

Nevada Alzheimer's Plan Task Force
Access to Services – Item #2
Overview

Detection

- | | |
|-----------------------|---|
| • Doctor | Neurologist |
| • Nurse practitioners | Health care providers |
| • Family | At home possible tests |
| • Spinal tap | PET scan |
| • Diary | Notes from caregiver |
| • Mobile unit?? | More information on detection/resources |

Diagnosis

- See above and below

Treatment

- | | |
|---------------------|------------------------|
| • Medication | Nutrition |
| • Activities | Brain health |
| • Brain stimulation | Research possibilities |

Transportation

- | | |
|------------|-------------------------------------|
| • Outreach | Taxis |
| • Buses | Friends – what are some liabilities |

Needs of younger versus older onset Alzheimer's

- | | |
|------------------------------|----------------------|
| • Understanding | Childcare |
| • Empathy from bosses | Are there other jobs |
| • Day care attendant/helper? | |

Access to services for people living in rural areas

- | | |
|----------------------------|--------------------------|
| • Outreach bus | Trainings |
| • Teleconferences | Trials |
| • Speakers | Reaching through |
| • Community centers | Senior centers |
| • Primary care physicians | Newspapers |
| • Eye care | Brochures/flyers |
| • Hearing and hearing aids | Dental care and dentures |

Socialization and support systems

- | | |
|--|----------------|
| • Adult day care | Weekly respite |
| • Support Groups – how do we increase attendance | |

Marketing of community resources

- | | |
|---------------|---|
| • Newspaper | Advertisements – television; radio/flyers |
| • Radio spots | Interviews |

Gaps in service

- See Access above

Cultural issues and considerations

- | | |
|-----------------------|---|
| • Diverse populations | Multi-lingual hand-outs, advertisements |
| • Interviews | |

Detection

Currently there is no cure for Alzheimer's disease. While there are medications that address behavioral issues and perhaps slow the progress of the disease, victims of Alzheimer's spiral downward until death from the disease or from secondary conditions such as pneumonia.

It is critical that research continues to assure early detection so that medical professionals are able to stop Alzheimer's disease before it starts. To do this will require clinical trials, early detection so that medical professionals recognize potential manifestations of the disease before they can advance, health care providers and a public that is aware of ways to stop/prevent/control Alzheimer's disease today so that it may be eradicated in the future. It is essential that medical professionals and individuals who work with Alzheimer's disease victims and their caregivers and families have the best training in dealing with the many behaviors exhibited by those who have the disease.

An example of a need for training about Alzheimer's disease is law enforcement. Many times law enforcement officers are called when someone with Alzheimer's disease has become violent or committed some act that falls under a criminal act. There are many issues with this, as the person with Alzheimer's disease doesn't remember what they have done and/or have the "knowingly" element of the crime. There is difficulty with taking this person into custody for a criminal act. Most jails don't have a place to house and care for them adequately, and often they can become victims within the jail system due to their disease.

Often due to lack of training/knowledge, victims with Alzheimer's disease are held on a "Legal 2000" mental health hold, which really doesn't apply to them to have them transported to Las Vegas or Reno for emergency stabilization and then released on their own. If the person is found wandering/confused, s/he may be taken to a local hospital under the Legal 2000 because there isn't another option for law enforcement.

Goal #1: To advance early detection of Alzheimer's disease so that researchers, health care professionals, public servants, and victims and families recognize warning signs, that they know the medications that produce positive results, and that they are informed of best practices and treatments when working with individuals with Alzheimer's disease.

Objective #1: To study current and develop new medications that treat Alzheimer's disease and then to disseminate knowledge of treatments available to patients including:

- Approved drug regimens
- Trial drugs available to Nevada residents
- Side effects of the disease versus the medication
- Trained medical staff who recognize signs and symptoms of Alzheimer's disease so that they can best advise patients for treatment or further diagnosis

- Outreach training to other professionals such as law enforcement
- Victims and families who are informed about the many facets of the disease including signs, symptoms, treatments, and best health practices

Strategy: The Alzheimer's Association and the Department of Health along with researchers from hospitals, universities and colleges, and other health care centers will continue study and investigate new, advanced treatments for Alzheimer's disease and other dementias.

The Alzheimer's Association and the Department of Health will create training curricula with pertinent information pertaining to the diagnosis and care of victims of Alzheimer's disease. Requirements for this training will be extended to/but not limited to:

- Physicians
- Neurologists
- Gerontologists
- Nurses, CNAs, and others who perform duties with victims of Alzheimer's disease and other dementias
- Dentists, eye care and hearing professionals
- Secondary medical personal who are critical to rehabilitation: physical therapists, occupational therapists, respiratory therapists
- Home health consultants
- Workers in assisted and long-term care facilities
- Law enforcement including city and county police, highway patrol, and DMV employees
- Victims, caregivers, and family members

Indicator: Research findings will be explained and delineated on the Nevada Alzheimer's Disease link on the Nevada website (see Detection Objective #2 and Accessibility Objective #6). Trainings for medical personnel will take place throughout the state for those in private practice, hospitals, care facilities, law enforcements, victims and families, and all Alzheimer's disease advocates. Feedback will provide information through surveys and questionnaires for formulating future presentations. Trainings may be live or via tele-conference (both satellite and telephone) and will be mandatory.

