2019

KANSAS ALZHEIMER’S DISEASE PLAN

1/14/2019

Kansas Department for Aging and Disability Services
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https://www.kdads.ks.gov
THE FOLLOWING AGENCIES/ORGANIZATIONS WERE INVOLVED IN THE CREATION OF THIS PLAN:

Kansas Department for Aging and Disability Services
Tim Keck, Secretary
Ann Elifrits, Commissioner, Commission on Aging

- Alzheimer’s Association
- Kansas Advocates for Better Care
- Kansas Department for Aging and Disability Services
- Kansas Department for Children and Families
- Kansas Department of Health and Environment
- Kansas Department of Labor
- Kansas House of Representatives
- Kansas Sheriff’s Association
- Newman University
- Silver Haired Legislature
- The University of Kansas Alzheimer’s Disease Center
- The University of Kansas Medical Center

KDADS Mission:
The Kansas Department for Aging and Disability Services mission is to foster an environment that promotes security, dignity and independence for all Kansans.

KDADS Vision:
The Kansas Department for Aging and Disability Services envisions a community that empowers Kansas older adults and persons with disabilities to make choices about their lives.
Executive Summary

Every 65 seconds someone in the United States develops Alzheimer’s disease (when the terms “Alzheimer’s” or “Alzheimer’s disease” are used in this report, they should be understood as “Alzheimer’s disease or other dementia” unless otherwise indicated).

Alzheimer's disease is the most common type of dementia and accounts for an estimated 60-80 percent of cases. Alzheimer's is not a normal part of aging.

Dementia is an umbrella term for a decline in mental abilities severe enough to interfere with usual activities of daily life. Alzheimer’s and other types of dementia and their characteristics are listed in Appendix A. The most important dementia risk factors are ones we cannot change: age, family history and heredity. However, evidence acquired through research suggests there may be other factors we can influence. The majority of individuals with Alzheimer's are age 65 years and older, but it is not just a disease of old age as approximately 200,000 Americans younger than 65 years have younger-onset Alzheimer’s disease.

In fact, there are 53,000 Kansans age 65 years and older living with the disease. It is estimated that number will increase to 62,000 by the year 2025. Alzheimer’s is the sixth leading cause of death in all Kansans age 60 years and older. There are also about 150,000 caregivers and family members in Kansas who provide care and support for someone with the disease.

Treating persons with this disease is expensive. Kansas’ inconsistent approach to care and treatment contributes to tremendous costs on both the state and individual levels. In 2018, Kansas spent $424 million Medicaid dollars on individuals with this disease. These costs are expected to increase 25.8 percent from 2018 to 2025.1

In response to this looming health care crisis, in June 2018 Governor Jeff Colyer, M.D., by Executive Order 18-14, established the State of Kansas Alzheimer’s Disease Working Group (Appendix B).

“It shall be the duty of the Working Group” to:

Assess the current and future impact of Alzheimer’s disease on residents of the State of Kansas

Examine the existing industries, services and resources addressing the needs of persons with Alzheimer’s, their families and caregivers

Develop a strategy to mobilize a state response to this public health crisis.
The working group met at least bi-monthly between the months of August and November of 2018 and was chaired by Ann Elifrits, Commissioner, Commission on Aging, Kansas Department for Aging and Disability Services (KDADS). Working group members were appointed by either the Governor or other elected officials (Appendix C).

Working group members divided into sub-committees that studied, researched and documented the following topics for the plan:

1. Alzheimer’s Disease Facts and Figures
2. Caregivers of Individuals with Alzheimer’s Disease
3. Diagnosis and Treatment of Alzheimer’s Disease
4. Financing Alzheimer’s Care
5. Education and Training
6. Law Enforcement and First Responders
7. Public Awareness
8. Research
9. Legal Issues
10. The Service Continuum

The working group believes the recommendations proposed in this report can be made within the existing systems of care and services in Kansas. In fact, they could potentially also improve care management for other persons with chronic health conditions.

The working group endorses creating a state Alzheimer’s Disease Advisory Council in which individuals appointed would serve renewable two-year periods. The purpose of the Council would be to monitor and report progress and to describe barriers to implementation of the state plan. It would also begin the work of defining the key players to address plan strategies. Reports would be provided to the Governor and Legislature on the continuum of services available, data trends and policy recommendations.

The recommendations offered in this plan are within reach but are only the first steps to addressing this public health crisis. Systematic change requires time so urgent action is needed now.

In the fall of 2018, the working group conducted a six-week survey to obtain public comment and input on the needs of individuals with Alzheimer’s and their caregivers. It was distributed to mailing lists consisting of working group members and the organizations they represent. A total of 531 surveys were completed during that time (Appendix D).

I. ALZHEIMER’S DISEASE FACTS AND FIGURES

It is estimated approximately 5.7 million Americans of all ages are living with Alzheimer’s in 2018. This number includes an estimated 5.5 million people ages 65 years and older and approximately 200,000 individuals younger than 65 years who have younger-onset Alzheimer’s.¹

- One in 10 people age 65 years and older has Alzheimer’s
- The percentage of people with Alzheimer’s increases with age: 3 percent of people age 65-74 years, 17 percent of people age 75-84 years and 32 percent of people age 85 years and older have Alzheimer’s
- 81 percent of individuals with Alzheimer’s are age 75 years or older
Because Alzheimer’s disease is underdiagnosed and underreported, a large portion of Americans may not know they have it.

Kansas estimates are based upon specific data contained in The Alzheimer’s Association’s report, *2018 Alzheimer’s Disease Facts and Figures*¹ and data from the 2016 Kansas Behavioral Risk Factor Surveillance System (KS BRFSS).²

According to data collected in the 2016 KS BRFSS, Cognitive Decline Among Kansas Adults, approximately 9 percent of Kansans age 45 years and older have experienced confusion or memory loss more often or worsening during past 12 months (subjective cognitive decline). For those with worsening memory problems, 48.2 percent say it created “functional difficulties,” that is, it caused them to give up day-to-day activities and/or interfered with work or social activities. Of concern is the fact that 54.8 percent of individuals with memory problems reported they have not talked to their health care professional about their symptoms.
Certain segments of the population appear to be at greater risk of developing Alzheimer’s disease. Research indicates older Latinos are about one-and-a-half times as likely as older whites to have Alzheimer’s disease. Older African-Americans are about twice as likely to have the disease as older whites.

According to the National Institute on Aging\(^3\), many individuals with Down syndrome also develop Alzheimer’s disease. Estimates indicate 50 percent or more people in that population will develop Alzheimer’s. Typically, symptoms are present in their 50s or 60s.

According to the Alzheimer’s Association’s 2018 Alzheimer’s Disease Facts and Figures\(^1\) report there will be an estimated 17 percent increase in Alzheimer’s in Kansas from year 2018 to 2025. This increase will occur, in part, as the large “Baby Boom” population ages. It is projected that one out of every eight baby boomers will have Alzheimer’s disease or other dementia. Kansas needs an effective and comprehensive plan to address this disease as the costs to Kansans, their families and communities will be considerable.

Total per-person Medicaid payments for Medicare beneficiaries age 65 and older with Alzheimer’s disease were 23 times as great as Medicaid payments for other Medicare beneficiaries in 2018. Much of the difference in payments is due to the costs associated with long-term care and the percentage of people with dementia who are eligible for Medicaid.\(^1\)

II. CAREGIVERS OF INDIVIDUALS WITH ALZHEIMER’S DISEASE\(^1\)

Eighty-three percent of the help provided to older adults in the United States comes from family members, friends or other unpaid caregivers; 48 percent of those caregivers are providing care for a person with Alzheimer’s or other dementia.

There are three primary reasons caregivers provide care and assistance to a person with Alzheimer’s:

1) the desire to keep a family member or friend at home
2) proximity to the person with disease
3) the caregiver’s perceived obligation to the person.

Who are the caregivers?

- National surveys have found nearly one-fourth of Alzheimer’s disease caregivers are “sandwich generation” individuals caring for someone with Alzheimer’s disease and a child or grandchild at the same time
- About one in three caregivers is 65 years of age or older
- More than two-thirds of caregivers are married, living with a partner or in a long-term relationship.
- Approximately two-thirds of caregivers are women
- Approximately 40 percent of caregivers have a college degree or greater education
- Six in 10 caregivers were employed in 2017 providing care to an individual with Alzheimer’s disease and working an average of 35 hours per week; nine percent of caregivers gave up working entirely
Caregiving responsibilities can result in significant work-related changes as outlined in the following table:

<table>
<thead>
<tr>
<th>Caregiving Effect</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Had to go in late/leave early/take time off</td>
<td>57%</td>
</tr>
<tr>
<td>Had to go from full-time to part-time work</td>
<td>18%</td>
</tr>
<tr>
<td>Had to take a leave of absence</td>
<td>16%</td>
</tr>
<tr>
<td>Had to quit work entirely</td>
<td>9%</td>
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<tr>
<td>Turned down a promotion</td>
<td>8%</td>
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<tr>
<td>Lost job benefits</td>
<td>7%</td>
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</tbody>
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Kansas Caregiver Data:

- Number of Alzheimer’s and dementia caregivers: 151,000
- Hours of unpaid care provided: 172,000,000
- Value of unpaid care: $2,173,000,000
- Higher health care costs of caregivers: $101,000,000

Caregiver Support

Far too often caregivers become more isolated while caregiving for the person with Alzheimer’s disease. This results in caregiver fatigue, the sacrifice of personal health and depression. There is a growing need to create interventions which will support the Alzheimer’s disease caregiver.

