

December 12, 2017

Dementia Friendly Elko: Community Assessment

A Community-Action Group of the Nevada
Aging and Disability Services Division
Dementia-Friendly Nevada Initiative

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KEY FINDINGS – ELKO COMMUNITY ASSESSMENT

- According to the Nevada State Demographer, there are an estimated 632 individuals aged 65+, including 119 individuals aged 85+, living with dementia in Elko County.
 - It is estimated that 91 of those individuals aged 65+, who are currently living with dementia, live alone.
- 161 residents of Elko County completed the Community Awareness Survey, 75% of which were completed online (56 additional non-Elko residents completed the survey).
- Top sectors completing the survey were: Government (17%), Community-based services and supports (13%), and Education (13%).
 - Of note, the business / retail sector comprised 7% of responses.
- 66% of respondents reported some form of personal relationship with someone who is currently living with or who had lived with dementia.
- Overall, respondents in Elko County reported moderately positive attitudes toward individuals living with dementia, with an average score of 99/140 (70% of possible).
 - Respondents reported a moderately high level of comfort in engaging with individuals living with dementia, with an average score of 58/84 (69%).
 - Respondents reported relatively high knowledge regarding dementia, with an average score of 41/56 (73%).
- Considering sectors, individuals from residential care reported the highest positive attitudes (113), whereas individuals from the business/retail and general community sectors reported the lowest scores (93).
- Key community strengths reported include: 1) support groups, 2) senior center, and 3) community size.
- Key community weaknesses/gaps reported include: 1) lack of clinical services, 2) lack of community-based services, and 3) lack of education programs regarding dementia.
- Key community resources respondents would recommend to others include: 1) the local senior center, 2) Nevada Aging and Disability Services Division, and 3) long-term care providers.
- Service priorities, as ranked by the community, were: 1) increasing dementia-related resources, 2) increasing awareness of available resources and supportive organizations, and increasing staff and volunteer training on dementia-related communication techniques (tied), and 4) increasing community member skills for interacting with people with dementia, and increasing knowledge of the warning signs of dementia (tied).

PROJECT OVERVIEW

The Dementia-Friendly Nevada initiative, led by the Nevada Aging and Disability Services Division, is intended to engage community action groups (CAGs) across the state in developing local priorities for enabling people living with dementia to live well within the community. To inform community dialogue, the Sanford Center for Aging conducted a comprehensive community assessment, determining the current status within each community. Specifically, this evaluation project was undertaken to develop an understanding of individual community dementia capability based on existing and new data sources within Elko County. To that end, population estimates were calculated, estimating: 1) the number of elders (individuals aged 65+) who were currently living with dementia, 2) the number of elders aged 85+ who were currently living with dementia, and the number of elders 65+ who were currently living alone with dementia within the community. These estimates are based on the formula provided by Dementia Friendly America and use data obtained from the Nevada State Demographer. In addition to this demographic information, two surveys were conducted by the Sanford Center for Aging to determine: 1) community leader knowledge of state-wide programs for individuals with dementia, and 2) basic community attitudes and knowledge of dementia and dementia related services. This report details the findings of each of these community assessments in Elko County.

DEMOGRAPHICS OF DEMENTIA

To estimate the number of individuals currently living in Elko County with dementia, data was gleaned from the Nevada State Demographer. Overall, it is estimated that 11% of elders aged 65+ within Elko County are living with dementia. This estimate increases to 33% for elders aged 85+ within the community. Of those elders 65+ who are currently living with dementia, it is estimated that 14% live alone. Table 1 presents data estimates of the elder and dementia population in Elko County.

Table 1: 2016 Estimated Demographics – Elko County

	State Demographer Estimates
Total Aged 65+	5,685
Est. Total with Dementia	632
Est. W/ Dementia Living Alone	91
Total Aged 85+	357
Est. Total With Dementia 85+	119

Additionally, the Centers for Medicare and Medicaid Services (CMS) estimated that approximately 5.98% of Medicare beneficiaries, or 299 individuals, received services for Alzheimer’s disease or related dementia in 2015 within Elko County¹.

¹ The most current year data has been released by CMS. Data can be found at www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Dashboard/chronic-conditions-county/cc_county_dashboard.html

DEMENTIA-SERVICE RELATED KNOWLEDGE

To understand the level of knowledge regarding services specifically targeted towards individuals living with dementia currently offered through the state, a short survey was administered to Elko Community Action Group members. This survey was administered to 5 CAG members. This survey assessed knowledge regarding the state’s ‘dementia toolbox’, as well as additional programs that may be available in the community. Most programs are offered by the Alzheimer’s Association, including the Early Partners in Care (EPIC) program, the Care Partners Reaching Out (CarePRO) program, along with the Association’s other core services, such as education and support groups. In addition to these services, as part of the Nevada Dementia Toolbox, Nevada Senior Services offers the BRI/RCI Care Consultation model via telephone across the state.

This survey first asked about respondents’ awareness of the specific programs in the dementia toolbox, and if the respondents were aware of the service, asked about their level of knowledge regarding the programs. A majority of the respondents were aware of the core services offered by the Alzheimer’s Association. Only 2 respondents reported that they had heard of the EPIC program, and no respondents were aware of the services provided by Nevada Senior Services. Of those respondents who reported being aware of the programs, most reported little to no knowledge of the specifics about the program. A minority of respondents were able to identify other resources for individuals with dementia living in Elko County, including long-term care resources and community based supports (Table 2).

Table 2: Knowledge Regarding Dementia Services in Elko County (n=5)

	Aware	Very / Quite Knowledgeable	Little / Not at all Knowledgeable	No Prior Knowledge
Nevada Dementia Toolbox	3 (60.0%)	1 (20.0%)	2 (40.0%)	2 (40.0%)
EPIC Program	2 (40.0%)	0 (0.0%)	2 (40.0%)	3 (60.0%)
BRI Care Consultation	0 (0.0%)	0 (0.0%)	0 (0.0%)	5 (100.0%)
CarePRO	3 (60.0%)	0 (0.0%)	3 (60.0%)	2 (40.0%)
AZ Core Services	5 (100.0%)	2 (40%)	3 (60.0%)	0 (00.0%)
Other County Services	4 (80.0%)	~	~	~

Note. ~ Specific question not asked across participants. Knowledge question only asked of those individuals who reported knowing about the service