Funding: Department of Health and Legislative allocations for health care services and training.

Detection cont.

There is much confusion about Alzheimer's disease, how individuals "get the disease", and the negative perceptions of an uninformed public. It is critical that everyone becomes educated about the disease, its detection, diagnosis and

treatment, resources available for support and information, and details of the stages and progression of the disease.

Goal #2: To extend knowledge and updated information of Alzheimer's disease and other dementias so that the public, law enforcement, and medical professionals know and understand the many facets of this neurological disease.

Objective #2: To educate the public and public servants about Alzheimer's disease, its signs and symptoms, research and trial possibilities, and support group and help services available.

Strategy: Nevada will introduce news specials and advertisements for television, radio, newspapers, and magazines to better inform the public about Alzheimer's disease and other dementias to inform and enlighten while working to remove the stigma associated with the disease. These messages will be formulated by local Alzheimer's Association personnel and trained Alzheimer's care physicians and other medical staff to assure accuracy and the most update information. Segments will be small enough to clarify information and large enough to inspire action and understanding.

Nevada will also create, maintain, and support a link Nevada Alzheimer's Disease that will have information and links to inform the public about the disease, detection, treatment, diagnosis possibilities, and services available.

Indicator: Broadcast designers have methods to note the number of viewers and can also offer ways for viewers to respond to the broadcast (such as going to a television website and completing a survey, questionnaire, or simply by offering a response). Call-ins to radio stations will offer similar feedback. Newspapers and magazine will provide ways for readers to respond to information via email, letters to the editor, or a survey or questionnaire.

Individual leaders at health care facilities will share information with employees and record questions and input for creating further broadcasts. Support group leaders and Alzheimer's Association personnel will conduct further surveys and questionnaires within the of their workplace contacts.

The Department of Health, local Alzheimer's Association groups, and the state of Nevada will develop and maintain a website link Nevada Alzheimer's Disease replete with information on Alzheimer's disease including but not limited to:

- Education
- Detection
- Diagnosis
- Treatment
- Services available
- Culturally sensitive information
- Younger versus older onset Alzheimer's disease

- Social and support groups
- Hotlines
- Research
- Trials
- Alzheimer's Bill of Rights
- Caregiver's Bill of Rights

Funding: NPR, television and radio stations as public services, newspapers and magazines as public services, paid advertisement through the Division of Aging and Department of Health.

The website link will be a state project, perhaps developed by a graduate student from one of our colleges or universities as a term project, and will be maintained by the state of Nevada, Department of Health, and/or Division of Aging. The Alzheimer's Association will check to ensure that all information is updated and factual.

Diagnosis and Treatment

Whether in a metropolitan area such as Las Vegas or Reno or in a rural community such as Denio, Nevadans require access to up-to-date information of detection, diagnosis, treatment, and a variety of health services. Many victims of Alzheimer's disease and their families are not aware of specialized diagnosis of the disease through neurological examination and the availability of diagnosis and treatment. This problem is compounded because of the distance to services or a lack of awareness of specialists to consult. Nevadans deserve quality diagnosis and treatment with the most current information regardless of where they reside in the state.

Goal #3: To reach and teach all Nevadans about the diagnosis and treatments available so that the best and the wisest decisions are made for care and management of those who are afflicted with Alzheimer's disease or other dementias and their families.

Objective #3: To offer access to diagnostic and treatment services throughout Nevada through the use of "mobile neurologists", hospital services that provide spinal taps and brain scans, and tele-medicine with experts in the field of neurological disorders throughout the state.

Strategy: Nevada will create a working partnership among entities that specialize in neurological diagnoses and treatments to develop methods to reach all Nevadans through mobile and tele-medicine services. Public awareness through advertising such as that mentioned under Objective #2 will inform individuals of what medical services and personnel are available for appropriate diagnosis and treatment, where these are located, probable costs, and assistance services.

Indicator: Surveys and questionnaires will have an assessment portion for feedback on how, when, and if diagnosis and treatment are reaching individuals in need, especially those who have distance as a factor.

The Partnership between medical professionals will publish feedback on services and offerings that will be available to the public through the Nevada Alzheimer's Disease website link, feedback to care facilities and medical professionals who work with individuals and families who have a member with Alzheimer's disease.

Tele-medicine physician will maintain records of their medical contacts and use of services and notify designated individuals of the numbers of individuals who have taken advantage of this distance option.

Funding: Medical billing for diagnosis and recommendations for treatment will fall under the required medical coding for these services. The Partnership is excellent public relations for the community and state so perhaps institutions can fund this through their own marketing campaigns. The state statistician(s) will compile feedback information to notify legislators, institutions, and the public on how the state of Nevada cares for its citizens.

