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2013 Purple Ribbon Task Force Surveys on Alzheimer's Disease and Related Dementias

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Executive Summary

In 2012, the Florida State Legislature created the Purple Ribbon Task Force (PRTF) to address the growing epidemic of Alzheimer's disease and related dementias (ADRD). The major responsibilities of the Task Force include the development of a comprehensive state plan recommending state policy and strategies to mobilize a state response. To support this effort, the Department of Elder Affairs conducted five surveys developed in collaboration with the PRTF. The surveys addressed the experiences of five groups of stakeholders: persons with ADRD; family caregivers of persons with ADRD; concerned families and friends of persons with ADRD; healthcare providers and paid caregivers of persons with ADRD; and policy, legal, education, and other professionals. A total 840 people responded to the surveys.

The surveys included questions that identify various characteristics of the respondents and their experiences with Alzheimer's disease and related dementias. Respondents were asked a common set of questions to identify: the greatest challenges for persons with ADRD and their caregivers, the critical issues the State of Florida needs to address in the next few years, and the best ways to increase the public's awareness and understanding of the disease.

Challenges for Persons With ADRD

Persons with ADRD were most concerned about being a burden on others and reported that the loss of the ability to drive, anxiety, and depression were the most challenging issues they faced.

Challenges for Families and Caregivers

Caregivers and family and friends reported that losing control over their lifestyle, difficulty communicating with the person with ADRD, and changing family relationships were the most challenging issues for caregivers or families of persons with ADRD. Families and friends as well as healthcare providers and paid caregivers were also concerned about caregiver depression and anxiety. In contrast, healthcare providers and paid caregivers and other professionals considered paying for services the number one issue. Becoming a financial burden on children of families with a person with ADRD and dealing with financial, legal, and insurance issues were perceived as further major concerns for families involved with ADRD by respondents in the professional group.

Support Services Needed by Persons With ADRD to Stay at Home

Caregivers indicated several areas of help needed by persons with ADRD who wish to remain in their homes. These included respite for the caregiver (65%), personal care (58%), financial assistance (52%), medical care (41%), and legal advice (36%).

Barriers and Challenges for Caregivers, and Families

The main barriers that prevented caregivers from receiving the services or resources they needed were the inability to afford them (46%), lack of knowledge about where to find them (40%), lack of time (26%), and lack of availability (24%).

Respondents identified the following as the seven most challenging issues for caregivers and families of persons with ADRD:

- Communication with the person with ADRD,
- Changing relationships in the family,
- Feeling depressed or anxious,
- Losing control of lifestyle,
- Dealing with financial, legal, and insurance issues,
- Paying for services, and
- Becoming a financial burden on children.

While 39 percent of caregivers reported that they were employed, 49 percent of these respondents said their caregiving responsibilities affected their employment, often causing them to cut back on hours of work or leave their job.

Most Helpful Resources for Information

Caregivers and persons with ADRD were asked to indicate the most helpful ways of getting information about ADRD. They responded that they considered the best ways of getting information about ADRD to be Internet or web-based information and trainings, in-person support groups, one-on-one counseling, community education and training, toll-free 24-hour telephone help lines, case management, and seminars.

Best Ways to Raise General Awareness of ADRD in Florida

Respondents identified the following methods as best for increasing public awareness of ADRD: service announcements on radio and TV, websites with updated information, aging services and senior centers, physicians, and churches and faith communities. In addition, they considered the Veterans Administration, law enforcement, hospitals, nursing schools, and employers and the workplace as effective sources for raising ADRD awareness.

Most Important Critical Issues State Government Should Address

Most respondents identified access to affordable and appropriate dementia-specific care as a major critical issue state government should address. In addition, they recommended the following critical issues as “very important” for consideration: ensuring quality of care, research

on prevention and treatment with clinical trials, education and training for caregivers, having an educated and trained workforce assisting persons with ADRD, and assistance for families in paying for care.

Background

Alzheimer's disease is the sixth leading cause of death in the United States. More than five million Americans currently have the disease.¹ An estimated 14.7 percent of persons 70 years of age and older were afflicted with dementia in the United States in 2010. Research projects a threefold or greater increase in the total number of persons with Alzheimer's disease between 2000 and 2050, indicating it will continue to be a major public health problem during the coming decades.²

ADRD has a significant impact on the person suffering from the disease, their caregivers, families, and friends. Symptoms vary significantly by stage and type of ADRD, ranging from mild cognitive decline to the loss of ability to respond to the environment, control movement, and communicate, resulting in high reliance on help with daily personal care, eating, and using the toilet.³

Dementia presents an economic burden on individuals and society. For example, in 2010, the annual cost of care for a person with ADRD ranged from an estimated \$41,689 to \$56,290, depending on the method used to value informal care. Medicare paid approximately \$11 billion of the total cost of dementia care, estimated to be between \$157 and \$215 billion in 2010.⁴ The main contributors to the costs attributable to dementia identified in this research were the costs of institutional and home-based long-term care rather than the costs of medical services.⁵

Currently, more than 40 states have developed or are developing an Alzheimer's Disease Plan.⁶ In April 2012, the Florida Legislature established the Purple Ribbon Task Force (PRTF) to develop a comprehensive state plan to address the needs of individuals with Alzheimer's disease and their caregivers. The Task Force members were appointed to assess the current and future impact of Alzheimer's disease and related forms of dementia (ADRD) on the state; examine the existing industries, services, and resources in place that address the needs of individuals with Alzheimer's disease; develop a strategy to mobilize a state response to the Alzheimer's disease epidemic; and provide information regarding the development of state policy with respect to individuals with Alzheimer's disease, the role of the state in providing care to those with ADRD, and the number of people with ADRD in the state.

The task force consists of 18 volunteers who include six legislative staff members appointed by the Governor, at least one person having ADRD, one family caregiver of a person with

¹ http://www.alz.org/alzheimers_disease_facts_and_figures.asp#quickFacts

² Zimmerman, S. PD, Suchindran C., Reed P, Wang L, Boustani M, and Sudha S. The public health impact of Alzheimer's disease, 2000-2050: potential implication of treatment advances. *Annu Rev Public Health*. 2002;23:213-31. Epub 2001 Oct 25.

³ http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp?type=alzFooter

⁴ <http://www.nejm.org/doi/full/10.1056/NEJMsa1204629>.

⁵ <http://www.nejm.org/doi/full/10.1056/NEJMsa1204629#t=articleBackground>

⁶ http://act.alz.org/site/PageNavigator/state_plans.html

ADRD, and representatives of various entities involved with ADRD.

To support the PRTF in developing a Florida state plan addressing the growing public health impact of ADRD, the Department of Elder Affairs conducted surveys of major stakeholders in the state. These stakeholders included people with ADRD; family caregivers; concerned families and friends; healthcare providers; paid caregivers of people with ADRD; and policy, legal, education, and other professionals.

Methodology

Survey

The Florida PRTF prepared five web-based surveys designed for specific groups of individuals having expertise and/or experience with ADRD. These instruments, based in part upon surveys conducted by the State Plan for Alzheimer's Disease in Oregon (SPADO) Task Force, were developed for the following populations:

- People with ADRD;
- Family caregivers of people with ADRD;
- Concerned families and friends;
- Healthcare providers and paid caregivers of people with ADRD; and
- Policy, legal, education, and other professionals.

The number of questions varied among surveys, ranging from 12 questions for persons with ADRD and policy, legal, educational, and other professionals, to 41 questions in the survey for family caregivers.

Some questions overlapped across surveys, whereas others were specific to the knowledge and experience of the respondent group. Common questions included those identifying challenging issues for the individual with ADRD, the family, and caregivers; ways to increase public awareness; and critical issues related to ADRD for Florida state government to address.

The survey instruments are included in Appendix B.

Survey Procedures

The surveys were made available on the Department of Elder Affairs website April 15 through May 5, 2013. Respondents had the option of completing a survey electronically or printing and completing a survey on paper and mailing it to the Department.

840 people responded to the survey:

- 71 people with ADRD;
- 421 family caregivers;

- 143 concerned family and friends;
- 160 healthcare providers and paid caregivers; and
- 45 policy, legal, education, and other professionals.

Analysis

The Department analyzed the five surveys individually and identified characteristics of participants. Questions that were common across survey groups were analyzed in terms of the strongest response option chosen (e.g. most important, most challenging, strongly agree) to highlight aspects of highest concern for respondents. Please see Appendix A for detailed tables containing percentages of all survey responses.