COMMUNITY DEMENTIA ATTITUDE SURVEY

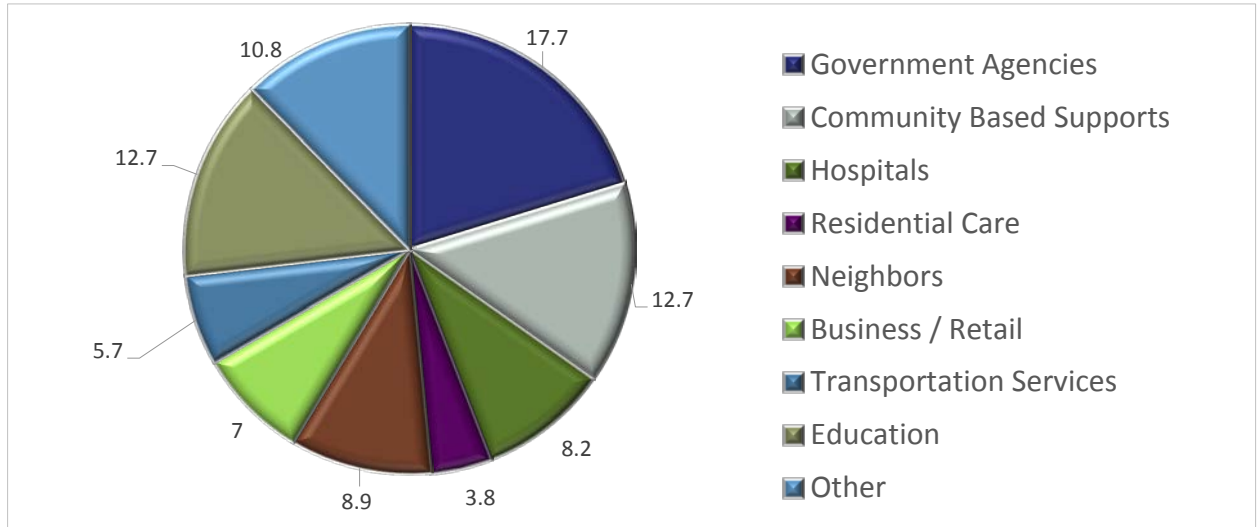
To assess community attitudes regarding dementia, the Sanford Center for Aging developed a survey intended to be administered community-wide to any community members willing to provide their perspectives. Attitudes were assessed in this survey using two tools selected by the Sanford Center for Aging. First, participants completed basic demographic questions, including a question asking them to identify the specific sector that they represent. Next, a measure designed to measure attitudes towards people living with dementia was completed, the Dementia Attitude Scale (O'Connor & McFadden, 2010). The goal of this measure was to determine the overall attitude of the community at large towards individuals living with dementia. Finally, participants completed questions to assess their personal experiences with people with dementia, as well as their experiences with dementia-related services within the Elko community.

A total of 216 Elko County community members completed the survey, either online or through a paper survey administration during the Fall of 2017. The paper version of the survey was administered with members of the community by community action group members at several locations within Elko County, resulting in 54 (25%) completed surveys. Members of the community action groups also helped spread the link to the online survey via their electronic personal and professional contact lists, resulting in 163 additional community members (75%) completing the survey.

To help identify if the link spread outside of Elko County, participants were asked to report their mailing zip code. Participants who did not report one of the zip codes belonging to Elko County were excluded from the current data analysis (see Appendix D for zip codes identified in the current study as belonging to Elko County). A zip code analysis indicated that 53 participants from outside Elko County completed the survey online and 3 individuals from outside Elko County completed the survey in person. These surveys were excluded from all other analyses as the major goal of the current assessment is to determine the attitudes and needs of individuals living within Elko County, leaving a total of 161 surveys from Elko residents.

Most survey respondents represented the government sector (18%), followed by community-based supports (13%) and education (13%). The sector with the lowest representation in the survey results was the residential care sector (4%), while Elko's business and retail sector represented 7%. To see the distribution of sectors represented in completing the survey, see Figure 1.

FIGURE 1. SECTORS REPRESENTED BY SURVEY RESPONDENTS BY PERCENTAGE



A majority of respondents (68%; Figure 2) reported having personal experience with someone living with dementia. The most common relationship between the respondent and the individual with dementia was ‘client or patient’ (52%), followed by ‘parent’ (49%), see Figure 3.

FIGURE 2. PERCENT REPORTING PERSONAL EXPERIENCE WITH DEMENTIA

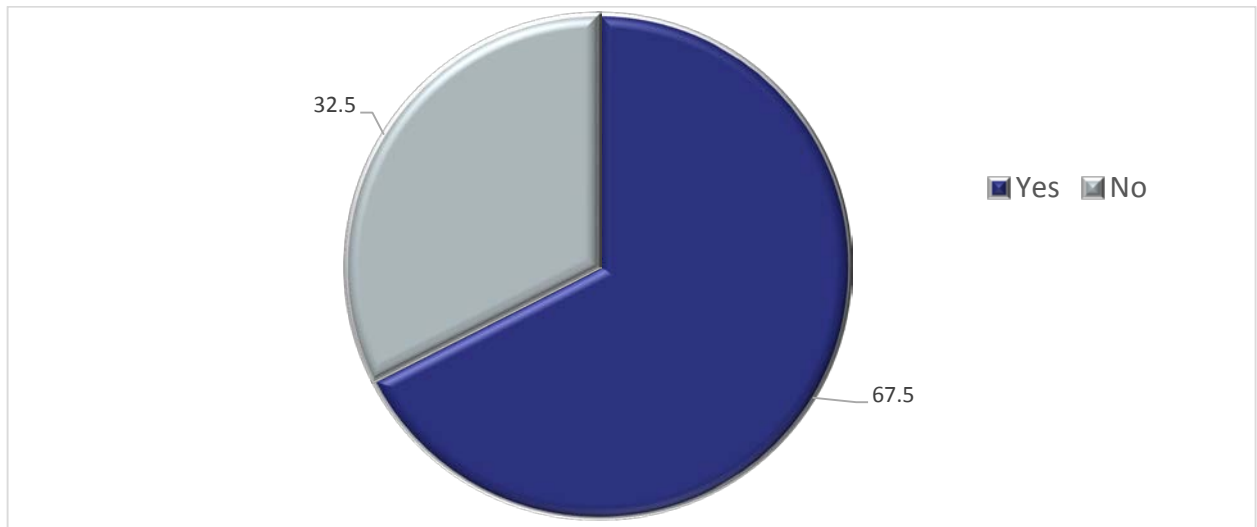
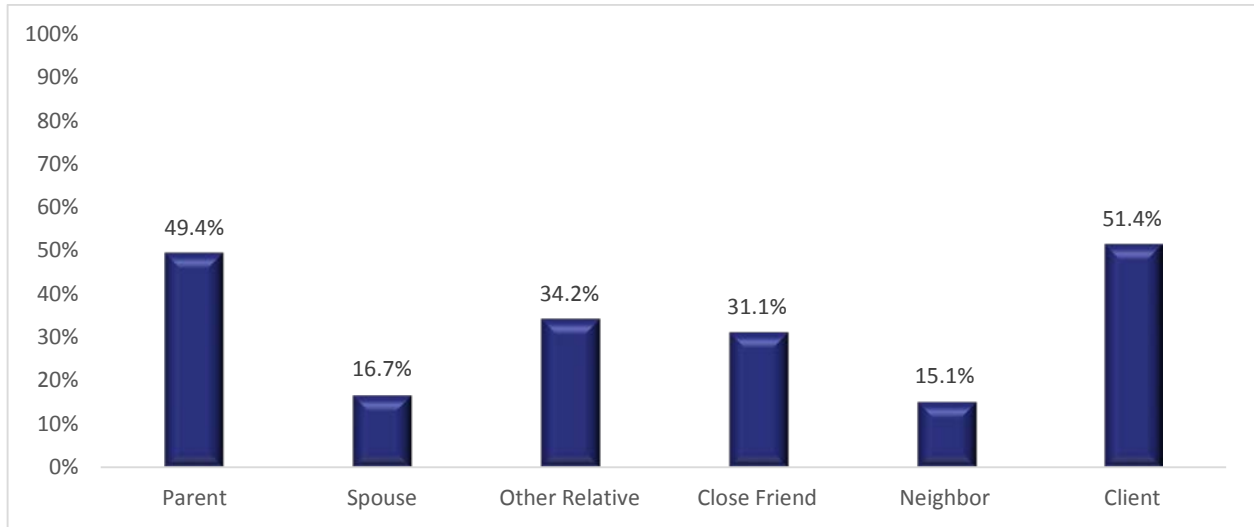


