the age of 65 develop dementia, the projected number of geriatricians needed by 2050 is 84, the actual number needed is higher because this number does not consider that a portion of every geriatrician's caseload is patients who do not have dementia.

In addressing the lack of certified health care professionals, there should be incentives to encourage more physicians, nurse practitioners, neurologists, physician assistants to choose geriatrics as a specialty. This will require action at the federal level, because it is CMS that sets provider reimbursement rates for Medicare. The rates need to be higher, and the set of billing codes related to senior care needs to be expanded to allow physicians to bill for more specific and often time-consuming services related to dementia diagnosis and care.

One of the issues of greatest concern in facing the growing impact of dementia is the lack of trained dementia care professionals that will be necessary to provide care for a much larger dementia population. This is an issue that must be faced at the beginning of the career pipeline, in the K-through-12 years when young people are beginning to think about what career path they might want to take in life.

Our educational institutions and partners need to develop initiatives such as career fairs, mentorship programs, and educational outreach that can effectively introduce students to the fulfilling opportunities in this field. By collaborating with schools, Nebraska can inspire the next generation of healthcare professionals to enter dementia care, ensuring a steady pipeline of skilled workers to meet future needs.

It is necessary to have a robust outreach program to connect with the younger generation. This can include people with dementia being pen pals with elementary school students. People with dementia can volunteer at elementary schools. Students can have days of service with schools or organizations. The Nebraska Hospital Association and Nebraska Health Care Association have collaborated to form an afterschool program for students in third grade or older that follows a curriculum provided by the Nebraska Health Careers Pipeline Initiative, which is aimed to grow Nebraska's healthcare workforce by teaching youth about the many healthcare settings. This program is possible because of financial support from Nebraska Health Care Foundation and Medica.

Facilities and other dementia care employers should participate in job fairs at local colleges and high schools and collect information about interested students. This information is then available for HR specialists to contact regarding the student's level of interest in applying for a position.

Nebraska Department of Education is a stakeholder in this process as well. There are current programs that with increased promotion could assist in growing the workforce in long-term care. Nebraska Vocation Rehab supports a solid program called Career Pathway Advancement Project (CPAP). The project builds off a previous Nebraska Career Pathways Advancement Project grant which promoted upskilling/backfilling and advancing incumbent workers with disabilities which is active until June of 2026. A proven Upskill/Backfill business model will be used to create opportunities for former VR eligible individuals to advance in their careers and provide new opportunities for other VR eligible individuals to backfill the vacant positions. Allowing new VR eligible individuals to enter a career pathway of their interest with opportunities for advancement.

Recommendations:

- Consider funding one time internship and apprenticeship programs that offer students hands-on experience in dementia care settings.
- Leverage current programs with Nebraska Hospital Association and Nebraska Health Care Association to provide education and experiences to students starting as young as third grade.
- Ensure that the Health Sciences Career Cluster of the Nebraska State Board of Education and other curricula have current content devoted to dementia.
- Work with the Nebraska Association of Teachers of Science to develop dementia-specific conference sessions for teachers.
- Work with Nebraska Vocational Rehab to increase the workforce in long term care facilities by using current and future national grant programs, such as CPAP.

Conclusion

In conclusion, the Alzheimer's Disease and other Dementia Advisory Council found that there are many forms of support for Nebraskan's living with the disease. It was also found that there are some successful programs currently helping caregivers in Nebraska. A successful program offered through the AAA's, Care Giver Support Program, is successful finding and paying for respite services for care givers with a loved one living with dementia. But it was also found that this successful program uses every dollar allowed each year. Throughout this plan there are findings that the first Nebraska State Plan for Alzheimer's Disease and Other Dementia that was presented to the legislature and governor in June 2016 by the Aging Nebraskans Task Force is having a positive effect. The 2016 plan is showing a good start but is not enough to successfully navigate the Alzheimer's and Other Dementia crisis we have in Nebraska in 2025. The implementation of the council's recommendation will be vital to successfully care for and support Nebraskan's that are affected in any way from a dementia diagnosis. The statistic shows this is not an issue that can be ignored. Many of the concerns are compounded by the reduced workforce and funding to provide quality services and outcomes.