The Veteran’s Administration Caregiver Support program offers a variety of programs for the caregiver of the veteran with Alzheimer’s disease who is enrolled in the VA.

The Caregiver Support Program offered through each regional Aging and Disability Resource Center (ADRC) is designed to assist caregivers through various available services.
Recommendations:

1. Enlist and educate civic organizations and faith communities as a resource for information and volunteer support for family caregivers.
2. Promote the Alzheimer’s Association 24/7 Helpline at (800) 272-3900 to caregivers, public and private community partners.
3. Expand the availability of innovative adult day programs for individuals with Alzheimer’s or other dementia in all Kansas counties. These innovative programs could include for example night support, the arts, exercise groups and intergenerational groups.
4. Offer accessible community and family caregiver disease education and training through a variety of offerings including webinars, community based and online educational programs in all Kansas counties.
5. Develop caregiver support groups in every Kansas county.

III. DIAGNOSIS AND TREATMENT OF ALZHEIMER’S DISEASE

Early diagnosis

An early disease diagnosis will provide the opportunity for the individual with Alzheimer’s to complete their financial and legal plans. Some individuals want to participate in clinical trials and others may want to partake in advocacy. Early diagnosis gives the caregiver and family members time to be educated about disease and make plans with the individual. Early detection can also result in better management of symptoms.4

More than 50 percent of individuals with Mild Cognitive Impairment (MCI) as well as those with early dementia are not identified by a physician and 30 percent go on to develop Alzheimer’s.5,6,7 This delayed or absent disease detection results in poorer clinical outcomes for the person. With more than 5 million Americans affected, a collective move toward early detection and diagnosis holds the potential of saving Medicare $3.3 trillion and Medicaid $2.3 trillion.7

Currently, there are too few dementia-specific clinicians such as neurologists and geriatric physicians in Kansas. Primary care physicians who refer to these specialties identify extended waits of up to six months for individuals to be seen. In 2012 there were only 21 geriatric physicians and 84 neurologists in the state.

Detection and a thorough diagnostic process also needs to be more accessible for populations with intellectual and developmental disabilities and individuals with mental illness.

Antipsychotic medications

Studies indicate that 80 percent of individuals with Alzheimer’s disease will face behavioral and mood challenges. These complications have been associated with premature disability, earlier institutionalization, poor quality of life and are the most strongly associated variable to caregiver burden and depression.8,9

When an individual with Alzheimer’s disease is experiencing a challenging behavior an assessment of contributing factors should always be conducted. Non-pharmacological interventions should be employed first to reduce the intensity and frequency of challenging behaviors. Environmental
interventions, communication modifications, medical intervention and therapeutic care should be considered. There are times when antipsychotic medications may be indicated as part of a treatment plan. The need for these powerful medications should be carefully assessed, with vigilant oversight of potential side effects versus benefits and regular therapeutic dosage reduction. Both professional and family caregivers should be informed of drug side effects which need to be carefully monitored.

Transitions of care

In the hospital environment, individuals with Alzheimer’s dementia are more likely to utilize emergency rooms, have extended hospital stays and are high-risk for hospital acquired adverse events such as delirium.\textsuperscript{10}

Hospital admission represents one of multiple care transitions that a person with Alzheimer’s disease may experience. At least 25 percent of individuals with Alzheimer’s disease will be discharged to another institution and 12 percent are discharged to home services.\textsuperscript{11} Some individuals with Alzheimer’s disease are at a high risk of experiencing multiple transitions between facilities due to their neuropsychiatric symptoms.

It is becoming increasingly uncommon for any one clinician to provide continuous care to a person transferring from the hospital to home or to a long-term care facility. Consequently, individuals are at risk of transferring between settings without a comprehensive and person-centered discharge plan.

Recommendations:

1. The working group recommends primary care physicians, nurse practitioners, social workers and nurses use effective dementia screening tools, which are sensitive to identifying early stage symptoms.
2. The working group recommends the expansion of Alzheimer’s education in the core curriculum of medical, nurse, social work and allied health programs in Kansas. Include early stage and MCI sensitivity screening tool training, dementia care interventions and disease management in the programs.
3. The working group recommends the creation of a Kansas “Dementia Curriculum of Excellence” recognition for college and university programs that integrate dementia training in their curriculum.
4. The working group recommends the state enforce the contractual obligation of managed care organizations (MCOs) to implement the Bridge Project protocols for individuals experiencing behavioral/mood challenges in community settings.
5. The working group recommends the state fund demonstration projects to expand the reach of dementia care through telehealth technology.
6. The working group recommends the integration and promotion of the Comprehensive Geriatric Assessment in hospitals and geriatric psychiatric units.
7. It recommends requiring the use of Delirium Reduction Protocols in all Kansas hospitals.
8. It recommends standardized discharge reports provided to families and facilities include non-pharmacological care assessments and recommendations.
9. The working group recommends the establishment of a clearinghouse for innovative projects which address the healthcare of individuals with Alzheimer’s disease and funding for pilot projects be explored.
IV. Financing Alzheimer’s Care

There are several ways individuals with Alzheimer’s dementia would be affected if Medicaid were expanded in Kansas. Medicaid expansion may provide coverage for early-onset Alzheimer’s patients who don’t yet qualify for Medicare. Expansion may ensure access to health care for rural patients with Alzheimer’s while at the same time supporting financial sustainability of rural hospitals. Medicaid expansion may provide coverage for many paid caregivers who care for people with Alzheimer’s disease in facilities. This could contribute to reducing staff turnover rates in long term care facilities, which remains high in Kansas.

Total costs for Kansas Medicaid members with Alzheimer’s and other dementia diagnoses for calendar year 2017 was $358,422,691 for a total of 13,135 beneficiaries.

For a detailed discussion of payment for various services for seniors and those with Alzheimer’s, please see Section X of this report, The Service Continuum (p. 13).

V. Education and Training

The progression of Alzheimer’s disease results in the individual being unable to accurately express their physical, social, spiritual and emotional needs. Consequently, it becomes difficult for the individual health care employee to care for the person with disease without suitable training. Currently, Kansas dementia training standards are too general and not uniform across service settings.

Current state training regulations for long-term care providers

- Skilled nursing facilities: “… shall provide a training program for each staff member before the member’s assignment to the section (Special care). Evidence of completion should be on file. The facility shall provide in-service training specific to the needs of the residents in the special care section. Direct care staff participate in at least 12 hours of general education per year.”
- Assisted living/Residential Healthcare/Home Plus/Adult Day Care: “If the facility admits residents with dementia, the administrator or operator shall ensure the provision of staff orientation and in-service education on the treatments and appropriate response to persons who exhibit behaviors associated with dementia.”
- Hospice: “If the hospice’s admission policies and the case-mix of patients demand that the aid care for individuals whose needs require additional competency beyond the minimum required in the regulations, the hospice must document how these additional skills are taught and tested.”
- Home Health: 12 hours per year of general education are required.
- Non-medical home care providers: no state defined requirement at this time.
**Recommendations:**

The working group recommends competency-based dementia training of all direct service, administrative, supervisory and other staff who are involved in the delivery of care to those with Alzheimer’s disease or other dementia employed by licensed providers. This training should include but not be limited to non-medical home care providers, home health agencies, hospice, adult day programs, assisted living, home plus and skilled nursing and residential care communities.

The working group recommends four hours of in person training and four hours of mentorship for all staff of long-term care providers which include skilled care, assisted living, residential care, adult day care and hospice. This training should include but not be limited to the following:

1. Disease overview- Understanding Dementia
2. Managing personal care
3. Challenging behaviors
   a. Identification of behavioral symptoms
   b. Communication
   c. Non-Pharmacological Interventions/Reducing antipsychotic use
   d. Validation therapy
   e. Individualized care/person-directed living
4. Engaging the person
5. Nutrition and hydration
6. Connecting with families
7. Capacity versus expressed need
8. Direct care staff self-care

**VI. LAW ENFORCEMENT AND FIRST RESPONDERS**

Law enforcement and first responder personnel are critical to the safety and health of individuals with Alzheimer’s disease or other dementia in the community. Dangerous situations may occur as the individual with Alzheimer’s disease experiences diminishing logic and problem-solving skills. Over time the person with Alzheimer’s disease loses their ability to assess if the environment or their behavior is safe or unsafe. Examples may include when the person is physically lost, is an impaired driver, or is trespassing, misusing fire arms or shoplifting. They may become disruptive or physically aggressive requiring skills to safely manage challenging behaviors. The individual with Alzheimer’s is at great risk for abuse, neglect and financial exploitation. In all of these situations the individual with Alzheimer’s disease may have limited understanding, feelings of paranoia or fear, and may be unable to explain what is happening to them.