FIGURE 3. RELATIONSHIP BETWEEN SELF AND INDIVIDUAL WITH DEMENTIA



NOTE: PERCENTS ARE NOT CUMULATIVE AS MULTIPLE RELATIONSHIPS COULD BE REPORTED. OTHER RELATIVE INCLUDES GRANDPARENTS AS WELL AS IN-LAWS. CLIENT INCLUDES INDIVIDUALS LISTED AS PATIENTS OF THE RESPONDENT.

DEMENTIA ATTITUDES

The Dementia Attitude Scale (DAS) was chosen to measure respondent attitudes towards individuals living with dementia. This scale consists of 20 items and contains two sub-scales (see Appendix H for scale items broken down into sub-scales). The first sub-scale is labeled “social comfort” and contains items measuring an individual’s overall comfort level interacting with individuals living with dementia. The second, “dementia knowledge” contains items measuring individual knowledge regarding dementia and the experience of living with dementia. Subscale items are listed in Appendix H. Full results of the DAS are presented in Table 2. Similar to previous results, individuals who reported knowing someone living with dementia also reported more positive attitudes toward individuals with dementia (Figure 4).

Overall, with a possible range of 20-140 on the DAS, Elko County community members reported generally positive attitudes toward dementia, with a score of 99, or 70% of the possible positive score.

- With a possible range of 12 – 84, Elko County community members scored a 58 (69%) on the social comfort subscale.
- With a possible range of 8 – 56, Elko County community members scored a 41 (73%) on the dementia knowledge subscale.

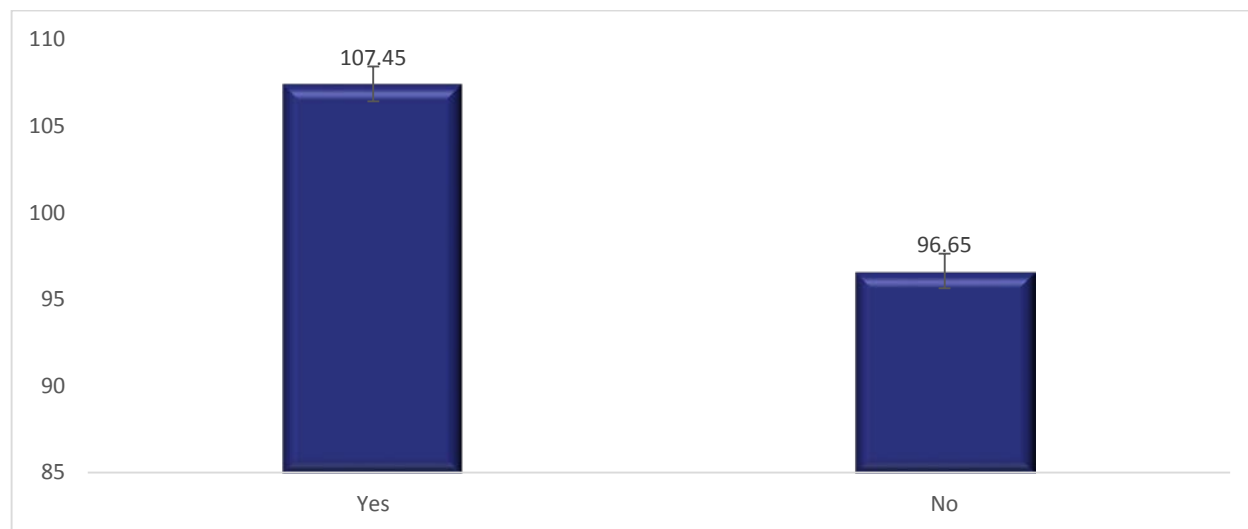
Table 3: Means and Standard Deviations for DAS by Specific Demographic Groups (n=161)

	Overall		Subscale 1: Comfort		Subscale 2: Knowledge	
	<i>Range: 20 – 140</i>		<i>Range: 12 – 84</i>		<i>Range: 8 - 56</i>	
	Mean	SD	Mean	SD	Mean	SD
Overall Sample	99	36.77	58	15.56	41	21.21
Gender						
Male	94	14.86	52	9.78	43	8.54
Female	105	15.04	58	11.52	46	7.11
Online	104	14.93	58	11.00	46	6.56
Paper	101	17.16	54	12.00	45	9.61

Further, there was a clear difference in positive views of dementia between respondents reporting that they know a person living with dementia versus those who do not (See figure 4).