When completing the state plan with findings and recommendations the council members found it difficult to prioritize which recommendations should happen first as all recommendations need to be considered and action must be taken. Additional resources, research and collaborations need to be explored, and we cannot forget our rural areas due the limited access to resources. Resources need to able to be offered in more than one language to assist those who English is not their first language.

The Alzheimer's Disease and Other Dementia Support Act requires the advisory council to submit an annual report on the status of implementing the recommendations contained in this plan. In addition, the plan as a whole will be revised every four years, meaning that the next iteration of the plan will be submitted to the legislature and governor at the end of 2025. The advisory council has done its best to break down the twenty-four topics listed in the statute into a series of projects, each with preliminary suggestions for an action plan to be carried out by stakeholders in that particular area. In the midst of all these projects, however, it is important to remember that our best chance of succeeding in implementing the new Nebraska's State Alzheimer's Plan comes when all stakeholders work together.

Addendum

Recommendations

Following is a chart of the recommendations, color-coded to the section of the Plan where they are found. Also noted are the other sections where the recommendation would cross over.

	State Plan Section					
Recommendations	**Increase Support for Caregivers**	**Provide Care Navigation Through Area Agencies on Aging**	**Increase Availability and Quality of Facility-Based Care**	**Increase Access for Rural and Underserved Communities**	**Increase Public Awareness and Education**	**Build the Dementia Care Workforce**
Explore feasibility of implementing Trualta or other on-line caregiver support platform and make access free for all Nebraska residents. The fiscal cost for this recommendation is $132,000 to $180,000 annually.	**X**			**X**	**X**	
Seek one time grant funding for long-term care and assisted living communities to establish adult day care programs. In rural areas consider including senior centers.	**X**		**X**	**X**		
Develop a respite admission program for long-term care communities to enable quick admissions for emergent respite stays.	**X**		**X**	**X**	**X**	
Create a two-year dementia care navigator pilot project within the Eastern Nebraska Office on Aging that serves both urban and rural caregivers/care partners. The projected fiscal expenditure for this recommendation is $100,000 per year.	**X**	**X**		**X**		
Engage with local hospitals, nonprofits, and support groups to create a comprehensive directory of services available for individuals with dementia.	**X**	**X**		**X**	**X**	
Educate the aging network on available programs and benefits such as the Caregiver Tax Credit. Have speakers such as AARP present to the AAAs & ADRCs	**X**	**X**			**X**	

	State Plan Section					
Recommendations	**Increase Support for Caregivers**	**Provide Care Navigation Through Area Agencies on Aging**	**Increase Availability and Quality of Facility-Based Care**	**Increase Access for Rural and Underserved Communities**	**Increase Public Awareness and Education**	**Build the Dementia Care Workforce**
The state should strongly consider increasing the reimbursement rate for memory care, which would increase availability for ADRD individuals as identified in the "Rate Study for AD Waiver, TBI Waiver and PAS Services (updated September 2023).			**X**			
Analyze previous efforts to develop centralized system for locating available beds in facilities across the state to simplify referral system.			**X**			
Investigate how Medicaid waiver home and community-based services can include all areas of need. This could include adult day service level of engagement within the home.	**X**		**X**	**X**		
Analyze previous efforts to have long term care facilities and hospitals develop centralized system for locating available beds in facilities across the state to simplify referral system.			**X**	**X**		
Explore incentives to increase the workforce in home care and home health workers in rural areas.				**X**		**X**
Implement targeted outreach by churches, doctor's offices, etc. to raise awareness about dementia within rural and ethnic communities.				**X**	**X**	**X**
Create one-time grant opportunities for healthcare staff members to learn a new language or pursue cultural studies focused on the populations they serve.			**X**	**X**	**X**	**X**