Transportation

Nevada is a unique state when one considers distances between cities and towns. The three metropolitan areas of the state, Reno/Sparks/Carson City, Elko, and Las Vegas mark three corners of the state with vast stretches of open road and smaller towns in between. As hospitals throughout the state extend the use of tele-medicine, diagnosis and treatment will be delivered in a more timely and progressive way. This will enable patients and families, physicians, and other medical personnel to act and interact to receive the best medical care.

However, distance still makes face-to-face doctor-patient visits problematic without access to transportation services to metropolitan and other areas that offer special services. Vans, buses, and other means of transportation with trained drivers and staff are essential to the best care of each individual with Alzheimer's disease and his/her family and caregivers.

Goal #4: To provide inexpensive or state-funded safe transportation to all Nevadans so that they can receive the best, up-to-date diagnosis and treatment for Alzheimer's disease and other dementias and so that these individuals are able to travel to meetings, appointments, senior center or other activities, adult day care, and other venues that add to an active, stimulating lifestyle and prevent isolation and depression due to inability to leave home.

Objective #4: To advance the use of vans and outreach services driven by trained drivers so that individuals with Alzheimer's and other dementias receive the best

medical care and have the means to maintain active lifestyles with purpose and stimulation.

Strategy: Most cities and towns throughout the Nevada have vans that take individuals who cannot or should not drive to scheduled meetings and appointments. It is difficult at times to offer adequate services to individuals with Alzheimer's disease or other dementias. This may be because individuals do not meet age requirements, caregivers do not meet guidelines for riding in the vans, or drivers and other staff are not trained to deal with the difficulties and confusion that may arise when a victim of dementia is forced into an unfamiliar situation.

Nevada will act to remove age barriers for those in need of transportation, making the diagnosis the guideline for riding rather than age.

Training will be designed to explain appropriate action and interaction for drivers and service staff when transporting individuals with Alzheimer's disease and other dementias.

Senior centers, care facilities, and other medical facilities will receive training on transporting individuals with Alzheimer's disease and other dementias. This will also be offered to taxi cab drivers as well as public transportation drivers such as bus drivers, to ensure safety and security for the individual, other passengers, and the driver.

Each community will devise methods to offer transportation to those in need including vans and buses mention above as well as possible volunteer transportation services through venues like RSVP or other types of respite.

Indicators: Surveys will be administered through city councils, senior centers, and care facilities to determine transportation means already in existence. When gaps in service are discovered, each community will determine ways to expand transportation services within the community as well as to appointments in metropolitan areas especially when specific services such as spinal taps or neurologist consultations are not available locally.

Laws will be reviewed and adjusted to reflect service based on need and diagnosis rather than age, especially in cases of early/younger onset Alzheimer's disease.

Training for service drivers will be required as part of driver training through the facility or community or the Department of Motor Vehicles.

Each county will report to the Department of Health transportation services in existence as well as needed changes. Services available will be posted on the Nevada Alzheimer's Disease website to better meet the needs of individuals. This may also include the creation of a volunteer driving service that includes training and information on liabilities and driver expectations.

Funding: Counties/senior centers and health facilities will be responsible for providing transportation to those in need through grants and possibly by designating available tax revenues.

Training for drivers and service personnel will be provided via tele-conferences or satellite courses or live sessions when possible and will be a

requirement of all drivers. This training will be open to all drivers of public transportation. The Alzheimer's Association, the Department of Health, or the Department of Motor Vehicles will supervise training so that best practices are in place.

Early/Younger Versus Older Onset

While Alzheimer's disease and other dementias are often clumped as one, there are different signs and symptoms for each plus a variety of individual manifestations with different neurological diseases. Alzheimer's disease also includes categories including early/younger versus older onset of the disease.

Early/younger onset victims face numerous challenges in the work place, in medical treatment, and in the availability of the best medical services. Many are denied the care and medications they need based on age. Many services, even transportation and Medicare, are not obtainable until age 65. Thus when a victim of early/younger onset Alzheimer's becomes disabled in his/her 30s, 40s, and 50s, extra stress and expense are heaped onto families who are already suffering. Young children and adolescents often find it impossible to cope with a parent or guardian who is incapable of living and maintaining a lifestyle as breadwinner, head of household, or mother/father.

Goal #5: To distinguish the unique needs of early/younger versus older onset Alzheimer's disease so that appropriate services are provided to each entity. Diagnosis must become the determiner of care and benefits rather than age (most often 65).

Objective #5: To adjust age requirements for disability services to meet the needs of early/younger Alzheimer's victims so that the diagnosis determines medical provision rather than age and to teach medical professionals and the public of early/younger onset versus older onset Alzheimer's disease.

Strategy: The Nevada Task Force for Developing a Plan for Alzheimer's Disease recommends that the state action to change age requirements for medical services for early/younger onset Alzheimer's disease to diagnosis of the disease regardless of age.