FIGURE 4. MEAN DEMENTIA ATTITUDE SCORE BY KNOWLEDGE OF ANOTHER LIVING WITH DEMENTIA

(possible range: 20 – 140)



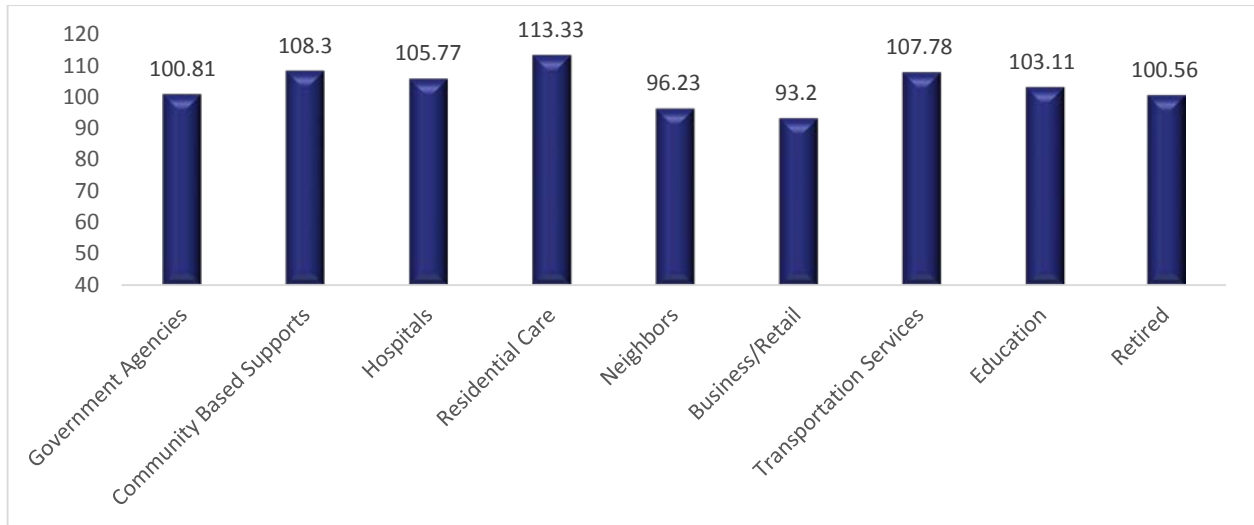
Note. Difference is significant at $p < .001$.

There were also differences between respondents' views regarding dementia depending on which sector the respondent reported representing (See Figure 5). Individuals who reported working in residential care facilities reported holding higher levels of positive attitudes toward individuals with dementia than the other sectors. It is important to note that this group is more

likely to be exposed to individuals who are living with dementia than other groups. This exposure is likely to influence the overall perceptions of these individuals.

FIGURE 5. MEAN DEMENTIA ATTITUDE SCORE BY SELF-REPORTED SECTOR

(possible range: 20 – 140)



STRENGTHS REPORTED WITHIN ELKO COUNTY FOR INDIVIDUALS LIVING WITH DEMENTIA

Individual participants were asked to report what they viewed as the strengths of Elko County in regards to meeting the needs of individuals living with dementia. In total, 72 individuals commented on this question. Complete comments are provided in Appendix E.

Some people (n = 16) listed area support groups, including support groups offered by the Alzheimer’s Association (n = 1); although others noted that access to these groups was limited due to the rural nature of the community and poor visibility of the service. The senior center was mentioned by several people (n = 6), as well as the classes and services offered there. In addition, the size of the community was mentioned by several (n = 4) participants. These individuals noted that many people did their best to look in on their neighbors, and noted that information, once available, spread throughout the community quickly. The local residential care home was also mentioned by several participants (n = 15) as a strength within the community.

Other respondents (n = 16) were more critical, reporting that they were unaware of any strengths relating to the treatment of individuals living with dementia within the county. Some noted that Elko used to have an adult day center, but that it had closed several years ago.

GAPS REPORTED WITHIN ELKO COUNTY FOR INDIVIDUALS LIVING WITH DEMENTIA

Similar to the strengths of the Elko County community, individuals were also asked to report on the perceived weaknesses of the community for individuals living with dementia. In total, 94 individuals commented on this question. Many people reported that they felt Elko County lacked both community based (n = 11) and clinical services (n = 24) for individuals living with dementia. Additionally, participants reported that education (n = 18), support groups (n = 15), and adult day (n = 11) as well as long term care (n = 12) services were lacking within the Elko County community. Many of the comments also stated that there were no respite opportunities for caregivers within the community (n = 9). Complete comments are provided in Appendix F.

RECOMMENDED RESOURCES FOR INDIVIDUALS LIVING WITH DEMENTIA

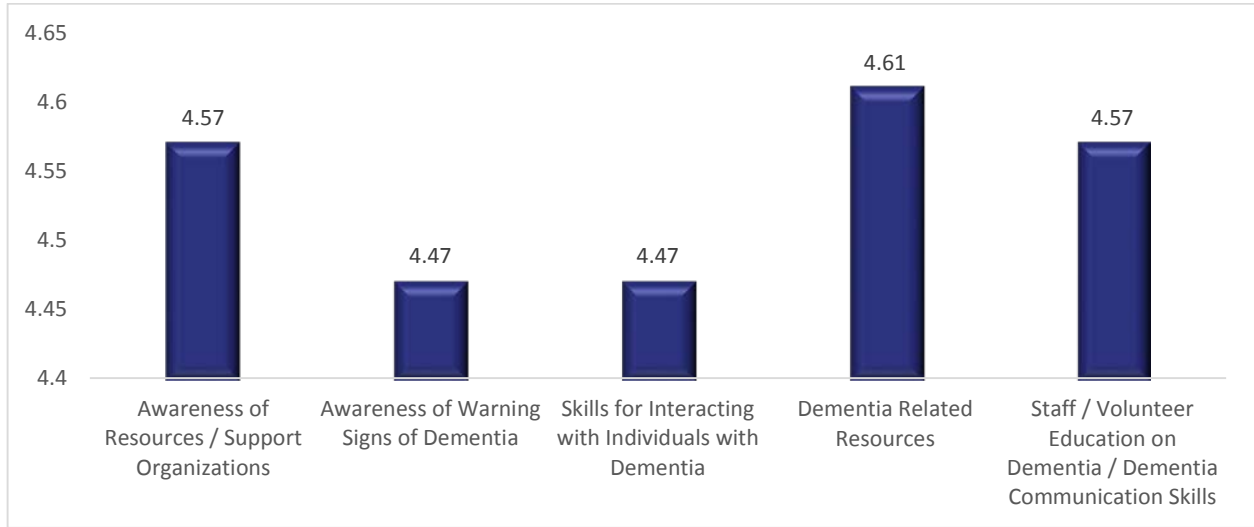
Participants were also asked to report what resources, if any, they would recommend to others who had either received a recent diagnosis of dementia, or who had had a family member or care partner diagnosed with dementia. In total, 71 participants completed the question. The highest percentage (22.5%, n = 16) reported that they would recommend seeking help from the local senior center. An approximately equal number of people recommended seeking resources from the local long-term care facility (n = 9), the Aging and Disability Service Division (n = 10), or from some form of clinical service (n = 114). Complete comments are provided in Appendix G.