	State Plan Section					
Recommendations	**Increase Support for Caregivers**	**Provide Care Navigation Through Area Agencies on Aging**	**Increase Availability and Quality of Facility-Based Care**	**Increase Access for Rural and Underserved Communities**	**Increase Public Awareness and Education**	**Build the Dementia Care Workforce**
Develop program for building partnerships between individual facilities and the communities where they are located.	**X**			**X**		
Establish partnerships with public health departments and the AAAs to develop awareness and education campaigns focused on brain health for individuals of all ages, with a specific focus on individuals in Nebraska's underserved communities.		**X**		**X**	**X**	
Create brain health curriculum that can be distributed to public school districts and taught to K-12 students.					**X**	**X**
Explore establishing a state-wide voluntary tracking system for dementia overseen by DHHS or a contracted entity such as UNL's Bureau of Sociological Research.	**X**			**X**	**X**	
Seek to increase research and federal funding to improve the lives of Nebraskans living with dementia.	**X**			**X**	**X**	
Consider reintroducing the dementia registry legislation introduced in 106th Congress, Second Session 2020 9 (LB 1138).	**X**			**X**	**X**	
Investigate and seek to improve how Nebraska policy makers and state medical director evaluate and adopt policies to assist individuals diagnosed with Alzheimer's disease or other dementia and their families.	**X**			**X**	**X**	
Work with Nebraska Vocational Rehab to increase the workforce in long term care facilities by using current and future national grant programs.						**X**

	State Plan Section					
Recommendations	**Increase Support for Caregivers**	**Provide Care Navigation Through Area Agencies on Aging**	**Increase Availability and Quality of Facility-Based Care**	**Increase Access for Rural and Underserved Communities**	**Increase Public Awareness and Education**	**Build the Dementia Care Workforce**
Fund internship and apprenticeship programs that offer students hands-on experience in dementia care settings.					**X**	**X**
Work with the Nebraska Association of Teachers of Science to develop dementia-specific conference sessions for teachers.					**X**	**X**
Leverage current programs with Nebraska Hospital Association and Nebraska Health Care Association to provide education and experiences to students starting as young as third grade.			**X**			**X**
Work with Nebraska Vocational Rehab to increase the workforce in long term care facilities by using current and future national grant programs, such as CPAP.					**X**	**X**

Appendix 1

Alzheimer's Disease and Other Dementia Advisory Council Members

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The Council thanks the many members of the subcommittees and other stakeholders who provided their time and expertise to this State Alzheimer's Plan.

Appendix 2

Understanding Dementia

Dementia is general term to describe a group of symptoms related to loss of memory, judgment, language, complex motor skills, and other intellectual function, caused by the permanent damage or death of the brain's nerve cells, or neurons. However, dementia is not a specific disease. There are many types and causes of dementia with varying symptomology and rates of progression (CMS, 2025)

Alzheimer's Disease is a progressive, degenerative form of dementia that causes severe intellectual deterioration. The first symptoms are impaired memory, followed by impaired thought and speech, and an inability to care for oneself. Onset can be associated with or preceded by depression. Alzheimer's disease is the most common type of dementia.

As the person ages, those affected by Down syndrome have a greatly increased risk of developing a type of dementia that's either the same as or very similar to dementia. In ways that scientists don't yet understand, the extra copies of genes present in Down syndrome cause developmental problems and health issues even though all three copies of the genes usually carry "normal" protein codes. Down syndrome nearly always affects learning, language and memory, but its impact varies from person to person (Rafii & Fortea, 2023).

Dementia with Lewy Bodies (DLB) is a type of progressive dementia that leads to a decline in thinking, reasoning, and independent function. Its features may include spontaneous changes in attention and alertness, recurrent visual hallucinations, REM sleep behavior disorder, and spontaneous features of parkinsonism. Many people with DLB experience symptoms such as rigidity, gait changes (shuffling walk), reduced arm swing, masklike appearance of face, and tendency to falls.