**Recommendations:**

1. The working group recommends implementing a comprehensive statewide training program for all first responders and law enforcement agencies. The training program should include a basic disease overview, possible situations which may occur, how to identify a person with Alzheimer’s disease and how to respond appropriately to the person.
2. The working group recommends agencies such as KDADS, Kansas Department for Children and Families-Adult Protective Services, the Kansas Attorney General’s Office, and programs such as Senior Medicare Patrol, collaborate to provide education to first responders regarding the risks, prevention, and mitigation of abuse and fraud specific to consumers with Alzheimer’s.

3. The working group recommends the state promote the use of locative technologies through Area Agencies on Aging and other agencies, at Senior Health Fairs, and in various media outlets. This could include, but not be limited to, cell phone technology, GPS systems, medical alert bracelets, video monitoring and door alarms.

4. The working group recommends the development of voluntary confidential registries in collaboration with local agencies. The registry would include pertinent data about the person with disease. This confidential data would be accessible to first responder personnel.

5. The working group recommends expansion of the current Crisis Intervention Team model across all Kansas counties.

6. The working group recommends designating a local Senior Liaison officer to conduct community education and outreach regarding abuse, neglect and exploitation of seniors, to chair a multidisciplinary team of community members and to serve as the lead in situations in which law enforcement personnel encounter individuals who may have Alzheimer’s disease or other dementia.

7. The working group recommends implementing a first responder peer council chaired by the designated Senior Liaison officer to share trends, best practices and to debrief crisis situations which occur involving individuals with Alzheimer’s disease.

8. The working group recommends the development of community para-medicine programs which would provide a social worker or case manager to partner with local hospitals, community mental health centers, jails, and first responders. This position would assist an individual with Alzheimer’s disease in a crisis.

VII. PUBLIC AWARENESS

The state should provide state-of-the-art information to Kansans about Alzheimer’s prevalence, early identification and the various treatment options for addressing Alzheimer’s. It is hoped by widely educating and informing Kansas communities, stigma related to Alzheimer’s dementia will be reduced and the likelihood of early diagnosis will increase. The state should develop a coordinated media campaign to reduce stigma, and to increase knowledge of resources available for people with Alzheimer’s disease.

Recommendations:

1. The working group recommends the Kansas Advisory Council on Alzheimer’s, as part of its ongoing duties, promote the first Kansas State Plan on Alzheimer’s disease to stakeholders including AAA’s, ADRC’s, hospitals, medical professionals, advocacy organizations, municipalities, civic and religious groups.

2. The working group recommends making the Kansas Alzheimer’s Disease Plan available electronically on the KDADS and Kansas Department of Health and Environment (KDHE) websites and in writing for widespread distribution.
3. The working group recommends resources are shared for specific at-risk/underserved groups such as individuals with intellectual/developmental disabilities, minorities, non-English language speakers and persons living in frontier/rural communities.

4. The working group recommends the establishment of a website linking multiple resources such as KDADS, KDHE, The Alzheimer’s Association, the state universities, health departments and other trusted resources to promote the dissemination of accurate and up-to-date information on Alzheimer’s disease.

5. The working group recommends the promotion of clinical trials for promising drug therapies and evidence-based treatments for individuals with Alzheimer’s in Kansas.

VIII. RESEARCH

Research efforts in Kansas have accelerated in recent years, advancing our understanding of Alzheimer’s disease, testing new prevention and therapeutic strategies and developing new models of care. Kansas is one of only 21 states to have a nationally designated Alzheimer’s Disease Research Center. Since receiving this designation in 2011, the University of Kansas Alzheimer’s Disease Center (KU ADC) has made strides in preparing the state for the rising prevalence of Alzheimer’s disease. Researchers, clinicians, and educators at other state universities, including Kansas State, Emporia State, Wichita State, and KU Wichita, among others, are also making an impact.

Scientists in Kansas are hard at work to determine better ways to diagnose the disease and develop cures. The KU ADC and KU-Wichita are at the forefront of clinical trials, developing novel drugs and partnering with others to test a variety of approaches to stop, slow, or prevent the disease. As one of 35 national sites to participate in the U.S. Department of Health & Human Services, National Institute on Aging’s, Alzheimer’s Clinical Trial Consortium, the KU ADC brings the most innovating and cutting-edge trial opportunities to Kansas. Kansas scientists also have unique drug development efforts and have helped usher in an entirely new field of prevention science.

In addition, researchers across the state are investigating how to best care for the increasing number of individuals with Alzheimer’s disease. New models of care are required to stem the rising tide of Alzheimer’s and better deliver today’s treatments and tomorrow’s cure. A public health crisis of this magnitude requires a unified community approach that aligns all the key stakeholders, with primary care physicians at the forefront. Kansas researchers are beginning to test new models of care that increase the reach of the highest quality caregivers, reduce costs and lower the health burden on patients and families.

More experts dedicated to fighting this disease are needed to transform our efforts to fight Alzheimer’s disease now and in the coming years. There is a critical shortage of physicians, nurse practitioners, and social workers. Kansas state universities have developed training programs to successfully launch young physicians, scientists, and health care workers into the fight. Kansas needs a robust education and training effort to continue to develop the next generation of scientists, clinicians, and other frontline health care workers fighting the disease.
These efforts in Kansas have accelerated in recent years setting the stage for Kansas to be a national leader in fighting the disease. To build and extend these efforts, the Alzheimer’s Disease Plan working group has three main recommendations.

**Recommendations:**

- The working group recommends intensifying research efforts across the state of Kansas by improving the state’s infrastructure for basic, translational, and clinical Alzheimer’s disease research.
  - The state should provide funding to accelerate the efforts of the state’s nationally designated Alzheimer’s Disease Center to develop new therapies and clinical approaches to fight the disease across the state.
  - The state should encourage public-private partnerships and enhance opportunities of privately-funded collaborative efforts to prevent, treat, and cure Alzheimer’s and related dementias.
- The working group recommends the state encourage strategic alliances across the state’s universities, health care systems, and private industry to advance research efforts and build a pipeline of future researchers and health care workers.
- The working group recommends the state engage and educate the public on the availability, purpose, and value of research, and encourage participation in clinical trials and other studies.
  - The state should engage physicians, practitioners, insurers, and state and community partners to educate constituents about clinical trials and participation opportunities
  - The state should develop viable pathways for rural Kansans to participate in research opportunities.
  - The state should translate evidence-based prevention and treatment programs into community practice by funding research and public health multi-sector collaborations, including state (KDHE, KDADS, KanCare), local (county health departments), private (employers, insurers) and federal (i.e., NIH, CDC) agencies.

**IX. Legal Issues**

While it is important for everyone to plan for their future, legal plans are especially vital for a person with Alzheimer’s. Once a person is diagnosed, it is recommended legal documents be completed early so they may actively participate in the planning process. Such legal documents may include a living will, power of attorney, power of attorney for health care and a will. Some individuals may also want to complete a living trust and a transportable physician order for patient preferences (TPOPP). TPOPP forms are approved as a working end-of-life document in Kansas but currently are not legally recognized.

Alzheimer’s also puts individuals at risk for poor financial decision making and financial abuse. Someone with disease may not be able to participate in logical decision making nor always be able to determine if someone is taking financial advantage of them.
The Senior Safe Act (S.223 – Senior$afe Act of 2017), enacted on May 2018, allows banks and other financial providers to report suspected financial abuse. The law extends immunity from liability to certain trained individuals and their employing financial institution who in good faith and reasonable care disclose suspected exploitation of a senior citizen to a regulatory or law enforcement agency.

Individuals residing in state-only licensed facilities such as assisted living, residential health care, home plus and boarding care homes are not adequately protected by current Kansas law. These facilities are operated under state regulations that do not offer patients protections and/or appeal rights if they are inappropriately discharged to another facility or home.

**Recommendations:**

1. The working group recommends promoting legal education for individuals and caregivers through community programs, websites and other resources on legal and financial issues facing individuals with Alzheimer’s.

2. The working group recommends the Kansas Legislature enact legislation to enable TPOPP to be used as a legal advance directive.

3. The working group recommends the state promote community programs to educate consumers and professionals regarding the risks, prevention and mitigation of abuse, fraud and exploitation specific to consumers with Alzheimer’s.

4. The working group recommends the State of Kansas commit to participation in the Bank Safe training program offered by AARP, which is being piloted in 11 states.

5. The working group recommends the Kansas Legislature enact legislation affording individuals with Alzheimer’s the legal right to appeal a proposed transfer or discharge from a state-licensed only facility to determine if the reason for discharge is valid and if the facility has taken appropriate action.

6. The working group recommends the Kansas Legislature enact legislation prohibiting state-licensed only facilities from refusing to readmit a person with Alzheimer’s following hospitalization or a therapeutic leave unless an appropriate rationale is clearly described in the discharge plan document.

**X. The Service Continuum**

**In Home Services and Supports**

Caring for a person with Alzheimer’s disease at home poses significant challenges for caregivers and family members. As the disease progresses the need for support and services both for the person with disease and their caregiver increases. The availability and scope of support varies widely throughout Kansas with many rural and frontier Kansas communities having limited access to in home service options. In home care can include a variety of medical and non-medical services.