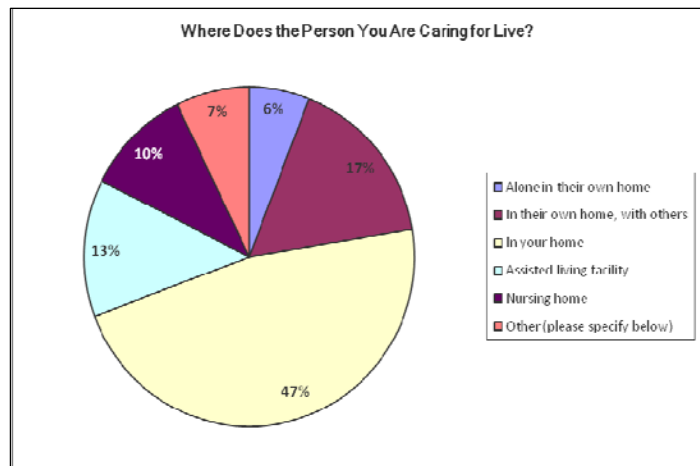
Survey Findings

Characteristics of Respondents and Their Experience With ADRD

Caregivers

The typical family caregiver responding to the survey was a 62-year-old white, non-Hispanic female. In general, a respondent was the primary caregiver. The majority of caregiving respondents (85%) lived in close proximity to the person with ADRD. Persons with ADRD receiving care from these caregivers were most frequently over 75 years of age and had Alzheimer's disease for more than 4 years.

Caregivers provided care an average of 69 hours per week. Over 40 percent took care of a spouse, while 39 percent took care of a parent. Approximately one-quarter (24%) have helped more than one person with ADRD.



Furthermore, more than one-third of the family caregivers were in the “sandwich generation” caring for younger loved ones, such as children, as well as elder parents or other elder family members. Caregivers said that the majority of persons with ADRD they were taking care of lived in the home of the caregivers (47%), 17 percent lived with others in their own home, 14 percent lived in an assisted living facility, 10 percent in a nursing home, and six percent lived alone in the home of the caregiver.

The estimated annual household income for 37 percent of responding caregivers was over \$46,000, while 17 percent estimated their income to be below \$25,000.

Persons With ADRD

The typical respondent with ADRD was a 69-year-old white, non-Hispanic female who had ADRD between one and five years.

While 46 percent of persons with ADRD who responded have an estimated annual income greater than \$46,000, 34 percent live on less than \$25,000 a year.

Concerned Families and Friends

The typical respondent in the family and friends survey category was a 57-year-old white, non-Hispanic female family member who cared for someone with ADRD an average of 23 hours a week.

Healthcare Providers and Paid Caregivers

The typical respondent in the healthcare provider and paid caregiver survey category was a 51-year-old white, non-Hispanic female. The majority (62%) said they had a training certificate or license. Forty-one percent had been providing care for persons with ADRD between six and 15 years. Respondents worked in a wide variety of settings caring for persons with ADRD including assisted living facilities (37%), private residences (21%), adult day or family care homes (19%), nursing facilities (12%), and hospice (8%). Sixty-five percent of the facilities employing the respondents offered cognitive assessments or screening.

Policy, Legal, Education, and Other Professionals

The typical respondent in the policy, legal, education, and other professionals survey category was a 51-year-old white, non-Hispanic female who was an educator, trainer, or academician. Forty-nine percent of the respondents had personal experience as a primary caregiver for someone with ADRD.

Diagnoses of Persons With ADRD

Reflecting national trends, caregivers as well as persons with ADRD reported that the most prevalent diagnosis was Alzheimer's disease (74% and 34%, respectively). However, as shown in the table below, the most frequent response of persons with ADRD was that they had not yet been diagnosed (38%). Family caregivers of persons with ADRD and respondents with ADRD reported that 28 percent and 19 percent of ADRD diagnoses, respectively, were dementia. An additional 15 and 24 percent reported memory loss. Eighteen percent of persons with ADRD reported a diagnosis with mild cognitive impairment compared to only four percent of persons with ADRD for whom family caregivers provide services. "Other" diagnoses included memory

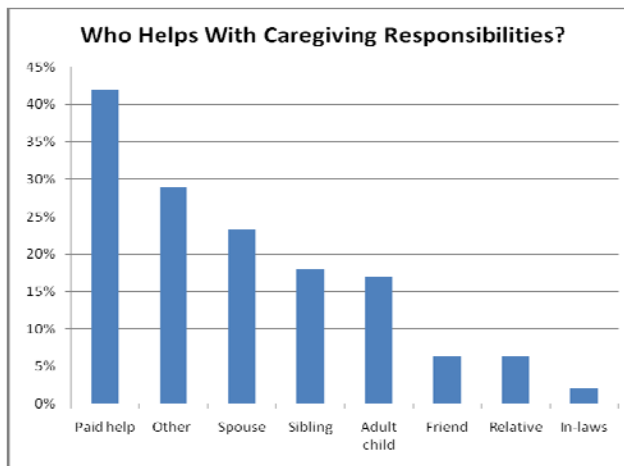
disorders that are complications of other diseases such as diabetes, Huntington's disease, reduplicative paramnesia, and muscular dystrophy.

Diagnosis	Response Percent	
	Family Caregiver	Respondent With ADRD
Alzheimer's Disease	74%	34%
Dementia	28%	19%
Memory loss	15%	24%
Vascular Dementia	9%	3%
Frontotemporal Dementia	5%	2%
Mild Cognitive Impairment	4%	18%
Stroke	4%	3%
Lewy Body Dementia	3%	2%
Parkinson's Disease	3%	0%
Other (please specify below)	3%	9%
Not diagnosed	1%	38%
Don't know	1%	2%

Family caregivers said that the majority of persons with ADRD were diagnosed by a neurologist (53%), followed by a family doctor or primary care physician (24%), a memory disorder clinic (9%), and a geriatrician (7%).

Who diagnosed the person you are caring for?	Response Percent
Neurologist	53.6%
Family doctor/Primary care physician	23.8%
(Florida) Memory Disorder Clinic	9.2%
Geriatrician	6.7%
Other	5.7%
Don't know	1.0%

Caregiver Support and Areas of Needed Help



Help for Caregivers

The majority of caregivers (73%) received some help from others in their caregiving responsibilities. The greatest sources of assistance were paid help (42%), spouses (29%), siblings (18%), and adult children (17%). “Other” sources of help consisted mostly of staff in nursing homes, hospices, assisted living facilities, and adult day care settings.

An open-ended question asked caregivers who provided routine assistance to the person with ADRD when the caregiver was absent. The largest percentage of respondents (34%) said that a family member, spouse, or friend would help. Twenty-two percent said there was no additional help, and, of these, one-fifth said they provided care 24/7.