SERVICE PRIORITIES FOR ELKO COUNTY

Participants were asked to independently rate several pre-selected goals drawn from the Dementia Friendly program from High (5-Strongly Agree) to Low (1-Strongly Disagree). No participant rated any priority as low (Strongly Disagree / Disagree), although a minority did report some of the priorities were only moderate (3-Neither Disagree / Agree). Mean scores for each goal are presented in Figure 6. Overall, participants reported that increasing dementia related resources (4.61) should be the most important goal, with increasing awareness of available resources and support organizations as well as increasing staff and volunteer knowledge regarding dementia the next most important goals for the initiative. Increasing the awareness of the warning signs of dementia and teaching community members skills for interacting with individuals living with dementia were both the lowest priority goals. These priorities match up with the expressed concern that existing support groups within Elko County are not well publicized, or that these groups are meeting in areas that may not be reachable by everyone who would benefit by the service.

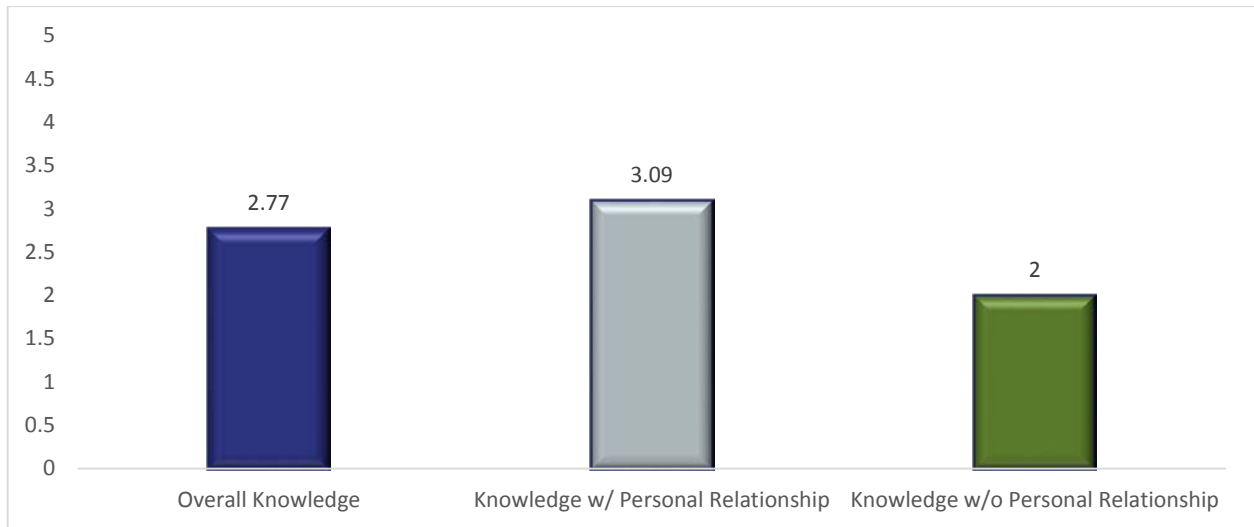
FIGURE 6. PRIORITY FOCUS AREAS FOR DEMENTIA-FRIENDLY ELKO COUNTY

(possible range: 1 – 5; strongly disagree to strongly agree)



Although low on the community generated goal list, increasing knowledge regarding the 10 warning signs of dementia should be seriously considered. Overall, Elko County respondents reported a moderate level of knowledge regarding these signs (2.77), with individuals who reported personal experience with dementia reporting a higher familiarity (3.09) than those who did not have such experience (1.95). Early detection of dementia has benefits for the person experiencing the symptoms, allowing for more effective treatment options and a greater involvement in their overall care plan. Additionally, early detection allows for the earlier activation of resources, decreasing overall caregiver burden. As such, it may be prudent to elevate this goal above the community’s perceived importance.

FIGURE 7. MEAN DEMENTIA KNOWLEDGE OF 10 WARNING SIGNS



APPENDIX A: SUMMARY OF PHASE 1 MATERIALS

Table A1

Summary of Phase 1 Materials

Evaluation Goal	Measure Name
Determine community readiness to engage in dementia friendly activities	Dementia Friendly RFP
Determine basic demographics of individuals living with dementia within Elko County	Dementia Friendly Initiative Demographics Sheet
Determine initial knowledge of dementia specific programs of community leaders within Elko County	Dementia Toolbox Programs Awareness Survey
Determine community members' basic attitudes towards individuals with dementia, as well as personal experience with individuals with dementia and dementia related services	DAS / Dementia Friendly Initiative Community Member Questionnaire

APPENDIX B: ELKO COUNTY RFP

Dementia Friendly Nevada ADSD-Sponsored Community Action Groups



Request for Proposals

FUNDING APPLICATION

The instructions and application form (in Word) can be downloaded from the Nevada State Task Force on Alzheimer 's disease website (<http://adsd.nv.gov/Boards/TaskForceAlz/TFAD/>), or through ADSD's grant opportunities webpage (http://adsd.nv.gov/layouts/Page_Style_1.aspx?id=62310). If you would like the instructions and application emailed to you, please contact: Jeff Doucet, ADSD, at jsdoucet@adsd.nv.gov

Complete applications will be accepted on or before 5:00 PM on Monday, May 1, 2017.

Please submit the Funding Application Form, which begins on the following page, in Word format using a minimum of 12 point font. Relevant attachments are acceptable but not required.

Email submissions are preferred. Please send your completed application to: Jeff Doucet, ADSD, at jsdoucet@adsd.nv.gov

Other options include mailing to:

Jeff Doucet, MBA, CPM

Management Analyst 3

Nevada Department of Health and Human Services

Aging and Disability Services Division, Resource Development

1860 E. Sahara Ave | Las Vegas, NV 89104

T: (702) 486-3367

APPLICATION FORM

Section A: Contact Information

Applicant/lead agency: Elko County: Elko Senior Activity Programs, Inc.

Name or description of community or communities within the project: Primary market area is City of Elko, Spring Creek and surrounding neighborhoods.

Preferred start date for funding (circle one): May 2017

Contact person: Kerry A. Aguirre

Mailing address: 1795 Ruby View Drive; Elko, NV 89801

Telephone: (775) 738-3030 office 775-397-1922 Kerry's Cell

Fax number: (775) – 738-4308

Email address: esap1@frontiernet.net

Name, address, and signature of person authorized to submit an application for funding and commit the applicant organization to the project:

Kerry A. Aguirre
Executive Director
Elko Senior Activity Programs, Inc.
1795 Ruby View Drive
Elko, NV 89801

(The narrative descriptions for Section B should not exceed two (2) single-spaced typed pages in a minimum of 12-point font.)