Frontotemporal dementia (FTD) or frontotemporal degeneration refers to a group of disorders caused by progressive nerve cell loss in the brain's frontal lobes. The nerve cell damage caused by frontotemporal dementia leads to loss of function in these brain regions, which variably cause deterioration in behavior, personality, and/or difficulty with producing or comprehending language.

Mixed dementia refers to the presence of more than one type of dementia in an individual. There are several common combinations of mixed dementia such as Lewy Body, Alzheimer's or Fronto-temporal degeneration and Alzheimer's. Causes may vary depending on lifestyle practices, environmental experiences, and genetics. Each type involves changes in cognition in behavior.

Parkinson's disease dementia is a neurological disorder that affects functional movement. It is caused by genetics, aging, loss of dopamine, and environmental factors. It is a progressive disease that worsens over time, and includes motor, and non-motor symptoms including tremors, difficulty walking, cognitive decline, and changes in speech.

Diagnoses can be difficult and often are identified by medical history and clinical symptoms. Treatment can be provided through medications and physical therapy, although there is no cure at this time.

Vascular dementia (VaD), a consequence of reduced blook flow to the brain, results in impaired thinking and reasoning. Unlike Alzheimer's disease, processing speed and problem

solving is more affected than memory. Long-term effects of VaD can also lead to strokes which will also further impact thinking. Finding ways to control such health conditions as diabetes, hypertension, and elevated cholesterol levels is key. Also eliminating smoking can also lower the risk of VaD. It is possible that a person with VaD may also be diagnosed with Alzheimer's disease (Mayo Clinic, 2021).

Korsakoff syndrome (also referred to as Wernicke-Korsakoff Syndrome) is generally the result of chronic alcohol abuse. It results in confusion, various physical symptoms, along with vision issues. It is a chronic memory disorder that is the result of severe deficiency of thiamine (vitamin B-1). In addition to alcohol abuse, Korsakoff syndrome may also be the result of other conditions and resulting symptoms. (NIH – NIAA, 2022)

Appendix 3

Terms

Activities of Daily Living

Activities of Daily Living (ADLs) refer to the basic tasks that are essential for self-care and everyday functioning. These activities are often used to assess an individual's ability to live independently. These tasks often include bathing, dressing, eating, and additional tasks required to maintain safety and personal hygiene.

Custodial Care

Custodial care refers to non-medical assistance provided to individuals who need help with activities of daily living (ADLs) due to age, disability, or chronic illness. This type of care focuses on support rather than medical treatment and is often provided in various settings, such as home care, assisted living facilities, or nursing homes.

Key Aspects of Custodial Care

1. Personal Assistance: Helps individuals with basic self-care tasks, including bathing, dressing, grooming, toileting, and eating.
2. Mobility Support: Assists with moving around, transferring from one position to another, and preventing falls.
3. Companionship: Offers social interaction and emotional support to reduce feelings of isolation or loneliness.
4. Household Management: May include light housekeeping, meal preparation, laundry, and medication reminders.
5. Supervision: Monitors individuals to ensure their safety and well-being, especially for those with cognitive impairments.

Instrumental Activities of daily living (IADLs) such as personal care, companionship, meals, laundry household assistance, and activities of daily living (ADLs), such as dressing, personal hygiene, bathing, showering, toileting and transferring.