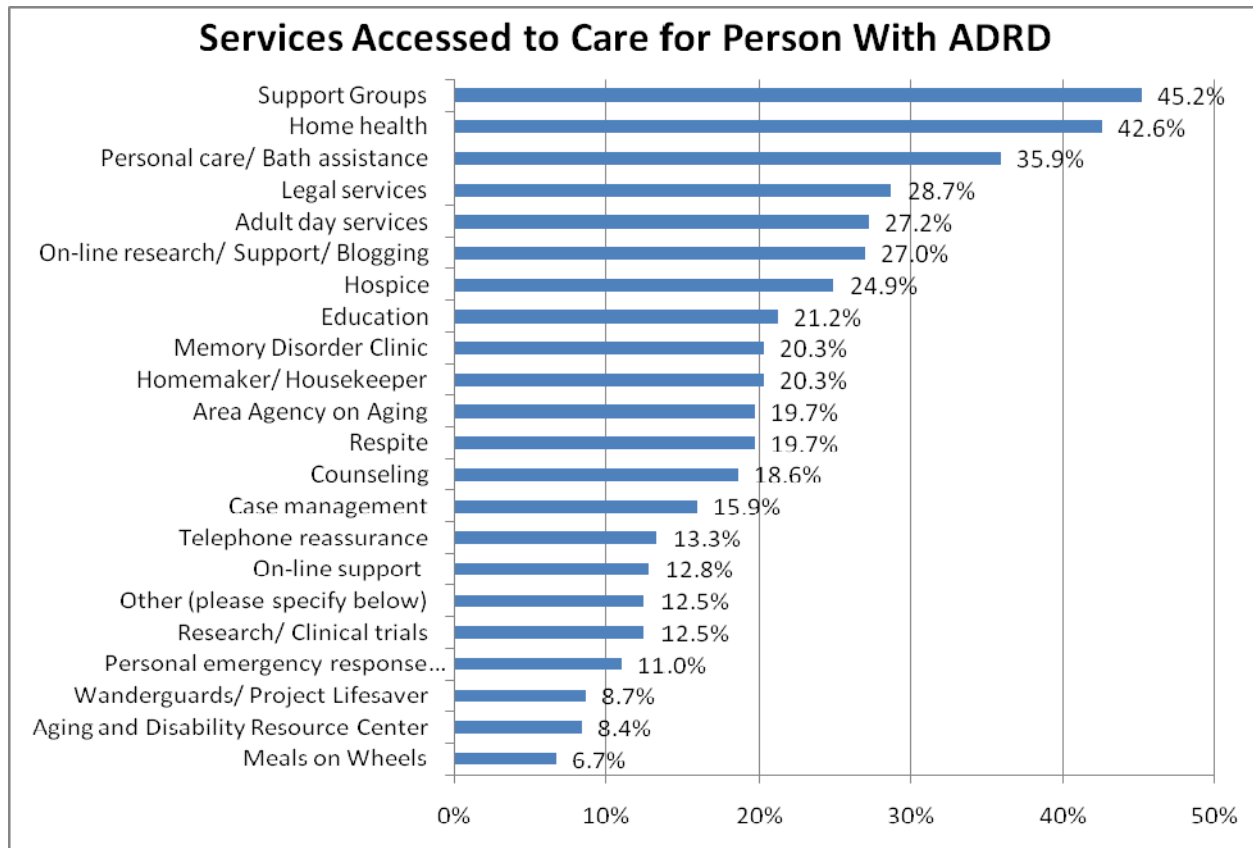
Help Needed by the Person With ADRD

Caregivers were asked to indicate the areas in which the person they care for needed “a lot of help.” The predominant area of help needed was transportation outside the home (78%); taking care of the person’s residence and personal living space (76%); and helping the person with activities such as eating, dressing, or bathing (41%). Sixty-nine percent of respondents said that care recipients needed help in “other” areas, consisting mostly of medication management, toileting, issues related to disorientation and confusion, unpredictable behavior, and communication issues.

Help Needed by the Person With ADRD	No Help	A Little Help	Some Help	Quite a Bit of Help	A Lot of Help
Transportation outside the home	6.2%	4.9%	4.1%	6.9%	77.9%
Taking care of residence, personal living spaces	3.0%	2.3%	5.5%	12.8%	76.3%
Other	11.3%	1.3%	3.8%	15.0%	68.8%
Taking care of himself/herself (eating, dressing, bathing)	11.0%	11.0%	16.5%	20.5%	41.0%
Communicating	9.0%	13.3%	23.4%	22.1%	32.2%
Relieving/decreasing anxiety or depression	8.5%	15.0%	23.0%	26.9%	26.6%
Moving around within the house	26.2%	17.0%	18.3%	14.8%	23.7%
Getting along with people	27.7%	19.5%	25.4%	13.8%	13.6%
Seeing or hearing	31.9%	18.1%	24.2%	12.5%	13.3%

Types of Services Accessed by Caregivers to Take Care of Person With ADRD

Caregivers reported that they mostly accessed services such as support groups (45%), home health (43%), personal care/bath assistance (36%), legal services (29%), adult day services (27%), and hospice services (25%) to care for persons with ADRD.



The majority of caregivers reported that services accessed were mostly private pay, either by the caregiver (74%) or by other family members (12%). Medicaid paid for 18 percent of service costs. Medicare was the most prevalent source of “other” payments (32%).

Source of Payment for Services

Source of Payment for Services	Response Percent
Private pay/ Out of pocket of person	73.6%
Medicaid	18.3%
Other (please specify below)	14.9%
Family supported	12.1%
Long-term care insurance	11.8%
Veterans Administration	8.7%
Government funding	8.4%
Nursing Home Diversion Medicaid Waiver	6.8%
Trust funds	4.3%
County/ City funding	4.0%
Employee Assistance Program	0.3%

Support Services Needed For Persons With ADRD

Caregivers reported several areas of help needed to keep the care recipient at home. The main types of support needed to help keep persons with ADRD at home included respite (65%), personal care (58%), financial assistance (52%), medical care (41%), and legal advice (36%).

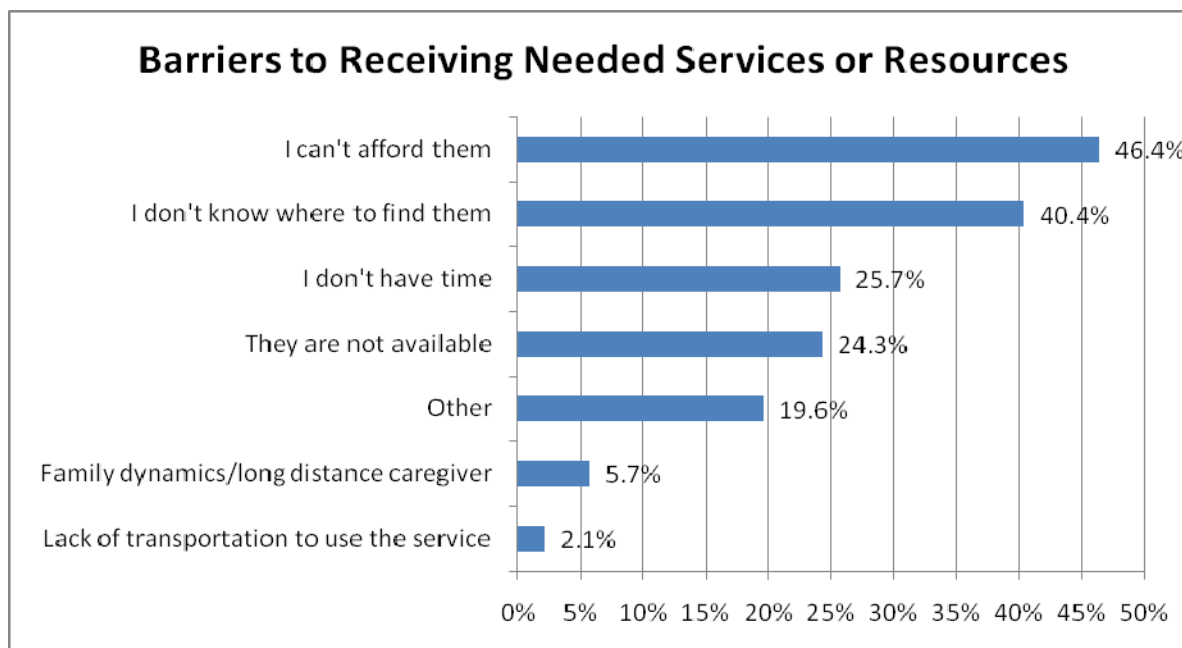
Type of Support Needed to Keep Person With ADRD at Home

Support Needed	Response Percent
Respite	64.6%
Personal care	57.9%
Financial assistance	52.4%
Medical care	40.5%
Legal advice	36.0%
Transportation	27.1%
Meals	26.2%
Education	18.0%
Other (please specify below)	16.8%

Forty-eight percent of caregiver respondents said they had not made any plans or other preparations for a natural disaster such as a hurricane. Only seven percent had registered with their local emergency management agency for assistance in evacuating to a special-needs shelter. This would indicate the need for intensified public-service efforts educating caregivers and persons with ADRD on how to plan and prepare for natural and man-made disasters.

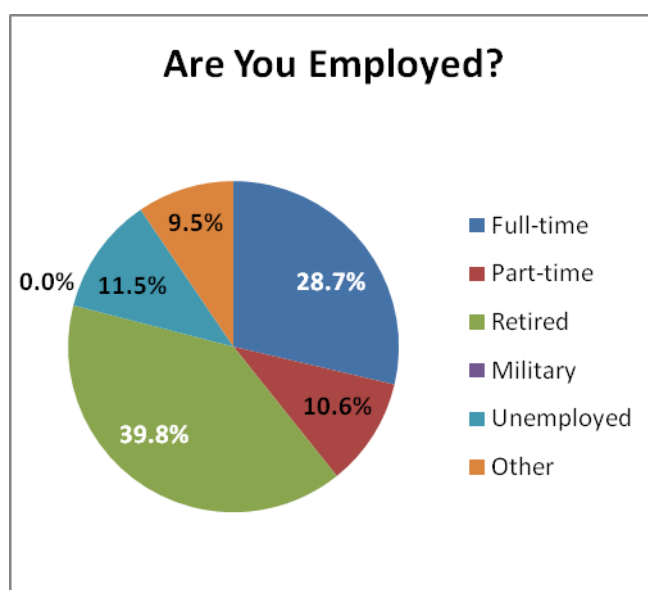
Barriers, Challenges, and Difficulties for Caregivers and Families

The main barriers that prevented caregivers from receiving the services or resources they needed were lack of affordability (46%), knowledge of where to find them (40%), insufficient amount of time (26%), and availability of the services (24%).