After diagnosis Alzheimer's disease victims will be eligible for disability reimbursement, Medicare or Medicaid services, transportation services, in-home health care treatment, and special services such as Meals on Wheels and free social worker advisement and legal advisement such as that which is offered at senior centers, health care facilities, and hospitals throughout the state.

Education for health care workers in the special needs of early/younger onset victims will be provided through the Department of Health. Further educational material will be available on the Nevada Alzheimer's Disease website link.

Education and outreach will reveal information and offer guidance for those with the disease and their families, for workers and bosses, and for the general public so that victims of the disease are able to maintain a profitable and meaningful life.

Indicators: Public Law that changes the requirements for services from age requirements to diagnosis with a recommendation that records are maintained to show the cost and the benefits of this change.

Surveys and questionnaires after training will provide feedback on the values of training while offering ideas to extend public and professional outreach.

The Nevada Alzheimer's Disease website link will monitor visits to the site and materials that are view the most frequently. Frequent updates will ensure that the most up-to-date information and research are always available on all facets of the disease including early/younger versus older onset.

Funding: A change of law will set activation of diagnosis-based services into action. Additional costs to Medicare and Medicaid because of increased patient load must be factored into the state allocation for medical care.

Training will come from the Department of Health and the Alzheimer's Association live or via satellite or telephone.

Accessibility

Because Nevada is a large state with communities spread out over great distance, it is vital that information on accessible services be available in every part of our state. Alzheimer's disease and other dementias are often misunderstood, as people perceive these as contagious, a normal part of aging, an inevitable end to life, and other widespread and varied misconceptions.

Many individuals do not know about the services already available to assist with detection, diagnosis, treatment, and support. It is important that every Nevadan have access to accurate, up-to-date information that educates, guides, instructs, and explains.

Goal #6: To add a link to the State of Nevada website to educate the public about the Nevada Alzheimer's Disease Plan and much other pertinent material. This link will offer information and guidance to individuals and families and the public in general about Alzheimer's disease and other dementias. This site must be accurate and up-to-date with the latest in research, trial opportunities, medication, and support information. Access will also link to other sites that offer essential information such as the Alzheimer's Association, the Nevada Department of Health, colleges and universities throughout Nevada, research facilities, and a variety of brain-health and neuro-health centers.

The Nevada Alzheimer's Disease link will include facts on signs, symptoms, services available, hotline telephone numbers, support groups, programs, and other assistance programs to help victims, families, and health professionals learn more about the disease and possible interventions and aid.

Objective #6: To develop and maintain a Nevada Alzheimer's Disease website link to educate and disseminate knowledge and information to all Nevadans who need information on Alzheimer's disease and other dementias.

Strategy: The Nevada Department of Health or the State of Nevada website link will arrange for information on Alzheimer's disease and other dementias to be available on a well maintained and up-to-date website to inform Nevadans about the disease and services available to them. This website link will contain accurate information provided by the Alzheimer's Association, the Department of Health, the Division of Aging, and other reputable resources along with links to signs, symptoms, services available, research, and trial opportunities. Continuous maintenance and updates will provide the best material and knowledgeable input to educate individuals, families, medical personnel, and the public.

Links to other reputable and viable sites will also be available such as the Alzheimer's Association or the Department of Health.

Surveys and questionnaires will also be on the site so that links and information can be adjusted to meet the needs of every Nevadan.

Indicators: A link that is up and running with a constant stream of hits will inform designers of the usefulness and needs of the site. Positive feedback as well as suggestions from viewers will ensure that this link offers the best and most critical information to support individuals, families and caregivers, health professionals, and the public.

Victims of Alzheimer's disease increase by number each second of the day. Sharing crucial information to all citizens will improve health care service as victims and families make informed decisions and detect the disease presence at earlier stages. Fear will decrease as choices and possibilities are made public. An active, educational website will answer questions and guide individuals and thus better serve all Nevadans because detection, diagnosis, and treatment will be more readily available and there will be less confusion because of widespread information from medical channels.

Funding: State of Nevada and Department of Health as they coordinate website information.

Accessibility through Tele-Medicine

With distance a serious factor in accessing information and medical information because of a limited number of trained neurologists, gerontologists, and other trained medical personnel in Alzheimer's disease and other dementias available in rural areas, technology becomes integral to disease detection, diagnosis and treatment.

Goal #7: To ensure accessibility to the finest medical care for every citizen of the state of Nevada regardless of where s/he lives by incorporating technology with face-to-face doctor/patient consultation.

Objective #7: To purchase tele-conference equipment for thorough evaluations and diagnoses of patients with Alzheimer's disease and other dementias for every hospital in Nevada. This technology will provide access to trained neurological and brain study specialists and their patients as well as an avenue for conferencing, training, and educational programs for victims and their families, care consultants, the Alzheimer's Association, and personnel as listed in Goal #1.