Section B: Community Readiness Questions

- 1. Can you identify several organizations and individuals, including representatives from at least four (4) community sectors, who are willing to be involved in a community action group to collectively address how to become dementia friendly and inclusive?**

Yes: X No: Maybe, with these conditions/exceptions: _____

Please describe: (While it is not required, please attach any letters of commitment from potential community action group members)

Community Based Services and Supports	Northeastern Nevada Regional Hospital
Emergency Planning and First Response Hospitals	Northeastern Nevada Regional Hospital
Community Based Services and Supports	Northeastern Nevada Regional Hospital
Neighbors and Community Members	Family Resource Center
Communities of Faith	Family Resource Center
Community Based Services and Supports	Kerry Aguirre
Neighbors and Community Members	Elko Senior Activity Programs
	Elko Senior Activity Programs

- 2. Does your community have an influencer/champion who is willing to endorse, kick off and co-facilitate a community action group and serve on the Statewide Advisory Team, and who can help the broader community commit to dementia friendly and inclusive principles?**

Yes: X No: Maybe, with these conditions/exceptions: _____

Please describe:

As the director of the Terrace at Ruby View: Elko’s Senior and Active Lifestyle Center, I (Kerry Aguirre) recognize a variety of age related physical and mental illnesses. Alzheimer’s disease and other forms of dementia are issues of great concern to all of us because the effects are often misunderstood and there is, to date, no known cure.

I am interested to champion a community action group – with support from Aging and Disability Services Division (ADSD) project partners - who will help to collectively address how our community might become informed, safe, respectful and inclusive of persons living with dementia and their care partners.

3. **Has your community shown an interest in dementia awareness, dementia capable, dementia friendly, or dementia inclusive initiatives in the past, specifically through involvement in local or regional efforts or related initiatives?**

Yes:

No:

Maybe, with these conditions/exceptions:

Please describe:

From Family Resource Center – Director, Judy Andreson: “Many people have worked in this area but we need to find a way to sustain the effort.”

From Kerry Aguirre, Director, Elko Senior Activity Programs, Inc.

I have served as director for the Senior Activity Programs since August 2013. Over these years the Alzheimer’s Association and The Cleveland Clinic; Lou Ruvo Center for Brain Health in Elko have reached out to our agency to present online seminars, onsite workshops and provide the latest available resources to families, caregivers and patients who seek helpful information about dementia and Alzheimer’s.

Although class attendance fluctuates, depending on the topic, there is always a show of interest and we look forward to the next presentation or broadcast.

4. **The process for becoming dementia friendly takes at least 18 months and is ongoing. With support from ADSD project partners, it engages the community through a community assessment, followed by data analysis and reporting, and then developing and implementing an action plan that addresses at least two (2) dementia friendly goals. Do you believe that with support your group can follow and accomplish this process?**

Yes:

No:

Maybe, with these conditions/exceptions:

Please Describe:

I believe our community, families, patients and caregivers need someone to act on this important initiative to develop and promote a community that is informed, safe, respectful and inclusive of persons living with dementia and their care partners.

As of this date, Judy Andreson the director of the Family Resource Center, Debbie Anderson director of Case Management at Northeastern Nevada Regional Hospital and I – Kerry Aguirre director of the Elko Senior Activity Programs, Inc. wish to take responsibility to rally the group of professionals, community members and business leaders who will begin this important and timely dialogue.

This survey is part of an evaluation of Dementia Friendly Nevada, funded by the NV Aging and Disabilities Services Division

APPENDIX C: PROGRAM AWARENESS SURVEY

Dementia Care and Support Services Awareness Survey (pre)

Thank you for agreeing to complete this short survey designed to measure public understanding of Nevada’s ability to provide care and supportive services to individuals living with dementia and their care partners. These responses will be used to help raise awareness of these services, as well as to implement new services in your community. Please mark only one response per question.

Thank you.

What is today’s date? _____

1. Are you aware that there is a *Nevada Dementia Supports Toolbox* of care and support services hosted by the NV Aging and Disability Services Division?

Yes No

IF YES: How knowledgeable are you about the *NV Dementia Supports Toolbox*?

Very Knowledgeable Quite Knowledgeable A Little Knowledgeable Not at all Knowledgeable

2. Are you aware of the Early-Stage Partners in Care (EPIC) program offered by the Alzheimer’s Association?

Yes No

Dementia Friendly Nevada Initiative – Elko

This survey is part of an evaluation of Dementia Friendly Nevada, funded by the NV Aging and Disabilities Services Division

IF YES: How knowledgeable are you about the EPIC program?

- Very Knowledgeable Quite Knowledgeable A Little Knowledgeable Not at all Knowledgeable

3. Are you aware of the Benjamin Rose Institute (BRI)-Care Consultation program offered by Nevada Senior Services?

- Yes No

IF YES: How knowledgeable are you about BRI-Care Consultation?

- Very Knowledgeable Quite Knowledgeable A Little Knowledgeable Not at all Knowledgeable

4. Are you aware of the Care Partners Reaching Out (CarePRO) program offered by the Alzheimer’s Association?

- Yes No

IF YES: How knowledgeable are you about the CarePRO program?

- Very Knowledgeable Quite Knowledgeable A Little Knowledgeable Not at all Knowledgeable

Dementia Friendly Nevada Initiative – Elko

This survey is part of an evaluation of Dementia Friendly Nevada, funded by the NV Aging and Disabilities Services Division

5. Are you aware of the core services provided by the Alzheimer’s Association (Information & Referral, Care Consultation, Education, Support Groups, and Safe Return)?

Yes No

IF YES: How knowledgeable are you about the core services provided by the Alzheimer’s Association?

Very Knowledgeable Quite Knowledgeable A Little Knowledgeable Not at all Knowledgeable

6. Within Elko County, are you aware of any other community programs that offer care and/or support for individuals living with dementia or their care-partners?

Yes No

IF YES: Please provide the names of these programs in the spaces below.

Dementia Friendly Nevada Initiative – Elko

This survey is part of an evaluation of Dementia Friendly Nevada, funded by the NV Aging and Disabilities Services Division

Please tear off this sheet and turn it in separately.

Would you be interested in helping create a dementia friendly community?

Yes No

Would you like to be periodically updated on how the project is progressing?

Yes No

If you marked “Yes” to either question above, please tell us your contact information below.

Name:

Mailing
Address:

City:

Zip Code:

Phone Number:

Email Address:

APPENDIX D: ELKO COUNTY ZIP CODES

TABLE D1
ZIP CODES IDENTIFIED AS BEING WITHIN ELKO COUNTY

89801	89802
89803	89815
89822	89823
89824	89825
89826	89828
89830	89831
89832	89833
89834	89835
89883	

APPENDIX E: STRENGTHS WITHIN ELKO COUNTY FOR INDIVIDUALS LIVING WITH DEMENTIA (DIRECT COMMENT TRANSCRIPTION)

- we used to have Bright path, Cleveland Clinic does telehealth at Morning star
- we do not have many if any services
- transportation, HHS. support groups
- transportation to services, clinical services
- The Terrace Senior Center's services and assisted living programs
- The main strengths are our small community. Information, when done correctly, spreads quickly.
- support groups, transportations services
- support groups, in home services
- support groups for caregivers of people with dementia, a facility that cares for those with dementia, a local initiative to create a dementia-friendly community
- Support groups , Nursing Home Transportation services
- Support Groups
- Starting a Dementia Friendly committee.
- Several community agencies who care about the health of residents across the lifespan.
- services
- Senior Center.