Employment Status and Impact of ADRD on Caregiver Employment

Forty percent of caregiver respondents said they were retired. Thirty-nine percent of caregivers reported that they were employed, of which 29 percent were employed full-time.



The ability to remain employed poses another challenge for caregivers. Forty-nine percent of respondents said that caregiving responsibilities affected their employment. Of those who said that caretaking responsibilities affected their employment, 47 percent indicated that they had to cut back on hours of work, while 33 percent reported that they had left their job.

Issues That Are Most Challenging For Persons With ADRD

Persons with ADRD were most concerned about being a burden on others and reported that the loss of ability to drive, anxiety, and depression were the most challenging issues they faced. Examples of “other” challenges included getting an exact diagnosis, difficulty of the family to accept the situation, and finding support groups.

Answer Options	How challenging are the following issues for you?					
	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know
Worrying about being a burden on others	11.1%	13.3%	8.9%	13.3%	48.9%	4.4%
Loss of ability to drive	28.3%	10.9%	4.3%	6.5%	41.3%	8.7%
Other (please specify below)	25.0%	0.0%	0.0%	12.5%	37.5%	25.0%
Depression or anxiety	17.8%	13.3%	17.8%	13.3%	35.6%	2.2%
Paying for services	33.3%	6.7%	17.8%	6.7%	28.9%	6.7%
Changing relationships in the family	26.7%	11.1%	13.3%	15.6%	26.7%	6.7%
Dealing with financial, legal and insurance issues	17.8%	13.3%	28.9%	11.1%	24.4%	4.4%
Communication with family and friends	28.3%	10.9%	17.4%	17.4%	21.7%	4.3%
Access to medical care for yourself	36.2%	17.0%	21.3%	10.6%	10.6%	4.3%
Access to support groups	30.4%	26.1%	15.2%	6.5%	8.7%	13.0%
Getting helpful information on Alzheimer's disease and related dementias	37.0%	30.4%	19.6%	8.7%	2.2%	2.2%

Issues Affecting Persons with ADRD That Are Most Challenging for Caregivers and Their Families

In addition to asking persons with ADRD to indicate the most challenging issues for them, the other survey respondents were asked to report what they considered the most challenging issues related to ADRD for persons with ADRD, their caregivers, and their families. Some of the response categories for this question overlapped with those for the previous question addressed to persons with ADRD.

Issues Affecting ADRD Persons	“Very” Challenging Issues Affecting ADRD Individuals, Caregivers and Families			
	Caregiver	Families and Friends	Health Care Providers/Paid Caregivers	Professionals
Other	55.4%	51.9%	33.3%	66.7%
Losing control over lifestyle	49.3%	62.8%	55.2%	52.5%
Difficult behaviors	37.6%	59.3%	62.1%	58.5%
Loss of ability to drive	36.1%	48.8%	55.7%	58.5%
Depression or anxiety of the person with Alzheimer’s disease or related dementia	34.8%	49.2%	54.3%	51.2%
Becoming a financial burden	26.8%	48.0%	54.0%	53.7%
Wandering or safety	25.7%	55.3%	53.6%	56.1%

Of the issues presented, family caregivers considered the care receiver’s loss of control over his/her lifestyle (49%), difficult behaviors (38%), and the loss of the ability to drive (36%) as most challenging. More than half of respondents in the caregiver, family and friends, and professional survey categories included an “other” response. These comments were varied and described the challenges of coping with the depression and anxiety of the loved one (e.g., “watching the fear of dementia appear in her eyes”), hallucinations, or the person’s inability to find things. In addition, survey respondents commented on the complete dependency of the person with ADRD on others, and the challenge this poses to caregivers and families. Caregivers reported that symptoms associated with ADRD have a detrimental impact on relationships in the family or between spouses, described in terms of the loss of a companion or friend. These symptoms also negatively affected families’ ability to raise their children.

Respondents in the families and friends survey category considered loss of control by the person with ADRD over lifestyle (63%), difficult behaviors (59%), and wandering or safety (55%) as most challenging to persons with ADRD. Among the “other” issues added by respondents were difficulties communicating with, and changes in the personality of, the person with ADRD.

Healthcare providers and paid caregivers viewed difficult behaviors of persons with ADRD (62%) as a major challenge, followed by the loss of ability to drive (56%), and losing control over lifestyle (55%). “Other” issues described by these respondents were the loss of independence and identity, and getting expert help.

Survey participants in the policy, legal, education and other professionals survey category perceived the greatest challenges for persons with ADRD to be difficult behaviors and the loss of driving ability (59% each) with wandering and safety closely following at 56 percent.

Professionals identifying “other” issues affecting individuals with ADRD reported that their loss of independence, stress related to anticipating disease progression, and finding needed support and knowledgeable health professionals were major challenges.

Challenging Issues for Caregivers and Families Involved With ADRD

Respondents in the family caregivers and families and friends survey categories reported that the most challenging issues for them were loss of control over lifestyle (45% and 47%, respectively), communication with the person with ADRD (40% and 53%), and changing relationships in the family (38% and 50%). Caregivers who included “other” issues as most challenging (53%) identified mental issues such as depression, anxiety, and stress; not living close to the person with ADRD; and not being able to get enough support to perform caregiving functions.

Most Challenging Issues for Caregivers and Families	Caregiver	Families and Friends	Health Care Providers/Paid Caregivers	Professionals
Other	52.6%	40.7%	66.7%	53.3%
Losing control of lifestyle	45.1%	47.2%	47.9%	51.2%
Communication with the person with ADRD	40.2%	53.3%	47.9%	53.7%
Changing relationships in the family	37.9%	50.4%	48.9%	40.0%
Paying for services	32.1%	44.9%	55.7%	62.5%
Dealing with financial, legal, and insurance issues	29.0%	45.1%	48.2%	60.0%
Dying before the person with ADRD	24.2%	24.0%	32.1%	34.1%
Access to respite care, adult day care, etc.	24.1%	23.3%	27.5%	36.6%
Loss of employment	18.7%	25.0%	35.3%	31.7%
Getting information about community resources	14.7%	18.7%	23.6%	22.0%
Access to support groups	12.1%	13.9%	10.1%	7.3%
Access to medical care for caregivers	11.9%	17.9%	21.3%	22.5%
Getting an appropriate diagnosis	11.1%	23.8%	31.7%	26.8%
Access to medical care for people with ADRD	10.2%	21.3%	24.1%	29.3%
Getting helpful information on ADRD	5.9%	11.4%	8.5%	7.3%
Becoming a financial burden on children	N.A.	36.1%	N.A.	62.5%
Caregivers feeling depressed or anxious	N.A.	48.4%	54.0%	46.3%
Understanding the disease	N.A.	23.5%	35.8%	23.1%
Caregivers feeling resentful	N.A.	20.7%	30.5%	17.1%

N/A: not applicable – question was not included in particular survey.

A table including responses to all response options is included in Appendix A.

Similar to the family caregiver survey category, respondents in the families and friends survey category also considered the most challenging issues to be the loss of control over lifestyle, communication with the person with ADRD, and changing relationships in the family. In addition, paying for services was a major challenge for caregivers and families. Forty-one percent of families and friends respondents reported “other” challenges, which included the lack of resources, refusal of caregivers to accept outside help, and living too far away from the person needing help.

In contrast to the caregiver and family and friends survey categories, respondents in the health care providers and paid caregivers survey category identified the following as the top three challenging issues for caregivers and families: paying for services (56%), depression and anxiety of caregivers (54%), and changing relationships in the family (49%). In addition, 54% identified depression and anxiety of caregivers as a major concern. Sixty-seven percent identified “other” issues as most challenging including coping with grief, the loss of friends, isolation, and finding appropriate resources for help.