Medical services include care ordered by a physician and provided by licensed professionals including nurses, occupational/speech/physical therapists, social workers and certified nurse aides. This type of care is usually paid by Medicare, Medicaid or private insurance.

Non-medical services may include:
• Companion services; socializing, supervision, recreational activities and appointments
• Attendant care; bathing, dressing, toileting, nutrition, exercising and personal care
• Homemaker services; housekeeping, shopping or meal preparation
• Case management or coordination of services
• Home delivered or congregate meal
• Legal services provided free or reduced cost for persons age 55 years or older by Kansas Legal Services
• Access to adult day programs
• Night support for the person with disease so the caregiver can sleep

Non-medical care is usually paid privately, by long-term care insurance policies or through federal and state funded programs.

**Federal and state-funded programs in Kansas**

KDADS’ Commission on Aging administers federal and state grant funding to help older adults remain in their homes to prevent or prolong the need for institutional care. Federal funding for the Older Americans Act (OAA) is allocated to each state from the U.S. Department of Health and Human Services Administration for Community Living, Administration on Aging. The funds are distributed to the eleven Kansas Area Agencies on Aging (AAA) who contract with public or private groups to provide services. Services include information and referral, nutrition program, disease prevention and health promotion and caregiver support. In Federal Fiscal Year (FFY) 2017 there were 34,311 unduplicated clients served through the entire OAA program in Kansas.

The Senior Care Act (SCA) is funded by State General Funds and by a portion of the Social Services Block Grant. Available funds are allocated to each Area Agency on Aging (AAA) for distribution. The Senior Care Act program provides services in the home to those 60 years of age and older. These services include homemaker, chore, attendant care and case management. Participant’s contributions are determined by a sliding fee scale based upon self-reported income. In State Fiscal Year 2017 there were 2,970 clients served in this program.

**Medicaid waiver programs**

Low-income persons with Alzheimer’s disease or other dementia who meet the criteria for nursing home care may be eligible for services provided through the Kansas Medicaid program, KanCare. Home and Community Based Services (HCBS) waivers are Kansas Medicaid programs which provide services to an individual in their community instead of a facility. KDADS oversees HCBS waiver programs. These programs require individuals meet both functional and financial eligibility (Medicaid) standards.
HCBS services in Kansas that may provide services to individuals with Alzheimer’s disease include:

1. **Frail Elderly** – current caseload = 4,653 individuals
   Services include adult day care, assistive technology, personal care services, comprehensive support, financial management, home telehealth, medication reminder, nursing evaluation visit, oral health services, personal emergency response, enhanced care services and wellness monitoring.

2. **Intellectual and Developmental Disabilities (IDD)** – current caseload = 9081 individuals
   Individuals with intellectual disabilities may be eligible if they have impaired function in at least two adaptive skills areas. Services include assistive devices, adult day supports, financial management services, medical alert rental, overnight respite, personal care services, residential supports, specialized medical care, supported employment, supportive home care and wellness monitoring.

3. **Institutional Transitions**
   An Institutional Transition is the process for moving residents of qualified institutional settings into the community. This process identifies individuals who have expressed their desire to return to the community and provides them with supports to aid them in maintaining residence in the least restrictive setting of their choice.

4. **Intermediate Care Facilities for Individuals with Intellectual Disabilities** (ICF-IID);
   specific guidelines must be met for the person to eligible for Medicaid-funded ICF-IID:
   - Have active treatment needs as defined by 42 CFR §483.440
   - Be determined program eligible by your local Community Developmental Disability Organization (CDDO)
   - Meet the level of care eligibility score
   - Be financially eligible for Medicaid

5. **Traumatic Brain Injury (TBI)** – current caseload = 452 individuals
   The TBI program is for individuals age 16-65 years who have a traumatic brain injury that has caused temporary or permanent impairment to their behavioral, cognitive or physical functions who would otherwise require institutionalization in a TBI rehabilitation facility. Services include assistive devices, financial management, home delivered meals, medication reminder, personal care services, rehabilitation services, transitional living skills and enhanced care services.

6. **Program of All-Inclusive Care for the Elderly** (PACE) – current caseload = 562
   The PACE program is designed to promote quality and comprehensive health services for older adults. The primary care physicians and interdisciplinary team of professionals provide and coordinate all services. Most services are provided in the home and at the PACE Center. The person must be age 55 years or older, certified by the state as meeting the need for a nursing home level of care and must be able to live safely in the community. PACE uses Medicare and Medicaid funds to cover all medically necessary care and services. KDADs is in the process of overseeing the expansion of the PACE program in Kansas from 8 to 59 counties and more than 700 individuals.
**Recommendations:**

1. The working group recommends the Legislature increase state funding for the SCA.
2. The working group recommends the state assess the current and future capacity of the PACE program to determine how it can be leveraged to address the gaps in services for people with Alzheimer’s disease.
3. The working group recommends the state restore case management for persons served by the HCBS-Frail Elderly waiver.
4. The working group recommends the state provide incentives for individuals with Alzheimer’s to receive care at home to retain and reinvest cost savings back into the Kansas long-term care infrastructure.
5. The working group recommends the state research the option of state-sponsored long-term care insurance and encourage that insurance to cover home based models of care.

**Adult care home services**

There are 354 licensed skilled nursing facilities and approximately 450 licensed assisted living, residential care and home plus facilities in Kansas. Some of these facilities are stand-alone memory care facilities and there are also memory care units within some buildings.

Licensed facilities must provide individuals with Alzheimer’s or other dementia an environment designed to maintain the highest level of functioning and wellbeing as possible. Currently, there are no specific licensure requirements for “dementia capable” care. This term is used to describe care across the service system which meets the specific physical, psychosocial, emotional and spiritual needs of individuals with Alzheimer’s.

**Cost to families**

Care provided in long-term care facilities are available for persons to pay privately. Medicaid pays the medical costs for individuals with limited income and resources. Some long-term care facilities accept Medicaid payment, and some do not. Medicare pays for a limited amount of skilled nursing care. Long term care insurance coverage varies depending on specific policies.

**Estimated costs of long-term care services:**

<table>
<thead>
<tr>
<th>Service</th>
<th>Estimated Private Pay Rates</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home Care Service</td>
<td>$48,000 per year</td>
</tr>
<tr>
<td>Adult Day Health Care</td>
<td>$20,000 per year</td>
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<tr>
<td>Assisted Living Facility Care</td>
<td>$51,000 per year</td>
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<tr>
<td>Adult Family Home Care</td>
<td>$46,000 per year</td>
</tr>
<tr>
<td>Nursing Home Care</td>
<td>$66,600 per year ($183 per day)</td>
</tr>
</tbody>
</table>
Recommendations:

1. The working group recommends the state formally define the required criteria for “dementia capable” facilities or units.
2. The working group recommends the state add the designation of “dementia capable” care to the KDADS list of Kansas facilities.
3. The working group recommends the state require the specific quantity of facility staff based on care planning.
4. The working group recommends the state require the caregiver and person with Alzheimer’s disease involvement in developing the care plan whenever possible.
5. The working group recommends the state require specific training for the Kansas long term care surveyors on depression and delirium.

Quality Assurance

Kansas should evaluate whether the service system for seniors, both in the home and in institutional care settings regardless of funding source (e.g., private pay, Medicaid, Medicare) is “dementia capable.” Opportunities to improve the quality assurance system exist to ensure seniors are not abused/neglected/exploited. Several Kansas entities are responsible for conducting quality assurance activities in settings where seniors receive in-home and institutional services. These activities are generally not coordinated among quality assurance entities and do not involve or engage advocacy organizations or family/caregivers/persons served. In some cases, the sample sizes of persons reviewed are not large enough to consider survey results robust or representative of services provided in Kansas.

When concerns arise, available penalties lack legal or sufficient recourse to discourage providers from allowing the abuse/neglect/exploitation of seniors. Financial management of the provider entity and residents’ personal accounts should be included in quality assurance reviews. Recently the state has placed several nursing facilities in receivership as the result of financial mismanagement of facility operations and resident funds.

The KDADS Survey, Certification and Credentialing Commission (SCC) employs a team of surveyors who make routine visits to nursing facilities to assess quality of care. SCC staff issue “tags” for deficiencies found in nursing facilities, but often there are no real legal or financial consequences imposed on entities who may be owned by out-of-state, for-profit organizations that are primarily focused on the bottom line.

The KDADS Commission on Aging employs staff responsible for conducting quarterly file reviews and home visits for seniors receiving services through OAA, SCA and the Client Assessment Referral and Evaluation (CARE) program. Staff review the service plans and then visit with the individuals in their homes to ascertain whether the care plan is implemented as written and if the individual is satisfied with services received.

The Long-Term Care Ombudsman program employs a team of volunteers who respond to complaints from seniors who reside in long-term care settings, such as skilled nursing facilities. The Kansas Long-Term Care Ombudsman program is made up of paid staff and more than 130 volunteers. The Ombudsman is an advocate for people who live in long-term care facilities, including nursing homes, assisted living facilities, board and care homes, home plus facilities, adult day care centers and residential health care facilities. Kansas’ Long-Term Care Ombudsman program is a resident-centered
program designed to advocate for the civil and human rights of individuals and give a voice to those who might otherwise go unheard.