Appendix 4

Resources

Dementia Types

Alzheimer's Association. What is Dementia? https://www.alz.org/alzheimers-dementia/what-is-dementia

Alzheimer's and Related Dementias Resources for Professionals | National Institute on Aging (nih.gov)

CDC. Alzheimer's Disease and Dementia. https://www.cdc.gov/alzheimers-dementia/

https://www.cms.gov/files/document/qso-25-12-nh.pdf

Data shows racial disparities in Alzheimer's disease diagnosis between Black and white research study participants | National Institute on Aging (nih.gov)

How Is Alzheimer's Disease Diagnosed? | National Institute on Aging (nih.gov)

Vascular Dementia https://www.mayoclinic.org/diseases-conditions/vascular-dementia/symptoms-causes/syc-20378793

Wernicke-Korsakoff Syndrome https://www.niaaa.nih.gov/publications/brochures-and-fact-sheets/wernicke-korsakoff-syndrome

Elder Justice Issues

Elder Abuse Prevention | ACL Administration for Community Living

NCEA: Red Flags of Abuse (pacourts.us)

NCLER | Home (acl.gov)

Office of Public Guardian https://supremecourt.nebraska.gov/programs-services/office-public-guardian

Office of Long-Term Care Ombudsman https://dhhs.ne.gov/Pages/Aging-Ombudsman.aspx

Fall Prevention and Safety Issues

Alzheimer's Caregiving: Home Safety Tips | National Institute on Aging (nih.gov)

Falls and Fractures in Older Adults: Causes and Prevention | National Institute on Aging (nih.gov)

Protecting Older Consumers, 2022-2023 (ftc.gov)

Safe Driving for Older Adults | National Institute on Aging (nih.gov)

Life at Home – Managing the Care Partnering Relationship

ALZNavigator | Alzheimer's Association – planning now and for the future.

Alzheimer's caregiving | National Institute on Aging (nih.gov)

Best Programs for Caregiving (caregiver.org)

CaregiverTipSheet_IDEA-strategy.pdf (alzheimersla.org)

Dementia, Caregiving, and Controlling Frustration - Family Caregiver Alliance

Eldercare Resources (acl.gov)

Home | The DICE Approach

Manage Your Chronic Condition | CMS

Pathways to Well-Being with Dementia: Manual of Help, Hope and Inspiration | Dementia Action Alliance (daanow.org)

Support Groups | Alzheimer's Association https://www.alz.org/help-support/community/support-groups

Tips for Caregivers and Families of People with Dementia (alzheimers.gov)

Nursing/Long-term Care Facilities and Services

Rosters of Facilities and Services (ne.gov)

LeadingAge https://www.leadingagene.org/

Nebraska Health Care Association https://nehca.org/

Office of Long-Term Care Ombudsman Office of Long-Term Care Ombudsman https://dhhs.ne.gov/Pages/Aging-Ombudsman.aspx

Revised Long-Term Care (LTC) Surveyor Guidance: Significant revisions to enhance quality and oversight of the LTC survey process, QSO-25-07-NH, Released 11.18.2024 https://www.cms.gov/files/document/revised-long-term-care-ltc-surveyor-guidance-significant-revisions-enhance-quality-and-oversight-ltc.pdf

https://www.cms.gov/priorities/innovation/innovation-models/guide

Preparing for a Medical Visit

Complete Care Plan form (cdc.gov) https://www.cdc.gov/caregiving/media/pdfs/Complete-Care-Plan-Form-5081.pdf

Geriatrics and Senior Care | Omaha, NE | Nebraska Medicine

PDF_Output.pdf (alz.org) – questions that may come up during a visit

The Doctor Thinks it's FTD. Now What? | AFTD (theaftd.org)

What Do I Need to Tell the Doctor? | National Institute on Aging (nih.gov)

Payment Sources for Medical Visits

Medicare Coverage and Payment of Cognitive Assessment & Care Plan Services (youtube.com)

MLN6775421 – Medicare Wellness Visits (cms.gov)

Resolving Family Issues/Conflict

Consensus Management Model for Families Caring for a Loved One with Dementia (joe.org)

Resolving Family Conflicts | Alzheimer's Association

Working with Your Family | Memory and Aging Center (ucsf.edu)