The top three challenging issues reported by respondents from the professionals survey category were different from those for the other respondent groups. They included paying for services (63%); becoming a financial burden on children (63%); and dealing with financial, legal, and insurance issues (60%). “Other” issues (53%) included coping with feelings of frustration and guilt, communicating with health professionals, planning for disease progression, and the impact on children.

The Impact of Caretaking on Caregivers

Caregivers were asked about the specific difficulties they experienced as a consequence of their caregiving. The highest rated difficulties reported were lack of time for themselves(53%); anxiety and depression (47%); “other” difficulties (46%); and to an equal extent financial burdens, difficult behaviors, and not enough time for oneself and family (39% each). “Other” difficulties reported by caregivers included understanding ADRD, the challenge of communicating with family and friends who are not educated about ADRD, loss of friends and feelings of social isolation, and feeling guilty about placing the person with ADRD outside of the home.

Difficulties experienced by caregivers	Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree	N/A
Doesn't leave enough time for yourself	52.8%	27.8%	12.9%	3.0%	2.4%	1.1%
Creates anxiety or depression	47.0%	39.5%	7.6%	1.6%	2.2%	2.2%
Other	45.7%	4.3%	0.0%	0.0%	4.3%	45.7%
Creates a financial burden	39.1%	31.0%	15.1%	4.3%	5.9%	4.6%
Difficult behaviors	39.1%	39.1%	11.1%	2.4%	3.5%	4.9%
Doesn't leave enough time for your family	39.0%	26.9%	18.3%	6.2%	3.0%	6.7%
Affects family relationships	31.5%	41.2%	14.3%	5.4%	4.9%	2.7%
Interferes with your work	28.9%	26.5%	12.4%	3.2%	2.4%	26.5%
Wandering or safety	28.7%	31.7%	17.8%	3.8%	5.7%	12.3%
Creates or aggravates health problems	26.2%	36.2%	22.4%	7.6%	4.3%	3.2%
Interferes with employment/loss of employment	26.2%	18.9%	14.6%	3.8%	2.4%	34.1%
Understanding the disease	21.6%	37.4%	18.9%	9.8%	7.7%	4.6%
Feeling resentful	21.2%	26.6%	27.4%	12.6%	9.7%	2.4%

N/A: not applicable

Helpful Resources for Information

Caregivers and persons with ADRD were asked how best to disseminate information about dementia. Caregivers responded that the most helpful ways were Internet or web-based information and trainings (74%), in-person support groups (55%), one-on-one counseling (44%), community education and training (42%), toll-free 24-hour telephone helplines (33%), case management (35%), and seminars (34%). Respondents with ADRD considered the Internet and in-person support groups the most helpful (64% each), followed by community education and training (44%), one-on-one counseling (38%), and toll-free 24 hour telephone helplines (22%).

Answer Options	Caregivers	Persons With ADRD
Internet or web-based information and training	74.3%	64.4%
In-person support groups	55.4%	64.4%
One-on-one counseling	43.5%	37.8 %
Community education and training	42.1%	44.4%
Toll-free 24-hr telephone helpline	32.8%	22.2 %
Case management	34.7%	N.A.
Seminars	33.9%	N.A.
Employers	7.9%	13.3%
Other (please specify below)	9.0%	N.A.

Best Ways to Raise General Awareness of ADRD in Florida

All respondents, except persons with ADRD, were asked to identify the best ways to raise public awareness of ADRD in the community. Public service announcements on radio and TV were the highest rated way to raise public awareness, ranging from 71 percent for professionals to 77 percent for families and friends of persons with ADRD. In addition, 65 percent or more of respondents considered the following among the best means of increasing public awareness: website with updated information, aging services and senior centers, physicians, and churches and faith communities. Between 63 and 76 percent of healthcare providers and paid caregivers considered the Veterans Administration, law enforcement, hospitals, nursing schools, and employers and the workplace as optimal venues for raising ADRD awareness. Seventy percent of healthcare providers and paid caregivers chose nursing schools as an optimal venue for raising public awareness of ADRD issues.

Best Ways to Raise Public Awareness of ADRD	Caregiver	Families and Friends	Health Care Providers/Paid Caregivers	Professionals
Public service announcements on radio and TV	72.1%	76.9%	75.0%	70.7%
Website with updated information	69.1%	68.6%	69.3%	63.4%
Aging services and senior centers	68.8%	76.9%	82.1%	68.3%
Physicians	67.4%	69.4%	77.9%	70.7%
Churches and faith communities	64.9%	68.6%	77.9%	70.7%
Employers and workplaces	55.7%	69.4%	76.4%	61.0%
Hospitals	45.7%	54.5%	66.4%	56.1%
Medical training schools	44.0%	65.3%	58.6%	61.0%
Nursing schools	43.7%	54.5%	70.0%	51.2%
Veterans Administration	42.6%	52.9%	62.9%	51.2%
Religious organization	42.3%	52.9%	55.7%	51.2%
Law enforcement	37.9%	53.7%	62.9%	46.3%
Other	10.9%	16.5%	14.3%	26.8%

Most Important Critical Issues State Government Should Address

All respondent groups were asked to identify the most critical ADRD issues state government should address. The majority of family caregivers indicated that access to affordable and appropriate dementia-specific care (85%), ensuring quality of care (80%), research on prevention, treatment, and clinical trials (77%), education and training for caregivers (75%), having an ADRD educated and trained workforce (75%), and assisting families in paying for care (72%) were “very important” issues for state government to address. The other survey response groups rated these issues similarly in importance, ranging from 56 to 85 percent.

Some of the “other” critical issues recommended were fostering quality nursing homes that accept Medicaid, promoting caregiver support, better coordination of fragmented ADRD services, implementing a centralized informational resource for answering questions about service and payment availability, and offering more services.

“Very Important” Critical Issues State Government Should Address	Caregiver	Families and Friends	ADRD	Health Care Providers/Paid Caregivers	Professionals
Access to affordable and appropriate dementia-specific care	84.5%	77.6%	61.9%	81.8%	85.0%
Ensuring quality of care	80.3%	82.9%	71.4%	77.4%	77.5%
Research on prevention, treatment, and clinical trials	76.6%	78.4%	76.7%	62.3%	66.7%
Education and training for caregivers	75.4%	70.1%	60.5%	77.5%	64.1%
Having an educated and trained workforce on Alzheimer's disease and related dementias	74.6%	73.3%	66.7%	76.6%	70.0%
Assisting families in paying for care	71.8%	62.1%	55.8%	75.5%	70.7%
Protecting people with Alzheimer's disease and related dementias	69.7%	65.8%	58.1%	68.6%	55.0%
Economic impact of ADRD on communities, workplaces, and citizens	68.0%	59.8%	47.6%	61.3%	63.4%
Specialized care facilities	67.3%	68.1%	56.1%	54.8%	60.0%
Tax credits for caregivers	67.2%	54.8%	52.4%	53.0%	62.5%
Clinical assessment, diagnosis, and testing	66.3%	69.0	74.4%	56.9%	52.6%
Medical care	65.9%	53.5%	52.4%	52.2%	43.6%
Mental health/depression	65.1%	64.3%	48.8%	58.8%	66.7%
Other (please specify below)	61.8%	38.1%	57.1%	63.6%	50.0%
Emergency management/disaster preparedness	46.7%	40.4%	50.0%	42.1%	47.5%
Transportation	41.2%	35.7%	42.9%	46.2%	51.2%
Access to non-dementia-specific services	34.0%	26.8%	37.8%	32.1%	37.5%
Employment	28.6%	19.6%	19.5%	28.2%	33.3%

APPENDIX A: Response Tables

The following tables include detailed response options for those questions addressed in this report.

Persons With ADRD: Issues of People With Alzheimer’s Disease and Related Dementias.