**Recommendations:**

1. The working group recommends the state conduct a state-wide needs assessment to determine the capacity, availability, cost and qualities of existing dementia care facilities and services.
2. The working group recommends the state develop dementia care standards for facilities and home and community-based care providers in partnership with stakeholders (consumers, families, caregivers, professionals, advocacy organizations, MCOs), including training on evidence-based practices, person-centered models of care, behavior management strategies, effective direct care staff ratios, standards for emergency care and inter-facility transfers.
3. The working group recommends the state develop standards based on provider/facility type and level of dementia care provided, and acuity of persons served.
4. The working group recommends the state develop standards for services to persons with Alzheimer’s dementia who live alone and/or who have no natural supports (e.g., family, guardian). This would include the type/frequency/intensity of supports needed to decrease incidents of abuse/neglect/exploitation and to prolong the independence of individuals with Alzheimer’s dementia living alone in the community.
5. The working group recommends the Legislature increase funding to strengthen the Long-Term Care Ombudsman program’s presence through increasing staff, advocacy activities and visits (scheduled/unannounced) to facilities; Long-Term Care Ombudsman visits should be coordinated in partnership with local agencies, the state certification entity and advocacy organizations.
6. The working group recommends the state obtain and document feedback from persons with Alzheimer’s and their families/caregivers through regularly occurring quality assurance activities. The state should synthesize and trend data for inclusion in annual reports to the governor and Legislature. The state should invite a patient/caregiver representative to sit on a quality review board.
7. The working group recommends the state collect continuous improvement feedback on long-term care in which data is tracked and compared over time, including outcome data, with the goal of guiding and improving practice standards. Data tracked should include individual health outcomes, hospital re-admissions, use of antipsychotics, depressive symptoms, evictions, transitions from facility to facility.
8. The working group recommends the state ensure standardized facility-specific data is available and accessible to the Alzheimer’s Disease Advisory Council and the public including information regarding education and certification providers.
9. The working group recommends the state explore the feasibility of linking facility/provider ratings with value-based payments or performance-based incentives.
10. The working group recommends the state ensure that “dementia capable” long-term services and supports are available in the setting of each individual’s choice.
11. The working group recommends the Legislature provide supplemental funding to the regional AAA and ADRCs to enable them to provide more comprehensive information and resources for persons with Alzheimer’s and their families to review options, cost and availability of services.
XI. CONCLUSION

The Kansas State Plan on Alzheimer’s Disease is a call to action for state and local government, health care providers, educators, first responders, civic and faith communities and many other Kansas stakeholders. In June 2018, Governor Jeff Colyer, M.D., by Executive Order 18-14, established the State of Kansas Alzheimer’s Disease Working Group. The Alzheimer’s Disease Working Group began meeting in August 2018 to develop a state plan to address Alzheimer’s disease. The working group has researched Alzheimer’s disease and developed the recommendations included in this report as the first step in our shared journey to address this health crisis. If we are to be successful in preventing and treating this disease we will need to regularly monitor, update and adjust our plan to fit the unique needs of Kansans within our service system. Kansas’ need for a comprehensive and effective plan to address Alzheimer’s disease is vital if we are to contain costs which are expected to increase 25.8 percent from 2018 to 2025.

Because of the evolving nature of our knowledge of Alzheimer’s disease and its effective treatment, members of the working group support an ongoing, long-term approach to address Alzheimer’s disease in our state. The working group endorses the creation of the Alzheimer’s Disease Advisory Council in which individuals appointed would serve renewable two-year periods. The purpose of the Council would be to monitor, to report progress and to describe barriers to implementation of the state plan. The Alzheimer’s Disease Advisory Council would also begin the work of identifying and engaging key players to address plan strategies and resources. Reports would be provided to the Governor and Legislature on the continuum of services available, data trends, stakeholder feedback and policy recommendations. On behalf of the citizens of Kansas we urge you to support the Kansas State Plan on Alzheimer’s Disease to improve the quality of life for our friends and family living with the disease.
GLOSSARY

A

**Anti-psychotic medications** – Anti-psychotics also known as neuroleptics or major tranquilizers are a class of medications primarily used to manage psychosis including delusions, hallucinations, paranoia or confused thoughts.

B

**BankSafe training program** – an online pilot training program that provides frontline staff with the knowledge, skills and confidence to detect and prevent financial exploitation of older consumers.

**Behavioral Risk Factor Surveillance System (BRFSS)** – is the nation’s premier system of health-related telephone surveys that collect data about U.S. residents regarding their health-related risk behaviors, chronic health conditions and use of preventive services. It is designed by the Centers of Disease Control and Prevention. It is conducted in all 50 states and U.S. territories. The Kansas Department of Health and Environment conducts the survey in Kansas.

C

**Clinical trials** – Clinical trials are research studies that explore whether a medial strategy, treatment or device is safe and effective for humans. Without clinical trials with human volunteers, there can be no better treatments, no prevention and no cure for Alzheimer’s disease.

**Cognitive decline** – Cognitive decline refers to a progressive loss of cognition or mental abilities.

**Comprehensive Geriatric assessment** – multidimensional, multidisciplinary diagnostic process used to determine medical, functional and psychosocial problems and capabilities in an elderly person who may be at risk for functional decline.

**Cultural sensitivity** – Cultural sensitivity is an awareness of the ways in which clients’ values and perceptions about health care differ from our own.

D

**Delirium** – Delirium is a serious disturbance in mental abilities that results in confused thinking and reduced awareness of the environment. The start of delirium is usually rapid within a few hours or a few days. Delirium may have a single cause or more than one cause.

**Dementia capable care** – a high quality individualized, coordinated and integrated system of care to meet the medical, physical, psycho-social and spiritual needs of a person with Alzheimer’s disease or other dementia.
Evidence based practices – the use of systematic decision-making processes or provision of services which have been shown through available scientific evidence to consistently improve measurable patient outcomes.

Geriatric psychiatric inpatient unit – a specified facility or unit of a hospital that provides assessment and treatment for individuals with a mental illness or Alzheimer’s disease and other dementia accompanied by behavioral issues and other mental illness occurring during the aging process.

Kansas Dementia Bridge Project – a dementia crisis support to individuals with Alzheimer’s disease or other dementia. The Alzheimer’s Association assists with dementia assessment, education, care plan recommendations, resource navigation, support and follow up. It is a partnership between Kansas Department of Aging and Disability Services and the Alzheimer’s Association.

Mild Cognitive Impairment (MCI) – MCI causes a slight but noticeable and measurable decline in cognitive abilities including memory and thinking skills. A person with MCI is at an increased risk of developing Alzheimer’s disease or other dementia.

Neuropsychiatric symptoms – Eighty percent of individuals with Alzheimer’s disease or other dementia will experience neuropsychiatric (behavioral and affective) symptoms. The many serious consequences of these complications are greater impairment in activities of daily living, more rapid cognitive decline, worse quality of life, earlier institutionalization and greater caregiver depression.

Person-centered care – Person centered care is a philosophy and practice of basing all individual care decisions on an individuals’ needs, preferences and expectations.

Receivership – the state of a business that has been placed under the control of a receiver because it is bankrupt.
Skilled facilities – a nursing home recognized by the Medicare and Medicaid systems as meeting long term care needs for individuals who have the potential to function independently after a limited period of care. A multidisciplinary team guides health care and rehabilitative services, including skilled nursing care.

Senior Safe Act – allows banks and other financial providers to report fiduciary abuse. The law extends immunity from liability to certain trained individuals and their employing financial institution who, in good faith and with reasonable care, disclose suspected exploitation of a senior citizen to a regulatory or law enforcement agency.

Support group – Support groups are a group of individuals who have common experiences or concerns who provide each other with encouragement, comfort and advice.

Transition of care – refers to changing the setting in which a person is being treated. For example, if a person is transferred from inpatient hospital care to a nursing home after their hospital stay, then that person has experienced transition of care between two different facilities.
REFERENCES

APPENDICES


Appendix B: Executive Order 18-14

Appendix C: Members of the State of Kansas Alzheimer’s Disease Working Group

Appendix D: 2018 Community Survey for Alzheimer’s Disease Plan
APPENDIX A: CAUSES OF DEMENTIA AND ASSOCIATED CHARACTERISTICS

Alzheimer’s Disease
Most common cause of dementia; accounts for an estimated 60 percent to 80 percent of cases. Autopsy studies show that about half of these cases involve solely Alzheimer’s pathology; many of the remaining cases have evidence of additional pathologic changes related to other dementias. This is called mixed pathology, and if recognized during life is called mixed dementia.

Difficulty remembering recent conversations, names or events is often an early clinical symptom; apathy and depression are also often early symptoms. Later symptoms include impaired communication, disorientation, confusion, poor judgment, behavioral changes and, ultimately, difficulty speaking, swallowing and walking.

Revised guidelines for diagnosing Alzheimer’s were proposed and published in 2011. They recommend that Alzheimer’s be considered a slowly progressive brain disease that begins well before clinical symptoms emerge.