Signs and Symptoms – for Family Care Partners

About the ADEAR Center | National Institute on Aging (nih.gov), https://www.nia.nih.gov/health/alzheimers-and-dementia/about-adear-center

Dementia Friends Rooms Experience | International Association for Indigenous Aging (iasquared.org), https://iasquared.org/dementia-friends/rooms/

Home | NADRC (acl.gov) – National Alzheimer's Dementia and Resource Center

What Are the Signs of Alzheimer's Disease? | National Institute on Aging (nih.gov)

Worried-About-Memory-Healthy-Brain-Fact-SheetFINAL.pdf (virginia.gov)

Signs and Symptoms – for Health Care Professionals

About the ADEAR Center | National Institute on Aging (nih.gov)

Alzheimer's and Related Dementias Resources for Professionals | National Institute on Aging (nih.gov)

Assessing Cognitive Impairment in Older Patients | National Institute on Aging (nih.gov)

Cognitive Assessment & Care Plan Services | CMS, https://www.cms.gov/medicare/payment/fee-schedules/physician/cognitive-assessment

Frontotemporal dementia - Symptoms and causes - Mayo Clinic

How Is Alzheimer's Disease Diagnosed? | National Institute on Aging (nih.gov)

Training Resources and Educational Resources

24/7 helpline: 24/7 Helpline: 1.800.272.3900 | Alzheimer's Association https://www.alz.org/help-support/resources/helpline

Alzheimer's Association https://www.alz.org/help-support/brain_health/10-healthy-habits-for-your-brain

Alzheimer's Association (2021). Dementia-related Behaviors https://www.alz.org/help-support/caregiving/stages-behaviors

Alzheimer's Foundation of America. https://www.alzfdn.org/AboutDementia/definition.html

Appendix 5

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ALZNavigator | Alzheimer's Association https://www.alz.org/help-support/resources/alznavigator

Assessing Cognitive Impairment in Older Patients | National Institute on Aging https://www.nia.nih.gov/health/health-care-professionals-information/assessing-cognitive-impairment-older-patients

Awareness Cards | AFTD https://www.theaftd.org/living-with-ftd/resources/awareness-cards

Best Programs for Caregiving, https://www.caregiver.org/

BOLD Public Health Center of Excellence https://bolddementiadetection.org/wp-content/uploads/2024/02/BOLD_Toolkit_HSP_2024.pdf

Home - Powerful Tools for Caregivers

Caregiver Tip Sheets https://www.alzheimersla.org/wp-content/uploads/2018/06/CaregiverTipSheet_IDEA-strategy.pdf

Caregiver Training Videos - Dementia Care | UCLA Health https://www.uclahealth.org/medical-services/geriatrics/dementia/caregiver-education/caregiver-training-videos

Cognitive Impairment Care Planning Toolkit https://www.alz.org/careplanning/downloads/care-planning-toolkit.pdf

Cognitive Assessment & Care Plan Services https://www.cms.gov/medicare/payment/fee-schedules/physician/cognitive-assessment

Complete Care Plan form https://www.cdc.gov/caregiving/media/pdfs/Complete-Care-Plan-Form-5081.pdf

Consensus Management Model for Families Caring for a Loved One with Dementia https://archives.joe.org/joe/1999december/a6.php

Dementia, Caregiving, and Controlling Frustration - Family Caregiver Alliance https://www.caregiver.org/resource/dementia-caregiving-and-controlling-frustration/

Dementia and Related Dementias Resources for Professionals | National Institute on Aging https://www.nia.nih.gov/health/health-care-professionals-information/alzheimers-and-related-dementias-resources

Dementia Caregiving | National Institute on Aging https://www.nia.nih.gov/health/alzheimers-and-dementia

Dementia Friends Rooms Experience | International Association for Indigenous Aging, https://iasquared.org/dementia-friends/rooms/

Dementia Unplugged™ Dementia Foundations™ - YouTube, https://www.dementiasociety.org/dementia-unplugged