Persons With ADRD Survey

4. How challenging are the following issues for you?

Answer Options	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know	Rating Average	Response Count
Worrying about being a burden on others	11.1%	13.3%	8.9%	13.3%	48.9%	4.4%	3.62	45
Loss of ability to drive	28.3%	10.9%	4.3%	6.5%	41.3%	8.7%	2.96	46
Other (please specify below)	25.0%	0.0%	0.0%	12.5%	37.5%	25.0%	2.63	8
Depression or anxiety	17.8%	13.3%	17.8%	13.3%	35.6%	2.2%	3.29	45
Paying for services	33.3%	6.7%	17.8%	6.7%	28.9%	6.7%	2.71	45
Changing relationships in the family	26.7%	11.1%	13.3%	15.6%	26.7%	6.7%	2.84	45
Dealing with financial, legal and insurance issues	17.8%	13.3%	28.9%	11.1%	24.4%	4.4%	2.98	45
Communication with family and friends	28.3%	10.9%	17.4%	17.4%	21.7%	4.3%	2.80	46
Access to medical care for yourself	36.2%	17.0%	21.3%	10.6%	10.6%	4.3%	2.30	47
Access to support groups	30.4%	26.1%	15.2%	6.5%	8.7%	13.0%	1.98	46
Getting helpful information on Alzheimer's disease and related dementias	37.0%	30.4%	19.6%	8.7%	2.2%	2.2%	2.02	46

How Challenging Are Issues Affecting the Persons With ADRD For Persons With ADRD; Family Caregivers; and Their Families?

Caregivers Survey

18. Please indicate how challenging the following issues affecting the person with Alzheimer's disease or related dementia have been for you and your family. Check N/A if the topic is not applicable to you.

Answer Options	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	N/A	Rating Average	Response Count
Loss of ability to drive	14.5%	8.9%	16.1%	10.5%	36.1%	13.9%	3.52	380
Depression or anxiety of the person with Alzheimer's disease or related dementia	6.3%	15.6%	19.3%	21.9%	34.8%	2.1%	3.65	379
Difficult behaviors	7.0%	12.5%	22.2%	18.5%	37.6%	2.1%	3.69	383
Wandering or safety	18.9%	17.6%	15.0%	14.2%	25.7%	8.7%	3.11	381
Becoming a financial burden	27.0%	15.2%	16.0%	9.2%	26.8%	5.8%	2.93	381
Losing control over lifestyle	3.4%	8.5%	13.3%	20.2%	49.3%	5.3%	4.09	377
Other (please specify below)	2.7%	1.4%	5.4%	12.2%	55.4%	23.0%	4.51	74
Other (please specify)								79

Concerned Family and Friends Survey

5. How challenging do you feel the following issues are for individuals with Alzheimer's disease and related dementias and their families?

Answer Options	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know	Rating Average	Response Count
Loss of ability to drive	4.9%	4.1%	9.8%	26.8%	48.8%	5.7%	3.93	123
Depression or anxiety of the person with Alzheimer's disease or related dementia	1.6%	4.1%	9.8%	32.0%	49.2%	3.3%	4.13	122
Difficult behaviors	0.0%	4.1%	10.6%	25.2%	59.3%	0.8%	4.37	123
Wandering or safety	2.4%	6.5%	8.1%	25.2%	55.3%	2.4%	4.17	123
Becoming a financial burden	7.3%	3.3%	13.8%	18.7%	48.0%	8.9%	3.70	123
Losing control over lifestyle	0.8%	5.0%	8.3%	19.8%	62.8%	3.3%	4.29	121
Other (please specify below)	3.7%	3.7%	3.7%	0.0%	51.9%	37.0%	2.81	27
Other (please specify)								14

Healthcare Providers and Paid Caregivers Survey

9. How challenging do you feel the following issues are for individuals with Alzheimer's disease or related dementia and their families?

Answer Options	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know	Rating Average	Response Count
Loss of ability to drive	1.4%	4.3%	7.9%	27.1%	55.7%	3.6%	4.21	140
Depression or anxiety of the person with Alzheimer's disease or related dementia	1.4%	3.6%	10.0%	30.0%	54.3%	0.7%	4.30	140
Difficult behaviors	0.0%	3.6%	9.3%	23.6%	62.1%	1.4%	4.40	140
Wandering or safety	1.4%	4.3%	9.3%	29.3%	53.6%	2.1%	4.23	140
Becoming a financial burden	1.4%	4.3%	10.8%	25.9%	54.0%	3.6%	4.16	139
Losing control over lifestyle	1.5%	1.5%	10.4%	29.9%	55.2%	1.5%	4.31	134
Other (please specify below)	11.1%	11.1%	0.0%	11.1%	33.3%	33.3%	2.44	9
Other (please specify)								9
<i>answered question</i>								140

Policy, Legal, Education and Other Professionals Survey

5. How challenging do you feel the following issues are for individuals with Alzheimer's disease or related dementia and their families?

Answer Options	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know	Rating Average	Response Count
Loss of ability to drive	2.4%	4.9%	7.3%	26.8%	58.5%	0.0%	4.34	41
Depression or anxiety of the person with Alzheimer's disease or related dementia	0.0%	7.3%	7.3%	34.1%	51.2%	0.0%	4.29	41
Difficult behaviors	0.0%	4.9%	12.2%	24.4%	58.5%	0.0%	4.37	41
Wandering or safety	0.0%	0.0%	14.6%	29.3%	56.1%	0.0%	4.41	41
Becoming a financial burden	4.9%	4.9%	14.6%	22.0%	53.7%	0.0%	4.15	41
Losing control over lifestyle	2.5%	2.5%	10.0%	30.0%	52.5%	2.5%	4.20	40
Other (please specify below)	0.0%	0.0%	0.0%	0.0%	66.7%	33.3%	3.33	12
Other (please specify)								8

Challenging Issues for Caregivers of People with Alzheimer’s Disease and Related Dementias.

Family Caregivers Survey

19. Please indicate how challenging the following issues are (or have been) to you as a caregiver.								
Answer Options	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	N/A	Rating Average	Response Count
Getting helpful information on Alzheimer's disease and related dementias	38.8%	21.8%	25.3%	7.7%	5.9%	0.5%	2.20	376
Getting information about community resources	24.5%	20.5%	22.1%	16.0%	14.7%	2.1%	2.75	375
Access to medical care for yourself	50.1%	14.9%	10.9%	5.8%	11.9%	6.4%	2.09	377
Access to medical care for your family member with Alzheimer's disease or related dementia	38.8%	22.5%	15.5%	10.2%	10.2%	2.9%	2.28	374
Dealing with financial, legal, and insurance issues	14.8%	19.9%	18.5%	15.6%	29.0%	2.2%	3.25	372
Access to support groups	35.2%	20.7%	14.5%	10.2%	12.1%	7.3%	2.39	372
Access to respite care, adult day care, and other services	19.3%	13.7%	15.8%	11.0%	24.1%	16.1%	3.08	373
Paying for services	17.0%	14.8%	14.0%	14.8%	32.1%	7.3%	3.33	371
Changing relationships in the family	9.5%	14.4%	17.1%	16.5%	37.9%	4.6%	3.62	369
Communication with the person with Alzheimer's disease or related dementia	4.0%	12.4%	19.7%	19.4%	40.2%	4.3%	3.83	371
Dying before the person with Alzheimer's disease or related dementia	23.4%	8.2%	11.1%	6.8%	24.2%	26.4%	3.00	368
Losing control of lifestyle	4.3%	12.8%	20.1%	13.0%	45.1%	4.9%	3.86	369
Loss of employment	28.4%	6.9%	7.2%	5.0%	18.7%	33.9%	2.68	363
Getting an appropriate diagnosis	35.3%	18.3%	14.7%	10.6%	11.1%	10.0%	2.38	360
Other (please specify below)	12.3%	0.0%	5.3%	1.8%	52.6%	28.1%	4.15	57
Other (please specify)								49

Challenging Issues for Families of People with Alzheimer’s Disease and Related Dementias