- respite care offered, in home health services, education, and residential care available. Also a good senior center where they can go for a variety of classes.
- Religious organizations, F.I.S.H., and hospice care.
- Our community is trying it's best, but not needs more strength
- Our community does have a wonderful assisted living and memory group home/housing that is offered. I have noticed that many people who live here most of their lives do try to keep tract and help their neighbors. However, there is need for more day treatment centers, respite, and support for both those with dementia and those who care for them. We also have a specialty clinic with providers who travel from Las Vegas once a month to evaluate dementia patients in this area. However, they do not see NV Medicaid participants which leaves a big gap in community care.
- one strength is the medical community is very aware of the needs of our community for the families
- nursing home
- Not many
- NONE
- none
- need more support group facilities for dementia patients
- minimal services available in Elko/Spring Creek
- Local services and small town environment
- I doubt we have many strengths in Elko or Nevada since our healthcare in Nevada is so poor. We used to have a day care for persons with dementia, so family members could continue employment and/or get the much needed break from constant care. But that closed several years ago. All I know of now is the long-term care center, which is a for-profit company that provides basic needs but little else.
- i don't see many things done at this time
- i don't know of any
- i don't know
- I do not know of any resources for people with dementia in our community.

- i am not very familiar with available services, except for highland manor, which seems to provide adequate services
- Highland Village of Elko
- Highland memory unit
- Helping community members get the right type of education and support. Helping caregivers know how to help a loved one with Dementia but also helping them recognize when going to a facility is the most safe and appropriate action
- help from others
- Elko's senior center, nursing home - Highland Manor, Get My Ride
- Elko really does not have a lot of community supports for people with dementia since, there is no longer any Adult Day Care.
- Elko has no help for families. They have closed all the agency's that could help working families. IE BeeHive Homes and Bright Path Adult Enrichment Center. As a caregiver for my Mother-in-law I know how difficult it is and still hold a job.
- Elko does not have many resources for people with dementia and I only know of a few support groups that help clients and families with dementia.
- Currently Elko does not have many strengths in dealing with dementia. It is heartbreaking and quite unfortunate.
- community support
- community based services
- bright path (they still exist?), highland village, senior center
- An active senior center. An existing dementia treatment/residential facility. Close community and family support systems whenever possible.
- alzheimer's unit, transport services, support groups
- All the above
- all that are listed, awareness
- all of the above
- ADSD
- i'm not sure, i know there are support groups
- i don't really know

- alzheimer's association workshops, support groups, and respite care grant, family and friends, knowledgeable and compassionate physician and staff, legal counsel
- support groups is all there is at present
- don't know
- support, health services, safe living situations, health care needs,, med care, medications
- support groups, community services, counseling, transport services, free clinic service
- i think we are lacking all areas of services for families and folks w/ dementia
- i think there are strengths, such as support groups and community based services, but i do not feel these are visible or easy to locate in our community
- support groups, lots of training for people working in a memory care facility, active participation of workers in memory care with residents these, praying, catching, listening to music with them, working puzzles with them, etc.
- don't know what's available
- help from family, living at the estates, my doctor
- community based services
- all of the above

APPENDIX F: GAPS/WEAKNESSES WITHIN ELKO COUNTY FOR INDIVIDUALS LIVING WITH DEMENTIA (DIRECT TRANSCRIPTION)

- yes
- We used to have an adult day care, which would be helpful for those care givers that work and those that just need a day off.
- Unaware of any support groups, transportation or community-based services
- truly understanding how to deal with dementia especially for the family members, more support groups so they don't feel alone
- transportation,
- transportation to appointments, assistant caregivers, affordable LTC placement, Adult day care
- transportation services
- they need more help
- There are not many places, staff, or training for patients with dementia. Not many permanent homes and not much respite care for families of patients who have dementia. Not much education about how to care for family members with dementia.
- the need for support groups, and other programs in the community
- support groups, respite for people caring for demented people
- support groups, day care,

- Support groups, community based services, clinical/medical services and transportation
- support groups and educating families
- support groups
- support groups
- Support group
- support
- Specialized medical care
- senior day services, mow
- respite care, education, more manor care, more available care givers
- People suffer alone because they are too proud to reach out for the help that is available
- overall understanding of what dementia and is not little or no regular respite care for dementia affected individuals who still live at home with a family member or caregiver
- only one facility for residential memory care in the area, lack of in-home supports
- one-on-one supports, face-to-face services that have can take their time with you
- not enough services
- Not enough resources for those with dementia or family members
- Not enough assisted living options. The one assisted living option did not follow up with me after my visit. Other assisted living communities from out of town are always following up with me to see how my father and I are doing. There was not very many activities for my father to participate in at the assisted living community here in Elko. He is only 54- he needs to be active. Communication goes a long way.
- no services
- No group day treatment or care programs. Lack of Respite for caregivers. Lack of providers for NV Medicaid participants. Lack of education and recognition of when to be concerned, when to recognize decline. Lack of medical professional ability to recognize potential dementia vs. BH issues.
- no adult day care, lack of clinical services.
- No adult day care services. It's difficult to keep a person in their home without community support services such as adult day care
- more support groups

- more community services and clinical services, community education
- Mental Health Family member counseling and coping skills/support
- Local hospital and delays in court system.
- Legal services Obtaining Medicaid when needed
- Lack of trained personnel even at Highland Manor.
- lack of services, programs, education, awareness
- lack of services for the people
- Lack of resources for families who are trying to take care of a loved one in their home.
- Lack of information, resources, knowledge.
- lack of education for community support, lack of communication of support
- lack of clinical support
- Lack of clinical services (mental health providers)
- Just individual families not making the effort
- I think Northeastern Nevada lacks in care providers available to assist with people with dementia and the elderly population in general. Often times the family members taking care of them become burnt out and need to take a couple of respite days and take care of themselves but they are unable to because no one could watch their family member for them while they take a break.
- I feel that most services listed- are not available in this community.
- I don't think we have many local doctors that diagnose and work with dementia patients to provide them with the highest quality of life possible.
- i don't know
- I am not aware of actual organizations like Alzheimer's Association that support either people with dementia or their families in our community.
- Education on how to provide or get the right type of care
- Education in schools - elementary and high school.
- Day care and a somewhat reasonable care facility. The Highland Manor is \$7,000.00 plus for Alzheimer's patients. If you cannot care for your loved one and cannot afford the manor. Your choice is to leave town for a care facility, Then you are not there to check in on them.