Dementia & Dementia Training & Education Center

Details | NADRC, https://acl.gov/

Eldercare Resources https://acl.gov/news-and-events/announcements/acl-launches-redesigned-eldercare-locator-website-0

Free Dementia Training Materials • The DAWN Method, https://thedawnmethod.com/

Frontotemporal dementia - Symptoms and causes - Mayo Clinic https://www.mayoclinic.org/diseases-conditions/frontotemporal-dementia/symptoms-causes/syc-20354737

Geriatrics and Senior Care | Omaha, NE | Nebraska Medicine https://www.nebraskamed.com/geriatrics

Guiding an Improved Dementia Experience (GUIDE) Model, https://www.cms.gov/priorities/innovation/innovation-models/guide

Home | The DICE Approach, https://diceapproach.com/

How Is Dementia Disease Diagnosed? | National Institute on Aging https://www.nia.nih.gov/health/alzheimers-and-dementia/what-dementia-symptoms-types-and-diagnosis#diagnosis

National Center on Elder Abuse. [On-Line]. https://ncea.acl.gov

Nebraska Association of Teachers of Science, https://www.nebscinats.org/

Nebraska State Board of Education, https://www.education.ne.gov/stateboard/

Pathways to Well-Being with Dementia: Manual of Help, Hope and Inspiration | Dementia Action Alliance, https://daanow.org/pathways/

Resolving Family Conflicts | Alzheimer's Association https://www.alz.org/help-support/resources/resolving-family-conflicts

Resources For Integrated Care - Resources for Plans & Providers for Medicare-Medicaid Integration, https://www.resourcesforintegratedcare.com/

Support Groups | Alzheimer's Association https://www.alz.org/help-support/community/support-groups

The Doctor Thinks it's FTD. Now What? | AFTD https://www.theaftd.org/product/the-doctor-thinks-its-ftd-now-what-a-guide-for-managing-a-new-diagnosis/

Tips for Caregivers and Families of People With Dementia https://www.alz.org/help-support/caregiving/stages-behaviors

Train Health Care Workers About Dementia | Bureau of Health Workforce https://bhw.hrsa.gov/alzheimers-dementia-training#NursingHomeTrainingModules

University of Southern California. Training Resources on Elder Abuse. http://trea.usc.edu/

What Are Frontotemporal Disorders? Causes, Symptoms, and Treatment | National Institute on Aging https://www.nia.nih.gov/health/frontotemporal-disorders/what-are-frontotemporal-disorders-causes-symptoms-and-treatment

Age-Related Forgetfulness or Signs of Dementia? | National Institute on Aging https://www.nia.nih.gov/health/memory-loss-and-forgetfulness/age-related-forgetfulness-or-signs-dementia

What Do I Need to Tell the Doctor? | National Institute on Aging (nih.gov) https://www.nia.nih.gov/health/medical-care-and-appointments/what-do-i-need-tell-doctor

Worried About Your Thinking or Memory https://www.vdh.virginia.gov/content/uploads/sites/156/2023/11/Worried-About-Memory-Healthy-Brain-Fact-SheetFINAL.pdf

Working with Your Family | Memory and Aging Center https://www.ucsfhealth.org/clinics/memory-and-aging-center

Safety Tools

https://www.nia.nih.gov/health/safety/home-safety-checklist-alzheimers-disease

https://www.alz.org/help-support/caregiving/safety/dementia-driving

Research

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National Institute on Aging: https://www.nia.nih.gov/health/falls-and-falls-prevention/fallsand-fractures-older-adults-causes-and-prevention

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National Center on Elder Abuse: https://www.pacourts.us/Storage/media/pdfs/20210516/225550-ncea_redflagsea.pdf

National Institute on Aging: https://www.nia.nih.gov/health/falls-and-falls-prevention/falls and-fractures-older-adults-causes-and-prevention

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