The hallmark pathologies of Alzheimer’s are the progressive accumulation of the protein fragment beta-amyloid (plaques) outside neurons in the brain and twisted strands of the protein tau (tangles) inside neurons. These changes are eventually accompanied by the damage and death of neurons.

Vascular Dementia
The brain changes of vascular dementia are found in about 40 percent of brains from individuals with dementia. About 10 percent of brains from individuals with dementia show evidence of vascular dementia alone. However, it is very common as a mixed pathology in older individuals with Alzheimer’s dementia, about 50 percent of whom have pathologic evidence of infarcts (silent strokes).

Impaired judgment or impaired ability to make decisions, plan or organize is more likely to be the initial symptom, as opposed to the memory loss often associated with the initial symptoms of Alzheimer’s. In addition to changes in cognition, people with vascular dementia can have difficulty with motor function, especially slow gait and poor balance.

Vascular dementia occurs most commonly from blood vessel blockage or damage leading to infarcts (strokes) or bleeding in the brain. The location, number and size of the brain injuries determine whether dementia will result and how the individual’s thinking and physical functioning will be affected.

In the past, evidence of vascular dementia was used to exclude a diagnosis of Alzheimer’s (and vice versa). That practice is no longer considered consistent with the pathologic evidence, which shows the brain changes of Alzheimer’s and vascular dementia commonly coexist. When there is clinical evidence of two or more causes of dementia, the individual is considered to have mixed dementia.

Dementia with Lewy Bodies (DLB)
People with DLB have some of the symptoms common in Alzheimer’s but are more likely to have initial or early symptoms of sleep disturbances, well-formed visual hallucinations, and slowness, gait imbalance or other parkinsonian movement features. These features, as well as early visuospatial impairment, may occur in the absence of significant memory impairment.

Lewy bodies are abnormal aggregations (or clumps) of the protein alpha-synuclein in neurons. When they develop in a part of the brain called the cortex, dementia can result. Alpha-synuclein also
aggregates in the brains of people with Parkinson’s disease (PD), in which it is accompanied by severe neuronal loss in a part of the brain called the substantia nigra. While people with DLB and PD both have Lewy bodies, the onset of the disease is marked by motor impairment in PD and cognitive impairment in DLB.

The brain changes of DLB alone can cause dementia, but very commonly people with DLB have coexisting Alzheimer’s pathology. In people with both DLB and Alzheimer’s pathology, symptoms of both diseases may emerge and lead to some confusion in diagnosis. Vascular dementia can also coexist and contribute to the dementia. When evidence of more than one dementia is recognized during life, the individual is said to have mixed dementia.

**Mixed Dementia**
Characterized by the hallmark abnormalities of more than one cause of dementia — most commonly Alzheimer’s combined with vascular dementia, followed by Alzheimer’s with DLB, and Alzheimer’s with vascular dementia and DLB. Vascular dementia with DLB is much less common.

Recent studies suggest that mixed dementia is more common than previously recognized, with about half of older people with dementia having pathologic evidence of more than one cause of dementia. Recent studies also show that the likelihood of having mixed dementia increases with age and is highest in the oldest-old (people age 85 or older).

**Frontotemporal Lobar Degeneration (FTLD)**
Includes dementias such as behavioral-variant FTLD, primary progressive aphasia, Pick’s disease, corticobasal degeneration and progressive supranuclear palsy.

Typical early symptoms include marked changes in personality and behavior and/or difficulty with producing or comprehending language. Unlike Alzheimer’s, memory is typically spared in the early stages of disease.

Nerve cells in the front (frontal lobe) and side regions (temporal lobes) of the brain are especially affected, and these regions become markedly atrophied (shrunken). In addition, the upper layers of the cortex typically become soft and spongy and have abnormal protein inclusions (usually tau protein or the transactive response DNA-binding protein).

The symptoms of FTLD may occur in those age 65 years and older, similar to Alzheimer’s, but most people with FTLD develop symptoms at a younger age. About 60 percent of people with FTLD are ages 45 to 60. FTLD accounts for about 10 percent of dementia cases.

**Parkinson’s Disease (PD)**
Problems with movement (slowness, rigidity, tremor and changes in gait) are common symptoms of PD.

In PD, alpha-synuclein aggregates appear in an area deep in the brain called the substantia nigra. The aggregates are thought to cause degeneration of the nerve cells that produce dopamine.

The incidence of PD is about one-tenth that of Alzheimer’s.

As PD progresses, it often results in dementia secondary to the accumulation of Lewy bodies in the cortex (similar to DLB) or the accumulation of beta-amyloid clumps and tau tangles (similar to Alzheimer’s).
Creutzfeldt-Jakob Disease
This very rare and rapidly fatal disorder impairs memory and coordination and causes behavior changes.
Results from a misfolded protein (prion) that causes other proteins throughout the brain to misfold and malfunction.
May be hereditary (caused by a gene that runs in one’s family), sporadic (unknown cause) or caused by a known prion infection.
A specific form called variant Creutzfeldt-Jakob disease is believed to be caused by consumption of products from cattle affected by mad cow disease.

Normal Pressure Hydrocephalus
Symptoms include difficulty walking, memory loss and inability to control urination.
Accounts for less than 5 percent of dementia cases.
Caused by impaired reabsorption of cerebrospinal fluid and the consequent buildup of fluid in the brain, increasing pressure in the brain.
People with a history of brain hemorrhage (particularly subarachnoid hemorrhage) and meningitis are at increased risk.
Can sometimes be corrected with surgical installation of a shunt in the brain to drain excess fluid.

APPENDIX B: EXECUTIVE ORDER 18-14

State of Kansas

Governor Jeff Colyer, M.D.
Timothy Keck, Secretary

Alzheimer’s Disease Plan Working Group

WHEREAS, more than 5 million Americans suffer from Alzheimer’s, and that number is estimated to more than triple by the year 2050; and

WHEREAS, nearly one out of every three seniors who die each year suffer from some form of dementia; and

WHEREAS, Alzheimer’s is a serious disease that affects not only those who have it, but also their families and caretakers; and

WHEREAS, Kansas is the only state in the nation that is not currently drafting or implementing a comprehensive Alzheimer’s Disease Plan; and

WHEREAS, the severity of this health crisis necessitates the implementation of a statewide response plan; and

WHEREAS, this health crisis has a significant fiscal impact on the State of Kansas, which is estimated to keep increasing; and

WHEREAS, Alzheimer’s and other forms of dementia negatively impact the health and quality of life of Kansans.

NOW THEREFORE, pursuant to the authority vested in me as Governor of the State of Kansas, I hereby establish the Kansas Alzheimer’s Disease Working Group (“Working Group”):

1. Membership of the “Working Group” shall be comprised of the following members:
   1. One member appointed by the Speaker of the House;
   2. One member appointed by the House Majority Leader;
   3. One member appointed by the Minority Leader of the House;
   4. One member appointed by the Senate President;
   5. One member appointed by the Senate Majority Leader;
   6. One member appointed by the Minority Leader of the Senate;
   7. At least one person with Alzheimer’s disease;
   8. At least one caregiver of a person with Alzheimer’s disease;
9. A representative of the nursing facility industry;
10. A representative of the assisted living industry;
11. A representative of the in-home care/hospice industry;
12. A representative of the medical care provider community;
13. An Alzheimer’s disease researcher;
14. A representative of the of the Alzheimer’s Association;
15. A representative of the Kansas Silver Haired Legislature;
16. A representative from the law enforcement community;
17. A representative from the Kansas Department of Labor or Kansas Department of Commerce with knowledge of workforce issues;
18. Two (2) representatives from the Kansas Department for Aging and Disability Services with knowledge of mental health, developmental disabilities, aging, and long-term care issues; and
19. Two (2) representatives from the Kansas Department of Health and Environment with knowledge of Medicaid and public health issues.

2. The Kansas Department for Aging and Disability Services shall convene the Working Group and provide the necessary staffing and administrative support to the Working Group.

3. The Working Group shall be chaired by one of the members named above, as determined by the Governor.

4. Other members with relevant experience may be invited to join the Working Group by the Governor or Chair.

5. The Working Group shall meet monthly or as needed, at the discretion of the Chair.

6. Members of the Working Group shall not receive compensation, subsistence, allowance, or associated expenses. Officers or employees of state agencies who are appointed to the Working Group as part of their duties shall be authorized to participate on the Working Group and may claim subsistence, allowance, mileage, or associated expenses as permitted by law.

7. It shall be the duty of the Working Group to:
   1. Assess the current and future impact of Alzheimer’s disease on residents of the State of Kansas;
   2. Examine the existing industries, services, and resources addressing the needs of persons with Alzheimer’s, their families, and caregivers; and
   3. Develop a strategy to mobilize a state response to this public health crisis.

8. The Working Group shall also include an examination of the following in its assessment and recommendations:
   1. Trends in Alzheimer’s population and needs, including the changing population with dementia, including but not limited to:
      1. State role in long-term care, family caregiver support, and assistance to persons with early-stage and early onset of Alzheimer’s;
      2. Surveillance of persons with Alzheimer’s disease for purposes of having proper estimates of the number of persons in the state with Alzheimer’s disease; and
3. The inappropriate use of antipsychotic medications to treat symptoms of dementia, which is a multi-faceted issue that touches every major area of our state’s health care system, and comprehensive strategies to reduce this use.