Strategy: The Nevada Alzheimer's Disease website link will list facilities that offer tele-medicine. This list will also be distributed to physicians and other health care professionals so that they can inform patients of this valuable and convenient service. Patients will also be advised of hospitals and other facilities that specialize in Alzheimer's disease and other dementias so that appropriate evaluation tools such as spinal taps and PET scans can be administered and then interpreted by specialists in gerontology, neurology, and other trained physicians.

Indicators: The state statistician will be able to analyze "hits" to places on the Nevada Alzheimer's Disease website link that provide information about tele-medicine services. Hospitals and other health providers will report the number of tele-medicine sessions recommended to patients with follow-up on how many patients take advantage of this specialized service. Patient surveys and questionnaires will enable the tele-medicine service to meet demands as it updates and adjusts available conferences formats to best meet the needs of all patients of Nevada.

Technology, regardless of its enormous benefits, will never replace the doctor-patient relationship, knowing that personalized services help people deal with disease through one-on-one interaction. Thus tele-medicine technology, physician participation, and focused patient diagnosis and care must work in tandem to best provide the best treatment. Surveys and questionnaires from all entities will offer insight into how the program is working and where improvements must be made.

Funding: Monetary compensation will be made to hospitals, physicians, and other health care workers through insurance, Medicare, and Medicaid through correct

billing codes. Many individuals who take advantage of tele-medicine are not fee-based (such as the Alzheimer's Association or support group facilitators).

Marketing that Reaches All Nevadans

Many people are uninformed and/or misinformed about Alzheimer's disease and other dementias. It is imperative that Nevadans are educated about these neurological disorders so that they can better understand detection possibilities, diagnosis procedures, treatment options, signs and symptoms, and research and trial opportunities as they abolish fears and misconceptions.

Mass media presentations are essential to disseminate facts about these diseases to educate citizens and construct better understanding.

Goal #8: To inform all Nevadans about Alzheimer's disease and other dementias including facts, misconceptions, symptoms, signs, available services, and support possibilities through awareness campaigns.

Objective #8: To inform all Nevadans about Alzheimer's disease and other dementias to better advance truth and understanding about the disease and to thus eradicate the fear and stigmas associated with the disease. This will be accomplished through television and radio advertisements and information spots, informative advertisements and articles in newspapers and magazines, website and Internet connections.

Strategy: Contact will be made through legislators, the Alzheimer's Association, concerned citizens, and medical practitioners to radio and television stations to have audio and audio/visual spots during news broadcasts and during prime viewing times to inform the public about Alzheimer's disease and other dementias. Trained professionals will be interviewed for these public service announcements plus all materials will be studied for accuracy. Using Nevadans who live with the disease or who care for someone with the disease, assisted and skilled nursing practitioners, and Alzheimer's Association staff will be enlisted to appear with true-to-life representations.

Magazines and newspapers will print advertisements and articles about Alzheimer's disease and other dementias gleaned from the radio and television spots as well as soliciting writings and statements from Nevadans who live with the disease or who care for someone with the disease, assisted and skilled nursing practitioners, and Alzheimer's Association staff.

Indicators: Contact information to the Alzheimer's Association in both northern and southern Nevada will be listed with each radio and television spot as well as in articles and advertisements so receive feedback from viewers and readers. Radio and television stations can determine the number of viewers/listeners to their programs and add information on their individual websites for feedback.

Funding: Free Nevada Public Broadcasting services will be requested. Funds and grants are available for advancing public knowledge and understanding of Alzheimer's disease and will requested. The Division of Aging will also be contacted for possible monies available for educational services such as these.

Socialization and Support Networks

Many people believe that those with Alzheimer's disease and other dementias and their caregivers prefer to be alone. Because communication is difficult with sentences that are tangle and conversation that is incoherent otherwise well-meaning friends stay away, afraid of interfering as well as simply being afraid of the disease itself. A lack of knowledge and understanding of the need for socialization and support is often too evident.

Nevadans deserve socialization and support outlets to help them enjoy life to the best level possible. Caregivers need this to an even greater extent since caregiving becomes an overwhelming, frustrating, and lonely process.

Goal #9: To design and promote socialization and support networks throughout Nevada to educate and guide as well as to listen and offer encouragement and assistance and to expand adult day care programs throughout the state to meet the needs of individuals in need.

Objective #9: The Alzheimer's Association and trained gerontology/neurology facilitators will work to design adult day care programs throughout the state, both those run independently and those that work in conjunction with local hospitals and care facilities. Adult day care us often the most utilized service for victims and families as it combines caregiver respite with meaningful activities and interaction for victims.

Adult day care means that the victim of Alzheimer's disease has a welcoming place to go to spend a few hours or day(s) where there will be stimulating activities, conversations, crafts, exercise classes, and other activities to maintain a fit body and mind.