Concerned Family and Friends Survey

4. How challenging do you feel the following issues are for families involved with Alzheimer's disease and related dementias and caregiving?								
Answer Options	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know	Rating Average	Response Count
Getting helpful information on Alzheimer's disease and related dementias	20.3%	21.1%	29.3%	17.1%	11.4%	0.8%	2.76	123
Getting information about community resources	8.1%	16.3%	31.7%	20.3%	18.7%	4.9%	3.11	123
Caregivers feeling depressed or anxious	0.8%	6.6%	12.3%	27.9%	48.4%	4.1%	4.04	122
Caregivers feeling resentful	9.1%	14.9%	19.0%	26.4%	20.7%	9.9%	3.05	121
Access to medical care for caregivers	14.6%	13.8%	20.3%	20.3%	17.9%	13.0%	2.74	123
Access to medical care for people with Alzheimer's disease and related dementias	11.5%	18.0%	18.9%	23.8%	21.3%	6.6%	3.06	122
Dealing with financial, legal, and insurance issues	4.1%	8.2%	14.8%	22.1%	45.1%	5.7%	3.79	122
Access to support groups	18.0%	17.2%	22.1%	16.4%	13.9%	12.3%	2.54	122
Access to respite care, adult day care, and other services	5.8%	15.8%	19.2%	22.5%	23.3%	13.3%	3.02	120
Paying for services	5.9%	5.9%	12.7%	14.4%	44.9%	16.1%	3.38	118
Changing relationships in the family	0.8%	6.6%	11.6%	24.8%	50.4%	5.8%	4.00	121
Communication with the person with Alzheimer's disease or related dementia	2.5%	5.7%	13.9%	21.3%	53.3%	3.3%	4.07	122
Becoming a financial burden on children	12.3%	7.4%	11.5%	22.1%	36.1%	10.7%	3.30	122
Dying before the person with Alzheimer's disease or related dementia	12.4%	7.4%	15.7%	18.2%	24.0%	22.3%	2.67	121
Losing control of lifestyle	3.3%	8.9%	16.3%	17.9%	47.2%	6.5%	3.77	123
Loss of employment	24.2%	9.2%	5.8%	17.5%	25.0%	18.3%	2.55	120
Getting an appropriate diagnosis	9.8%	11.5%	15.6%	24.6%	23.8%	14.8%	2.97	122
Understanding the disease	10.1%	13.4%	23.5%	24.4%	23.5%	5.0%	3.23	119
Other (please specify below)	7.4%	3.7%	7.4%	3.7%	40.7%	37.0%	2.56	27
Other (please specify)								18

Healthcare Providers and Paid Caregivers Survey

8. How challenging do you feel the following issues are for families involved with Alzheimer's disease and related dementias and caregiving?

Answer Options	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know	Rating Average	Response Count
Getting helpful information on Alzheimer's disease and related dementias	10.6%	24.8%	34.0%	21.3%	8.5%	0.7%	2.90	141
Getting information on community resources	7.9%	12.9%	25.7%	29.3%	23.6%	0.7%	3.46	140
Caregivers feeling depressed or anxious	3.6%	4.3%	7.9%	28.1%	54.0%	2.2%	4.18	139
Caregivers feeling resentful	5.0%	12.1%	12.8%	36.2%	30.5%	3.5%	3.65	141
Access to medical care for caregivers	9.9%	14.2%	26.2%	25.5%	21.3%	2.8%	3.26	141
Access to medical care for people with Alzheimer's disease and related dementias	9.9%	15.6%	25.5%	23.4%	24.1%	1.4%	3.32	141
Dealing with financial, legal, and insurance issues	0.7%	6.4%	10.6%	28.4%	48.2%	5.7%	4.00	141
Access to support groups	13.7%	21.6%	33.8%	19.4%	10.1%	1.4%	2.86	139
Access to respite care, adult day care, and other services	10.9%	15.9%	21.0%	22.5%	27.5%	2.2%	3.33	138
Paying for services	1.4%	6.4%	9.3%	20.7%	55.7%	6.4%	4.04	140
Changing relationships in the family	1.4%	5.8%	12.2%	28.1%	48.9%	3.6%	4.06	139
Communication with the person with Alzheimer's disease or related dementia	2.1%	7.9%	11.4%	29.3%	47.9%	1.4%	4.09	140
Dying before the person with Alzheimer's disease or related dementia	2.9%	11.4%	14.3%	27.1%	32.1%	12.1%	3.38	140
Losing control of lifestyle	3.6%	8.6%	9.3%	27.9%	47.9%	2.9%	3.99	140
Loss of employment	6.5%	8.6%	14.4%	28.1%	35.3%	7.2%	3.55	139
Getting an appropriate diagnosis	3.6%	10.1%	24.5%	27.3%	31.7%	0.0%	3.65	139
Understanding the disease	5.1%	8.8%	16.8%	32.8%	35.8%	0.7%	3.83	137
Other (please specify below)	4.8%	4.8%	0.0%	0.0%	66.7%	23.8%	3.48	21
Other (please specify)								18

Policy, Legal, Education and Other Professionals

4. How challenging do you feel the following issues are for families involved with Alzheimer's disease and related dementias and caregiving?

Answer Options	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know	Rating Average	Response Count
Getting helpful information on Alzheimer's disease and related dementias	12.2%	17.1%	48.8%	14.6%	7.3%	0.0%	2.88	41
Getting information about community resources	4.9%	9.8%	31.7%	31.7%	22.0%	0.0%	3.56	41
Caregivers feeling depressed or anxious	2.4%	2.4%	12.2%	36.6%	46.3%	0.0%	4.22	41
Caregivers feeling resentful	4.9%	12.2%	29.3%	36.6%	17.1%	0.0%	3.49	41
Access to medical care for caregivers	2.5%	17.5%	30.0%	25.0%	22.5%	2.5%	3.40	40
Access to medical care for people with Alzheimer's disease and related dementias	9.8%	14.6%	19.5%	26.8%	29.3%	0.0%	3.51	41
Dealing with financial, legal, and insurance issues	0.0%	7.5%	5.0%	25.0%	60.0%	2.5%	4.30	40
Access to support groups	9.8%	17.1%	41.5%	24.4%	7.3%	0.0%	3.02	41
Access to respite care, adult day care, and other services	4.9%	19.5%	19.5%	14.6%	36.6%	4.9%	3.44	41
Paying for services	0.0%	0.0%	20.0%	17.5%	62.5%	0.0%	4.43	40
Changing relationships in the family	0.0%	2.5%	27.5%	30.0%	40.0%	0.0%	4.08	40
Communication with the person with Alzheimer's disease or related dementia	0.0%	2.4%	17.1%	24.4%	53.7%	2.4%	4.22	41
Becoming a financial burden on children	2.5%	0.0%	25.0%	10.0%	62.5%	0.0%	4.30	40
Dying before the person with Alzheimer's disease or related dementia	2.4%	14.6%	12.2%	29.3%	34.1%	7.3%	3.56	41
Losing control of lifestyle	4.9%	2.4%	7.3%	31.7%	51.2%	2.4%	4.15	41
Loss of employment	2.4%	12.2%	17.1%	34.1%	31.7%	2.4%	3.73	41
Getting an appropriate diagnosis	4.9%	9.8%	31.7%	22.0%	26.8%	4.9%	3.41	41
Understanding the disease	2.6%	10.3%	30.8%	33.3%	23.1%	0.0%	3.64	39
Other (please specify below)	0.0%	0.0%	6.7%	6.7%	53.3%	33.3%	3.13	15
Other (please specify)								10

Critical Issues that Florida Should Address in the Next Few Years

Family Caregivers Survey

28. In your opinion, what are the most critical issues that the state government in Florida should address in the next few years? Please rate the importance of the following possible issues that Florida might address.

Answer Options	Not Important	A Little Important	Some-what Important	Quite Important	Very Important	Don't Know	Rating Average	Response Count
Research on prevention, treatment, and clinical trials	2.0%	1.1%	4.9%	14.3%	76.6%	1.1%	4.59	350
Clinical assessment, diagnosis, and testing	1.4%	2.3%	5.7%	22.3%	66.3%	2.0%	4.44	350
Assisting families in paying for care	0.8%	1.1%	6.2%	17.8%	71.8%	2.3%	4.52	354
Protecting people with Alzheimer's disease and related dementias	0.9%	1.2%	6.9%	19.9%	69.7%	1.4%	4.52	347
Ensuring quality of care	0.6%	0.3%	3.4%	14.0%	80.3%	1.4%	4.69	351
Education and training for caregivers	0.6%	0.0%	5.7%	17.4%	75.4%	0.9%	4.65	350
Economic impact of Alzheimer's disease and related dementias on communities, workplaces, and citizens	0.9%	2.3%	8.6%	18.0%	68.0%	2.3%	4.43	350
Access to affordable and appropriate dementia-specific care	0.6%	0.3%	1.7%	11.5%	84.5%	1.4%	4.75	355
Having an educated and trained workforce on Alzheimer's disease and related dementias	0.6%	0.6%	4.0%	18.4%	74.6%	1.7%	4.61	347
Transportation	1.5%	5.3%	23.4%	24.0%	41.2%	4.5%	3.85	337
Employment	9.9%	8.1%	22.7%	12.4%	28.6%	18.3%	2.87	322
Tax credits for caregivers	3.5%	1.8%	7.6%	14.4%	67.2%	5.6%	4.23	341
Access to non-dementia-specific services	5.3%	10.3%	20.2%	16.8%	34.0%	13.4%	3.24	321
Specialized care facilities	0.6%	1.8%	8.8%	18.1%	67.3%	1.8%	4.39	342
Emergency management/disaster preparedness	2.1%	6.8%	18.6%	23.7%	46.7%	2.1%	4.00	338
Medical care	0.9%	1.5%	12.0%	18.4%	65.9%	1.5%	4.43	343
Mental health/depression	1.5%	1.2%	9.6%	20.8%	65.1%	1.8%	4.41	332
Other (please specify below)	2.9%	0.0%	2.9%	0.0%	61.8%	32.4%	3.21	34
Other (please specify)								32

Concerned Family and Friends Survey

7. In your opinion, what are the most critical issues the state government in Florida should address in the next few years? Please rate the importance of the following possible issues that Florida might address.