- DAY CARE LOCAL PROVIDERS OF ALL SORTS-NOT
TELEMEDICINE/TELE THERAPY RESPITE CARE
- community based supports for families
- Community Based Services, transportation, Geriatric medical care, adequate Senior Housing (2 year wait list), or affordable Assisted Living Facilities. Highland Manor is the only option for NF care and nobody wants to go there since the care is substandard.
- Community based services and clinical services
- communication on services if there are any
- Clinical services, care providers
- clinical services- physicians who take Medicare. communication about what is out there
- Clinical Services
- clinical services
- clinical services
- All the above
- all of them
- All of the above. We certainly don't have them for other kinds of public health issues.
- All of the above. There are not enough qualified and knowledgeable physicians to assist. Tele-physician is NOT the way to handle people with dementia. You can also add education to that list.
- All of the above listed, but especially affordable medical care.
- all of the above is needed, the family members taking care of the dementia patients are overwhelmed
- all of the above
- all
- Adequate medical care and lack of medical care and training at the manor and with home health services.
- adequate health care
- i don't know, i am not that closely involved in those areas
- having enough help
- respite care (when bright path closed it left a huge gap), training to community members interacting with people living with dementia (EMS, law enforcement, retail, banking, restaurants, transportation), limited beds for advanced dementia patients

- support groups, community based services, transportation services, clinical services, day care
- we need more community based accurate education, we need community based services, better transportation services and clinical services
- 0
- housing, support groups
- exposure to problem
- we need more info and support groups for families, activities for folks in assisted living are limited awaiting list for severe folks here, we need more educated helpers in housing for these people
- more informational classes/discussions about the disease, more information about facilities for people with disease
- i think clinical services, transportation services, and a network for connecting individuals would be wonderful additions to the community
- all of the above
- adult day care
- more transportation options
- clinical services, doctors
- none

APPENDIX G: RESOURCES FOR INDIVIDUALS LIVING WITH DEMENTIA

- UNR's dept of aging, to do out reach clinics/services in rural Nevada on a regular basis- Maybe articles in the paper along with informational flyers or webinars discussing the latest treatments and services available- or 'things to think about'- when to see a HCP, etc.,
- The Terraces, Highland Manor
- The Senior Center, Aging and Disability Services and Transit.
- support groups for care givers, community centers
- Support groups
- Specialized Physician, websites.
- Senior Center, welfare
- Senior center, PACE, Ruby Mtn Resource Center, Aging and disability, manor, Health providers,
- Senior Center Doctor
- Senior Center
- See their primary care, then a neuro, then seek support services and caregiver support
- See their physician to be diagnosed properly
- See previous answer
- see a doctor, veteran services, IHS
- Screening services at senior center
- Ruby Terrace Senior Center, Carlin Senior Center, NV Health Centers both Carlin and Elko

- Respite Care
- Religious organizations, F.I.S.H.
- Physicians. The Alzheimer associations in either Reno or Salt Lake.
- nursing home
- more in home facilities for dementia patients
- Local senior center and nursing home/assisted living because they could probably provide greater direction.
- local and community group or clinics
- I would recommend their caregivers have them participate in volunteering activities and watch for community events, museums, shows, art classes etc. There is not ONE organization that can really cater to all the needs and engagement activities an individual with dementia needs. It seems there has to be an individual who is willing to sift through the many resources and activities to really find what is available.
- I would not recommend any of the resources for dementia in my area.
- i don't know, not sure
- Hospital
- home health or support groups
- Highland manor, senior center
- go somewhere else
- Genesis home care, The Terraces Senior Center Highland Village of Elko
- figuring out what steps to take for themselves as well as the family members, a plan of action so it is less chaotic and stressful for everyone
- Elder care Lawyer
- don't even know where to start, division of aging maybe
- Dept. of Aging/Disabilities Family Resource Center 211 United Way National Dementia Hotline www.Alz.org
- Dementia support groups, Elko Senior Center, Highland Manor
- counseling
- consult w/ outside resources, manor (garden court if @ age)
- Cleveland Group, tele med, support groups,
- Cleveland Clinic Alzheimer's Support Group
- Cleveland Clinic
- caregivers, transportation, education, place for them to go during the day
- As per my experience both of Bee Hive Homes and the Bright Path Center were excellent alternatives for my family. And a support group that is now started would have been so useful at the time. You would like to know how other people are dealing with the same issues as you and what strategies they are using to deal with them. I have had a ton of people ask me questions when they found out we were caring for someone with dementia. More or less what working for us and what is not working for us. This is a very difficult disease. The mind is very complex.
- Alzheimer's Group Highland Village Garden Ct
- Aging Services and Mental Health Services
- Aging & Disability Services
- adult day care

- ADSD, Alzheimer's support group, respite care
- ADRC Cleveland Clinic
- Alzheimers Support Group
- support groups <<>> what they are going through
- i don't know of any
- senior center, fellowship of others
- referring them to talk to friends who are already or have dealt with family members with dementia
- i don't know
- the terraces for training and support group referrals, the alzheimers' association for information, training, respite grants, the cleveland clinic for education, faith communities for respite care givers, garden court @ highland village
- 0
- their family physicians, the support group, a parish nurse (if their church has one), pastor, if they are knowledgeable
- 0
- wander guard locators
- support groups, community services, counseling, transport services, free clinic services
- i don't know of any
- unsure
- nevada division of aging, highland village, alzheimer support group, elko clinic
- see your doctor and have him recommend
- division of aging
- my kids help me a lot, i would tell them to talk to my friend who also helps me
- social services
- support and community groups

APPENDIX H: DAS (O'CONNOR & MCFADDEN, 2010) SUBSCALES

Subscale 1 Comfort:

- I feel confident around people with dementia.
- I am comfortable touching people with dementia.
- I feel uncomfortable being around people with dementia.
- I am not very familiar with dementia.
- I would avoid an agitated person with dementia.
- I feel relaxed around people with dementia.
- I feel frustrated because I do not know how to help people with dementia.
- It is rewarding to work with people with dementia.
- I cannot imagine caring for someone with dementia.
- I am afraid of people with dementia.
- People with dementia can be creative.
- Every person with dementia has different needs.

Subscale 2 Knowledge:

- People with dementia like having familiar things nearby.
- It is important to know the history of people with dementia.
- It is possible to enjoy interacting with people with dementia.
- People with dementia can enjoy life.
- People with dementia can feel when others are kind to them.
- We can do a lot now to improve the lives of people with dementia.
- I admire the coping skills of people with dementia.
- Difficult behaviors may be a form of communication for people with dementia.