Many caregivers, especially those of victims of early/younger onset Alzheimer's disease are still working outside of the home and have children at home or in school. Knowing that the victim is safe and well cared for during the day, in a stimulating atmosphere with trained staff, offers peace of mind and thus better caregiving patience. Caregiver burn-out frequently leads to premature death of the caregiver. Adult day care offers a reprieve, respite, and essential time off to meet the other demands of daily living.

When adult day care is not available, other respite services such as RSVP are instrumental in offering care for the Alzheimer's victim and rest and diversion for his/her caregiver.

Strategy: Research and study of existing facilities (those in our three large metropolitan areas of Reno/Carson, Elko, and Las Vegas) will be studied so that best practices can be replicated in smaller communities. Hospital and care facility administrators will be presented with options for incorporating adult day care into their facilities.

When a facility is brand new, incremental steps in offering adult day care will be advised as clientele grows and so that local programs can monitor program benefits and pitfalls and then adjust accordingly.

The Nevada Alzheimer's Disease website link will list adult day care and respite services available in each community along with contact information.

Steps must be taken so that existing residential care facilities are able to add adult day care services without further licensing responsibilities and expenses.

Indicators: Surveys and questionnaires will be sent to existing adult day care facilities to learn of best practices and recommendations. The Alzheimer's Association, support groups, and medical staff dealing with individuals with Alzheimer's disease and other dementias will also have surveys and questionnaires to determine the need for adult day care in each town in Nevada.

Results from these will be used to generate recommendations and protocols for creating local adult day care centers. The Department of Health will oversee requests as plans are submitted to meet this critical need. Reports will be written and posted on the Nevada Alzheimer's Disease website link to assess needs and to let individuals know where services are available, where services are proposed, and where services are lacking.

Hospitals and care facilities will respond to questionnaires to decide how adult day care can be implemented statewide.

Funding: Medicare, Medicaid, the veterans association, and ILG offer funding for adult day care so reimbursement to facilities can be billed under the correct code. Grants through the Department of Health and the Division of Aging are also available to sustain and support adult day care programs. Families will pay for care in an income related sliding scale that is reasonable and within an individual's budget.

Caregiver Support Groups

Caregivers often feel alone and isolated, believing that only they can provide care even as they enter new phases of the disease that are confusing and that add stress. Support groups for caregivers are important for venting concerns, sharing worries, knocking out stress, and learning from others.

Goal #10: To develop support groups and support group networks in every community for caregivers of individuals with Alzheimer's disease.

Objective #10: To educate and inform caregivers of support group opportunities that will help them navigate the stages and complexities of Alzheimer's disease.

Strategy: While many communities already have support groups available, significant relief for all caregivers is essential. The Alzheimer's Association and volunteers will extend outreach by providing tele-conferences and tele-phone-ins to connect every needy individual with the necessary support and assistance as well as continue live support group meetings whenever possible.

Indicators: Support Group leaders will provide feedback to the Alzheimer's Association of attendance and points of discussion for live meetings and for those conducted via tele-conferencing or tele-phone-ins. Information gained will be shared with all facilitators as they search ways to reach and assist every needy individual in Nevada.

The annual Alzheimer's disease conferences held in the north and the south of Nevada will provide a time and place for facilitators and concerned individuals to meet, share, explain, and design best practices for the coming year. The conference will also offer a chance to learn of presentations available throughout the state to send knowledgeable speakers to every community to share information about Alzheimer's disease and other dementias, research and trials, and other pertinent information.

Funding: Support group facilitators are volunteers. Presentations and presenters will come from Alzheimer's staff and trained individuals so funding and honorariums will come through them.

Grants will be requested from the Department of Health and the Division of Aging to spread knowledge and understanding for better and healthier living for victims and for caregivers.

Early Stage Programs

Early stage Alzheimer's disease victims benefit from interaction with others who are facing the inevitable decline that comes with the disease. Programs designed just for early stage victims promote education and self-understanding while allowing for release of fear and frustration by Alzheimer's victims.

While support groups for caregivers provide ways to vent and cope with the trials of offering long-term care, early stage programs must be separate as victims learn about disease stages and manifestations and as they learn to manage a healthy and active life within the parameters of the disease.

Goal #11: To develop programs for individuals in the early stages of Alzheimer's disease when conversations with other victims can be insightful and helpful.

Objective #11: To educate and inform individuals in the early stages of Alzheimer's disease to alleviate some of the fear, stress, and unknowns of Alzheimer's disease and the associated sense of isolation and aloneness that often accompanies the disease.

Strategy: A service similar to that provided for caregivers will be offered to victims who are in the early stages of the disease when self-frustration and worry are formidable for the victim. Live meetings offer face-to-face interaction and provide excellent interaction potential. However, when this is not possible or practical, tele-conferencing/tele-phone-ins solve this issue. Sensitivity to the needs of early stage victims will be paramount in designing and driving the program(s).

Indicators: Early Stage Program leaders will provide feedback to the Alzheimer's Association of attendance and points of discussion for live meetings and for those conducted via tele-conferencing or tele-phone-ins. Information gained will be shared with all facilitators as they search ways to reach and assist every needy individual in Nevada.