2. Existing services, resources, and capability, including but not limited to the:
   1. Type, cost, and availability of dementia services;
   2. Dementia-specific training requirements for long-term care staff;
   3. Quality care measures for long-term care facilities;
   4. Capacity of public safety and law enforcement to respond to persons with Alzheimer’s;
   5. Availability of home- and community-based resources for persons with Alzheimer’s and respite care to assist families;
   6. Inventory of long-term care dementia care units;
   7. Adequacy and appropriateness of geriatric-psychiatric units for persons with behavior disorders associated with Alzheimer’s and related dementia;
   8. Assisted living residential options for persons with dementia; and
   9. State support of Alzheimer’s research through Kansas universities and other resources.

3. Needed State policies or responses, including but not limited to directions for the provision of clear and coordinated services and supports to persons and families living with Alzheimer’s and related disorders and strategies to address any identified gaps in services.

9. The Working Group is directed to hold public meetings and to utilize technological means, such as webcasts, to gather feedback on the recommendations from persons and families affected by Alzheimer’s disease and the general public. The Working Group shall be subject to the Kansas Open Records Act and the Kansas Open Meetings Act. Plans, reports, or recommendations of any nature adopted by the Working Group shall be considered advice to the Governor and Legislature, and shall not be construed as official policies, positions, or interpretations of laws, rules, or regulations by any department or agency of state government, nor shall any such department or agency be bound in any manner to consider such advice when conducting their regulatory affairs.

10. The Working Group is directed to submit a report of its finding and recommendations to the Legislature and Governor in the form of a Kansas Alzheimer’s Disease Plan by January 14, 2019, or as appropriate during the intervening period.

11. The Working Group shall sunset upon delivery of the Kansas Alzheimer’s Disease Plan to the Legislature and Governor. By further Executive Order, the Governor may reconvene the Working Group to update the plan in the future.

This document shall be filed with the Secretary of State as Executive Order No. 18-14 and shall become effective immediately.
APPENDIX C: WORKING GROUP MEMBERS

1. Debra L. Biehl, LNHA, Executive Director, Garden Terrace Alzheimer’s Center of Excellence; Overland Park, KS

2. Dr. Jeffrey M. Burns, M.D., M.S., Professor, Co-Director of the University of Kansas Alzheimer’s Disease Center, Neurocognitive Division Chief; Department of Neurology, University of Kansas Medical Center, Kansas City, KS

3. Janie Carney, Author/Writer, Community Advocate; Wichita, KS

4. Bill Carr, Sheriff, Kansas Sheriff’s Association; Ford County, KS

5. **Chair**: Ann Elifrits, MS, LCP, LCAC, Commissioner, Commission on Aging, Kansas Department for Aging and Disability Services

6. Jamie Gideon, Kansas Director of Public Policy, Alzheimer’s Association; Wichita, KS

7. Leslie Hale, LMSW, Deputy Director, Prevention & Protective Services, Department for Children & Families

8. Rick Hoffmeister, Policy Analyst, Division of Health Care Finance, Kansas Department of Health & Environment

9. Representative Eileen Horn, KS House of Representatives, District 10; Lawrence, KS

10. LaVeta Jarrett, APRN, hospital affiliations with Via Christi & Newton Medical Center; Wichita, KS

11. Ryan Lester, Director, MPH, Bureau of Health Promotion, Kansas Department of Health & Environment

12. Rev. William W. Mason; Community Member; Parsons, KS

13. Justin McFarland, Deputy General Counsel, Labor Market Information Services Director, Kansas Department of Labor

14. Mitzi McFatrich, Executive Director, Kansas Advocates for Better Care; Lawrence, KS

15. Cindy Miller, LPN, Dementia Care Specialist, Alzheimer’s Association; Topeka, KS

16. Michelle Niedens, LSCSW, Director, MyAlliance, University of Kansas Alzheimer’s Disease Center

17. Heather Porter, BSN, RN, Chief Clinical Officer, Newton Medical Center; Newton, KS

18. Representative Abraham Rafie, KS House of Representatives, District 48; Overland Park, KS
19. Amy Siple, APRN, GS-C, Associate Professor of Nursing, Newman University, and Nurse Practitioner at Wichita Medical Associates; Wichita, KS

20. Kathy Vance, MBA, MHSA, FACMPE, Retired Medical Practice Manager; Community Member; Overland Park, KS

21. Belinda Vierthaler, LMSW, LACHA, Director, Grow with Evergreen Resources for Transforming Innovations (GERTI); Olathe, KS

22. Don Woodard, Speaker, Silver Haired Legislature; Auburn, KS
APPENDIX D: 2018 COMMUNITY SURVEY FOR ALZHEIMER’S DISEASE PLAN

In the Fall of 2018, the working group conducted a six-week long survey to obtain public comment and input on the needs of Kansans. It was distributed widely to mailing lists of working group members and the organizations they represent. A total of 531 surveys were completed during that time. It included multiple choice questions as well as open-ended questions so respondents could share their own recommendations.

To view the Survey Monkey results in their entirety, including responses to the open-ended questions, click here https://www.surveymonkey.com/results/SM-PVXRTCLCV/.
Q1 What is your zip code?

Answered: 531  Skipped: 0
Q2 What is your age?

Answered: 531   Skipped: 0

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Q3 Which of the following best describes you? (Please select only one).

Answered: 531   Skipped: 0

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</tr>
<tr>
<td>TOTAL</td>
<td></td>
</tr>
</tbody>
</table>
Q4 On a scale from 1-5 with 5 being very concerned, how concerned are you about how dementia could potentially affect you or a loved one?

Answered: 531  Skipped: 0

<table>
<thead>
<tr>
<th>1. NOT CONCERNED AT ALL</th>
<th>2</th>
<th>3. SOMEWHER CONCERNED</th>
<th>4</th>
<th>5. VERY CONCERNED</th>
<th>I HAVE NOT THOUGHT OF HOW IT MIGHT AFFECT ME OR A LOVED ONE</th>
<th>TOTAL</th>
<th>WEIGHTED AVERAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>(no label)</td>
<td>0.56%</td>
<td>1.69%</td>
<td>15.82%</td>
<td>17.33%</td>
<td>63.84%</td>
<td>0.75%</td>
<td>4</td>
</tr>
</tbody>
</table>

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Q5 Do you provide in-home care or outside the home care for someone who has dementia?

Answered: 528  Skipped: 3

<table>
<thead>
<tr>
<th>ANSWER CHOICES</th>
<th>RESPONSES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>31.25%</td>
</tr>
<tr>
<td>No</td>
<td>68.75%</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
</tr>
</tbody>
</table>
Q6 Does anyone else provide care for the individual receiving care?

Answered: 119  Skipped: 412

<table>
<thead>
<tr>
<th>ANSWER CHOICES</th>
<th>RESPONSES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>84.03%</td>
</tr>
<tr>
<td>No</td>
<td>15.97%</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
</tr>
</tbody>
</table>
Q7 How many hours of care are provided for this individual per week?

Answered: 114   Skipped: 417
Q8 Do you feel you need more help than is available?

Answered: 117  Skipped: 414

<table>
<thead>
<tr>
<th>ANSWER CHOICES</th>
<th>RESPONSES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>57.26%</td>
</tr>
<tr>
<td>No</td>
<td>42.74%</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
</tr>
</tbody>
</table>
Q9 What limits you from getting more help? (Please select all that apply).

Answered: 114  Skipped: 417

<table>
<thead>
<tr>
<th>ANSWER CHOICES</th>
<th>RESPONSES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial resources</td>
<td>57.02%</td>
</tr>
<tr>
<td>Privacy issues</td>
<td>6.14%</td>
</tr>
<tr>
<td>Lack of outside resources</td>
<td>29.82%</td>
</tr>
<tr>
<td>Knowledge of resources</td>
<td>25.44%</td>
</tr>
<tr>
<td>Transportation issues</td>
<td>14.04%</td>
</tr>
<tr>
<td>Limited internet access</td>
<td>0.00%</td>
</tr>
<tr>
<td>Limited time to access resources</td>
<td>15.79%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>35.96%</td>
</tr>
</tbody>
</table>

Total Respondents: 114
Q10 If care is provided, how are the care and services paid for? (Check all that apply).