The annual Alzheimer's disease conferences held in the north and the south of Nevada will provide a time and place for facilitators and concerned individuals to meet, share, explain, and design best practices for the coming year. The conference will also offer a chance to learn of presentations available throughout the state to send knowledgeable speakers to every community to share information about Alzheimer's disease and other dementias, research and trials, and other pertinent information.

Funding: Program facilitators are volunteers. Presentations and presenters will come from Alzheimer's staff and trained individuals so funding and honorariums will come through them.

Grants will be requested from the Department of Health and the Division of Aging to spread knowledge and understanding for better and healthier living for victims and for caregivers.

Caregiver Respite and Relief Education

Many caregivers do not realize that there are services available to them that are free or that come at minimal cost. It is vital to share this information with every individual throughout the state.

Goal #12: To educate all Nevadans of caregiving support and supplement care for individuals with Alzheimer's disease and other dementias including distributing ideas for creating local hospice and in-home services.

Objective #12: To inform the public about services available to assist in the care and support of Alzheimer's victims and their families.

Strategy: Handouts and flyers will be produced and delivered to care facilities, police departments, hospitals, social workers, senior centers, and other individuals who work with Alzheimer's victims and their families to inform them of the many in-home services available in each community. These will include descriptions, locations, emails and telephone numbers for easy access.

Service providers include but are not limited to:

- RSVP
- Home Health
- Meals on Wheels
- Social worker and legal services provided at Senior Centers
- Hospice Services
- Volunteer agencies
- Adult day care services
- Support Groups
- Tele-conferencing and tele-phone-ins

A model for volunteer, in-home care is taken from the Humboldt Volunteer Hospice. This group receives grants and donations, operates a thrift store, and receives money from Newmont Legacy to fund:

- A director
- Office manager
- Case manager
- Thrift store director
- Training materials for volunteers
- Supplies needed for its patients such as hospital beds, walkers, and other medical supplies
- Medicines prescribed by physicians that an individual cannot afford

While called "hospice" the connotation in Humboldt County is in-home care for those in need, not necessarily those for whom death is within 6 months as with many hospice organization.

Humboldt Volunteer Hospice recruits volunteers who then choose their area of expertise:

- In-home services such as cleaning, shopping, companionship
- In-home services the registered CNAs or RNs can provide such as bathing
- Office staff volunteers for phone calls or organizing and running fund-raisers
- Thrift store workers

Volunteers are trained and report weekly with the number of hours served, services provided, and personal notes on the health condition and outlook of the patient.

Humboldt Volunteer Hospice works in conjunction with local physicians and health care providers to assist as requested including having an individual on staff who can act as coroner to avoid ambulances and emergency rooms.

The goal of the Humboldt Volunteer Hospice is to make life-to-death transitioning as comfortable and soothing as possible as relationships and excellent care are provided.

Indicators: Organizations such as RSVP and Home Health that provide services already have requirements for reporting services. Surveys and questionnaires would provide information on numbers served, types of service, and unanswered needs.

The Nevada Alzheimer's Disease website link will include a link to the Humboldt Volunteer Hospice overview.

Funding: The majority of these services are already funded by county, state, or federal programs. Volunteer services are self-funded.

Grants and legacies are available from a variety of sources to continue and to expand services to all towns and citizens.

Cultural Issues and Considerations

The State of Nevada values diversity and inclusiveness in its work with the Alzheimer's community. The State will meet the demand for culturally and linguistically sensitive information to increase awareness to persons living with and affected by Alzheimer's disease and other dementias.

Nevada will be inclusive in its approaches to serving all who are in any way affected by Alzheimer's disease. This diversity includes, but is not limited to race, gender, age, socioeconomic status, sexual orientation, regional or national origin, religion, language and persons with disabilities.

The State will develop relationships with diverse communities to educate, support, enhance care for, and inform diverse communities about Alzheimer's disease and other dementias. Some of the areas of education and support are:

- Reactions to the diagnosis—These may be of infinite variety and nearly impossible to predict.
- The family—Spouses/Partners and extended family may feel a sense of loss or loneliness as a result of the diagnosis and therefore need counseling and support
- Children—Children regardless of age may experience a wide range of emotions and may feel that they did something to cause the disease or may become resentful that they have to take on more responsibilities. In addition, some children feel they must quit school or a job to help support the family. Some children may feel they have to put their own futures on hold to help the immediate family during the journey of the disease. Counseling and support are essential.

- **Job**—A victim of Alzheimer’s disease or the caregivers may find work more difficult to perform and job requirements more problematic to complete. Eventually s/he may need to reduce work hours, change job duties, or leave the job. This will affect not only the person’s health insurance and benefits but possibly those of the whole family. It is critical that health care coverage be available and reasonable for victims, caregivers, and families.
- **Debt**—Reducing one’s work hours, changing job duties and eventually not working at all may affect the ability to pay a mortgage, buy essentials, and continue to have a source of income. Qualified financial consultants need to be trained so that they can share information on government assistance and to review personal disability insurance policies.
- **Legal issues**—Individuals with Alzheimer’s disease and their caregivers and/or family need to meet with an attorney to appoint a person to make financial and health care decision for the future.
- **Future Care**—Decisions about the day-to-day care of the person with dementia and the future care of the person with dementia must be made and recorded so that wishes can be met. The family caregiver will need respite as caregiving is a long, arduous process.

Goal #13: To guarantee that all Nevadans have access to services and health care recommendations available in their native language so that informed and safe decisions are made in the best interests of the victim, caregiver, family and others affected by Alzheimer’s Disease.

Objective #13: To disseminate knowledge of the many aspects of Alzheimer’s disease and other dementias in a variety of languages to meet the needs of every victim and caregiver regardless of race, gender, age, socioeconomic status, sexual orientation, regional or national origin, religion, language, and persons with disabilities.

Furthermore, all victims of Alzheimer’s disease, caregivers, and family members will be informed of their Alzheimer’s Disease Patient Bill of Rights (Appendix A) and Alzheimer’s Disease Caregiver’s Bill of Rights (Appendix B).

Strategy: The Alzheimer’s Association, the Department of Health, and the Division of Aging will create and produce flyers and brochures to be distributed to support group leaders, health care providers, physicians, and others concerned with Alzheimer’s disease and other dementias using the information provided above to educate all Nevadans.

These agencies will use personnel or websites such as www.athropolis.com/translate.htm/ or www.freetranslation.com to translate this information into the native tongue of the Alzheimer’s disease victim or caregiver and family.

Health care providers and support group leaders will receive training to be aware of culturally sensitive issues when caring for and helping families of different backgrounds so that the best, safest situation always surfaces.

Indicators: The Alzheimer's Association, the Department of Health, and the Division of Aging will record the number of flyers and brochures distributed and the languages that require translation. A survey or questionnaire on the flyer or brochure or contact information of the producer will increase knowledge of who is reading the flyers and brochures.

Research will be conducted and compiled by the Alzheimer's Association, the Department of Health, and the Division of Aging into needs and preferences of those served in Nevada with a training pamphlet available to all who work with individuals with Alzheimer's disease and other dementias.

Funding: The Alzheimer's Association, the Department of Health, and the Division of Aging will use funding provided for educational needs.

Appendix A

Alzheimer's Disease Patient Bill of Rights

Every individual diagnosed with Alzheimer's disease or other dementias deserves:

- To be fully informed of one's diagnosis.
 - To receive appropriate, ongoing medical care.
 - To remain productive and active in work and play for as long as is reasonably possible.
 - To express feelings and then to be taken seriously.
 - To be treated like a thinking, feeling, hearing, cognizant adult.
 - To live in a safe and predictable environment.
 - To participate in meaningful activities and conversations each day.
 - To be out-of-doors on a regular basis.
 - To be hugged, caressed, and physically engaged to increase a sense of safety and well-being.
 - To be with persons who know one's life story, history, cultural background, and religious training.
 - To be cared for by individuals who are trained in Alzheimer's disease and other dementias care.
 - To live with dignity and respect provided by caregivers, family, and health professionals.
 - To have the right to deny services through individual self-determination.
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Appendix B

Alzheimer's Disease Caregiver's Bill of Rights

Caregivers have the right to:

- Seek help.
- Receive support.
- Be angry and irritated.
- Take time to be alone.
- Request assistance.
- Decline assistance (even when it is in the caregiver's best interest).
- Trust one's own judgment.
- Acknowledge and address one's limits.
- Make mistakes.
- Grieve.
- Laugh and love.
- Maintain one's own active life.
- Reject attempts by relatives and friends to interject.
- Be granted consideration, affection, forgiveness, and acceptance.
- Expect that as new strides are made in finding resources to aid physically and mentally impaired individuals, similar strides will be made toward aiding and supporting caregivers.

Appendix C

Priorities

While every word in our Access to Services document is viewed as essential and critical to the well-being of every Nevadan touched by Alzheimer's disease and other dementias, we also recognize the sometimes priorities must be set. In our Access to Services review our top five priorities are:

- Caregiver Support Groups, Early Stage Programs for Victims, and Caregiver Respite and Relief (Goals 10, 11, and 12)
- Early-Younger Onset Versus Older Onset (Goal 5) so that Nevada law is amended to meet the needs of Alzheimer's disease victims based on diagnosis not age.
- Marketing that Reaches All Nevadans (Goal 8)
- Accessibility through Tele-Medicine (Goal 7)
- Cultural Issues and Considerations (Goal 13)

We also want to address titles such as Aging and Disability Resource Center that may lead early/younger onset victims away from educational opportunities and medical services because being forty may not feel like "age". Also the word "aging" carries the denotation of "natural process" of growing old while Alzheimer's disease should not be considered a "natural/inevitable process".