Answered: 118  Skipped: 413

<table>
<thead>
<tr>
<th>Answer Choices</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicare</td>
<td>44.07%</td>
</tr>
<tr>
<td>Medicaid</td>
<td>31.36%</td>
</tr>
<tr>
<td>Veteran's benefits</td>
<td>7.63%</td>
</tr>
<tr>
<td>Private insurance</td>
<td>33.05%</td>
</tr>
<tr>
<td>Family is financially helping</td>
<td>33.90%</td>
</tr>
<tr>
<td>They do not have health insurance</td>
<td>2.94%</td>
</tr>
<tr>
<td>Private pay</td>
<td>47.46%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>13.56%</td>
</tr>
</tbody>
</table>

Total Respondents: 118
Q11 Identify the most pressing needs in Kansas for persons impacted by dementia. (Please rank items 1 - 8)

Answered: 393  Skipped: 138

<table>
<thead>
<tr>
<th>Category</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>TOTAL</th>
<th>SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information about the types of services</td>
<td>29.58%</td>
<td>12.39%</td>
<td>12.96%</td>
<td>14.93%</td>
<td>12.68%</td>
<td>11.27%</td>
<td>6.20%</td>
<td>355</td>
<td>4.73</td>
</tr>
<tr>
<td>available and how to use them</td>
<td>105</td>
<td>44</td>
<td>46</td>
<td>53</td>
<td>45</td>
<td>40</td>
<td>22</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Access to services</td>
<td>16.43%</td>
<td>25.50%</td>
<td>22.38%</td>
<td>14.16%</td>
<td>12.46%</td>
<td>8.50%</td>
<td>0.57%</td>
<td>353</td>
<td>4.92</td>
</tr>
<tr>
<td></td>
<td>58</td>
<td>90</td>
<td>79</td>
<td>50</td>
<td>44</td>
<td>30</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of services</td>
<td>11.67%</td>
<td>16.11%</td>
<td>24.17%</td>
<td>25.00%</td>
<td>12.50%</td>
<td>6.94%</td>
<td>3.61%</td>
<td>360</td>
<td>4.54</td>
</tr>
<tr>
<td></td>
<td>42</td>
<td>58</td>
<td>87</td>
<td>45</td>
<td>37</td>
<td>25</td>
<td>13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Affordability of services</td>
<td>25.27%</td>
<td>24.18%</td>
<td>14.84%</td>
<td>14.01%</td>
<td>10.16%</td>
<td>7.14%</td>
<td>4.40%</td>
<td>364</td>
<td>5.01</td>
</tr>
<tr>
<td></td>
<td>92</td>
<td>88</td>
<td>54</td>
<td>51</td>
<td>37</td>
<td>26</td>
<td>16</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support for families and caregivers</td>
<td>8.31%</td>
<td>9.97%</td>
<td>12.47%</td>
<td>17.17%</td>
<td>30.47%</td>
<td>16.34%</td>
<td>5.28%</td>
<td>361</td>
<td>3.78</td>
</tr>
<tr>
<td></td>
<td>30</td>
<td>36</td>
<td>45</td>
<td>62</td>
<td>110</td>
<td>59</td>
<td>19</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education and training</td>
<td>5.18%</td>
<td>5.99%</td>
<td>9.26%</td>
<td>11.17%</td>
<td>17.17%</td>
<td>40.87%</td>
<td>10.35%</td>
<td>367</td>
<td>3.07</td>
</tr>
<tr>
<td></td>
<td>19</td>
<td>22</td>
<td>34</td>
<td>41</td>
<td>63</td>
<td>150</td>
<td>38</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health care, services, and information</td>
<td>4.75%</td>
<td>5.01%</td>
<td>2.37%</td>
<td>4.22%</td>
<td>5.01%</td>
<td>8.97%</td>
<td>69.66%</td>
<td>379</td>
<td>1.95</td>
</tr>
<tr>
<td>are available in your first language</td>
<td>18</td>
<td>19</td>
<td>9</td>
<td>18</td>
<td>19</td>
<td>34</td>
<td>264</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Q12 Based on your experiences in Kansas, please indicate your satisfaction with the following aspects of services and information available to individuals with dementia.

Answered: 391  Skipped: 140

<table>
<thead>
<tr>
<th></th>
<th>VERY DISSATISFIED</th>
<th>DISSATISFIED</th>
<th>NEITHER DISSATISFIED OR SATISFIED</th>
<th>SATISFIED</th>
<th>VERY SATISFIED</th>
<th>TOTAL</th>
<th>WEIGHTED AVERAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to services (health care services, supportive services such as meals, medication assistance)</td>
<td>6.70% (26)</td>
<td>26.80% (104)</td>
<td>46.62% (177)</td>
<td>18.81% (73)</td>
<td>2.06% (8)</td>
<td>388</td>
<td>2.83</td>
</tr>
<tr>
<td>Quality of services</td>
<td>7.59% (29)</td>
<td>24.08% (92)</td>
<td>45.29% (173)</td>
<td>20.42% (78)</td>
<td>2.62% (10)</td>
<td>382</td>
<td>2.86</td>
</tr>
<tr>
<td>Affordability of services</td>
<td>20.37% (77)</td>
<td>35.19% (133)</td>
<td>34.39% (130)</td>
<td>8.73% (33)</td>
<td>1.32% (5)</td>
<td>378</td>
<td>2.35</td>
</tr>
<tr>
<td>Support and education for families and caregivers</td>
<td>7.97% (31)</td>
<td>29.05% (113)</td>
<td>45.76% (178)</td>
<td>14.40% (56)</td>
<td>2.83% (11)</td>
<td>389</td>
<td>2.75</td>
</tr>
<tr>
<td>Education and training for professionals</td>
<td>6.98% (27)</td>
<td>25.84% (100)</td>
<td>43.41% (168)</td>
<td>22.22% (86)</td>
<td>1.55% (6)</td>
<td>387</td>
<td>2.86</td>
</tr>
<tr>
<td>Information about the types of services available</td>
<td>8.76% (34)</td>
<td>36.60% (142)</td>
<td>40.21% (156)</td>
<td>12.89% (50)</td>
<td>1.55% (6)</td>
<td>398</td>
<td>2.62</td>
</tr>
<tr>
<td>Information about how to use available services/Extent of services</td>
<td>11.28% (44)</td>
<td>35.38% (138)</td>
<td>40.51% (158)</td>
<td>11.79% (46)</td>
<td>1.03% (4)</td>
<td>390</td>
<td>2.56</td>
</tr>
</tbody>
</table>

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Q13 In your experience/observation, Kansas at the present time is doing __________ to address dementia in Kansas (fill in the blank).

Answered: 396  Skipped: 135

<table>
<thead>
<tr>
<th>ANSWER CHOICES</th>
<th>RESPONSES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doing more than enough</td>
<td>0.51%</td>
</tr>
<tr>
<td>Doing enough</td>
<td>6.31%</td>
</tr>
<tr>
<td>Not doing enough</td>
<td>39.65%</td>
</tr>
<tr>
<td>Not doing anywhere close to</td>
<td>27.02%</td>
</tr>
<tr>
<td>I don't know</td>
<td>26.52%</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
</tr>
</tbody>
</table>
Q14 What do you think Kansas is doing well related to dementia?

Answered: 291    Skipped: 240
Q15 What do you think is needed in Kansas to better help individuals with dementia? Give an example if possible of what you think is needed.

Answered: 319   Skipped: 212
Q16 When thinking about Kansas policies to help individuals with dementia and their caregivers, which are most important? (Please select only 3 items)

Answered: 388  Skipped: 143

<table>
<thead>
<tr>
<th>ANSWER CHOICES</th>
<th>RESPONSES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding and support for dementia research</td>
<td>16.49%</td>
</tr>
<tr>
<td>Alzheimer's Working Group Survey</td>
<td>SurveyMonkey</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------------------------------</td>
<td>--------------</td>
</tr>
<tr>
<td>Programs and services for individuals with dementia who have limited financial resources</td>
<td>53.87% 209</td>
</tr>
<tr>
<td>Support programs and services for all caregivers</td>
<td>29.12% 113</td>
</tr>
<tr>
<td>Affordable in-home services for individuals with dementia</td>
<td>51.55% 200</td>
</tr>
<tr>
<td>Improving care quality in residential settings like nursing homes or assisted living facilities</td>
<td>31.44% 122</td>
</tr>
<tr>
<td>A more professional workforce with knowledge of how to care for those with dementia</td>
<td>28.09% 109</td>
</tr>
<tr>
<td>A central point of dementia information and referral</td>
<td>14.18% 55</td>
</tr>
<tr>
<td>Access to assisted living for those with limited financial resources</td>
<td>29.64% 115</td>
</tr>
<tr>
<td>Transportation services for individuals living with dementia</td>
<td>5.15% 20</td>
</tr>
<tr>
<td>Employment support and transition programs for those with early onset dementia</td>
<td>3.61% 14</td>
</tr>
<tr>
<td>Mentorship programs for health and long term care staff caring for individuals with dementia</td>
<td>7.47% 29</td>
</tr>
<tr>
<td>Night care programs</td>
<td>15.21% 59</td>
</tr>
<tr>
<td>Access to wellness based activities for individuals living with early stage dementia</td>
<td>7.47% 29</td>
</tr>
<tr>
<td>Expedited Medicaid approval pathways for individuals that need urgent long-term care</td>
<td>28.35% 110</td>
</tr>
<tr>
<td>Access to health care providers with dementia expertise</td>
<td>23.45% 91</td>
</tr>
<tr>
<td>Total Respondents: 388</td>
<td></td>
</tr>
</tbody>
</table>
Q17 Who or what organizations would you first ask for help to deal with dementia, or if you have already asked for help who did you ask first?

Answered: 314    Skipped: 217