Answer Options	Not Important	A Little Important	Some-what Important	Quite Important	Very Important	Don't Know	Rating Average	Response Count
Research on prevention, treatment, and clinical trials	0.0%	0.9%	4.3%	15.5%	78.4%	0.9%	4.69	116
Clinical assessment, diagnosis, and testing	0.0%	1.7%	8.6%	19.8%	69.0%	0.9%	4.53	116
Assisting families in paying for care	0.0%	5.2%	10.3%	22.4%	62.1%	0.0%	4.41	116
Protecting people with Alzheimer's disease and related dementias	0.0%	0.9%	9.4%	23.9%	65.8%	0.0%	4.55	117
Ensuring quality of care	0.0%	0.9%	4.3%	12.0%	82.9%	0.0%	4.77	117
Education and training for caregivers	0.0%	0.0%	7.7%	22.2%	70.1%	0.0%	4.62	117
Economic impact of Alzheimer's disease and related dementias on communities, workplaces, and citizens	0.0%	2.6%	10.3%	23.1%	59.8%	4.3%	4.27	117
Access to affordable and appropriate dementia-specific care	0.0%	0.0%	6.9%	14.7%	77.6%	0.9%	4.67	116
Having an educated and trained workforce on Alzheimer's disease and related dementias	0.0%	0.0%	5.2%	20.7%	73.3%	0.9%	4.65	116
Transportation	2.6%	2.6%	21.7%	33.9%	35.7%	3.5%	3.87	115
Employment	8.0%	9.8%	29.5%	22.3%	19.6%	10.7%	3.04	112
Tax credits for caregivers	1.7%	4.3%	10.4%	26.1%	54.8%	2.6%	4.20	115
Access to non-dementia-specific services	6.3%	6.3%	25.9%	26.8%	26.8%	8.0%	3.38	112
Specialized care facilities	0.9%	2.6%	8.6%	18.1%	68.1%	1.7%	4.45	116
Emergency Management/ Disaster Preparedness	4.4%	6.1%	18.4%	27.2%	40.4%	3.5%	3.82	114
Medical care	1.8%	4.4%	11.4%	27.2%	53.5%	1.8%	4.21	114
Mental health/ Depression	0.0%	1.7%	12.2%	21.7%	64.3%	0.0%	4.49	115
Other (please specify below)	4.8%	0.0%	4.8%	14.3%	38.1%	38.1%	2.67	21
Other (please specify)								10

People with Alzheimer’s Disease and Related Dementias Survey

6. In your opinion, what are the most critical issues the state government in Florida should address in the next few years? Please rate the importance of the following possible issues that Florida might address.

Answer Options	Not Important	A Little Important	Some-what Important	Quite Important	Very Important	Don't Know	Rating Average	Response Count
Research on prevention, treatment, and clinical trials	0.0%	2.3%	11.6%	9.3%	76.7%	0.0%	4.60	43
Clinical assessment, diagnosis, and testing	0.0%	2.3%	7.0%	16.3%	74.4%	0.0%	4.63	43
Assisting families in paying for care	2.3%	0.0%	11.6%	27.9%	55.8%	2.3%	4.28	43
Protecting people with Alzheimer's disease and related dementias	2.3%	2.3%	7.0%	23.3%	58.1%	2.4%	4.12	43
Ensuring quality of care	0.0%	0.0%	2.4%	26.2%	71.4%	0.0%	4.69	42
Education and training for caregivers	0.0%	4.7%	11.6%	23.3%	60.5%	0.0%	4.40	43
Economic impact of Alzheimer's disease and related dementias on communities, workplaces, and citizens	0.0%	7.1%	11.9%	26.2%	47.6%	7.1%	3.93	42
Access to affordable and appropriate dementia-specific care	2.4%	0.0%	4.8%	26.2%	61.9%	4.8%	4.31	42
Having an educated and trained workforce on Alzheimer's disease and related dementias	0.0%	2.4%	2.4%	21.4%	66.7%	7.1%	4.31	42
Transportation	2.4%	14.3%	7.1%	23.8%	42.9%	9.5%	3.62	42
Employment	9.8%	12.2%	29.3%	14.6%	19.5%	14.6%	2.78	41
Tax credits for caregivers	2.4%	7.1%	9.5%	23.8%	52.4%	4.8%	4.02	42
Access to non-dementia-specific services	2.7%	10.8%	13.5%	18.9%	37.8%	16.2%	3.30	37
Specialized care facilities	0.0%	7.3%	4.9%	26.8%	56.1%	4.9%	4.17	41
Emergency management/ Disaster preparedness	0.0%	14.3%	14.3%	19.0%	50.0%	2.4%	3.98	42
Medical care	0.0%	9.5%	9.5%	23.8%	52.4%	4.8%	4.05	42
Mental health/ Depression	0.0%	4.9%	17.1%	26.8%	48.8%	2.4%	4.12	41
Other (please specify below)	0.0%	14.3%	0.0%	0.0%	57.1%	28.6%	3.14	7
Other (please specify)								2

Healthcare Providers and Paid Caregivers Survey

12. In your opinion, what are the most critical issues that the state government of Florida should address in the next few years? Please rate the importance of the following possible issues that Florida might address.

Answer Options	Not Important	A Little Important	Some-what Important	Quite Important	Very Important	Don't Know	Rating Average	Response Count
Research on prevention, treatment, and clinical trials	0.0%	4.3%	8.0%	25.4%	62.3%	0.0%	4.46	138
Clinical assessment, diagnosis, and testing	0.7%	2.2%	7.3%	32.8%	56.9%	0.0%	4.43	137
Assisting families in paying for care	0.0%	0.7%	6.5%	16.5%	75.5%	0.7%	4.65	139
Protecting people with Alzheimer's disease and related dementias	0.0%	2.9%	8.0%	19.7%	68.6%	0.7%	4.52	137
Ensuring quality of care	0.0%	1.5%	3.6%	16.8%	77.4%	0.7%	4.68	137
Education and training for caregivers	0.0%	0.0%	2.2%	20.3%	77.5%	0.0%	4.75	138
Economic impact of Alzheimer's disease and related dementias on communities, workplaces, and citizens	0.0%	1.5%	11.7%	24.1%	61.3%	1.5%	4.41	137
Access to affordable and appropriate dementia-specific care	0.0%	0.0%	2.2%	15.3%	81.8%	0.7%	4.77	137
Having an educated and trained workforce on Alzheimer's disease and related dementias	0.0%	0.0%	4.4%	19.0%	76.6%	0.0%	4.72	137
Transportation	0.0%	6.1%	22.0%	25.0%	46.2%	0.8%	4.09	132
Employment	3.8%	10.7%	22.9%	31.3%	28.2%	3.1%	3.60	131
Tax credits for caregivers	1.5%	5.2%	12.7%	24.6%	53.0%	3.0%	4.13	134
Access to non-dementia-specific services	4.5%	7.5%	26.9%	25.4%	32.1%	3.0%	3.65	133
Specialized care facilities	0.7%	3.0%	17.0%	23.7%	54.8%	0.7%	4.27	135
Emergency Management/Disaster Preparedness	0.8%	6.0%	21.1%	28.6%	42.1%	1.5%	4.01	133
Medical care	0.7%	1.5%	11.9%	33.6%	52.2%	0.0%	4.35	134
Mental health/depression	0.0%	3.1%	10.7%	26.7%	58.8%	0.8%	4.39	131
Other (please specify below)	0.0%	0.0%	0.0%	9.1%	63.6%	27.3%	3.55	11

Policy, Legal, Education and Other Professionals Survey

7. In your opinion, what are the most critical issues that the state government in Florida should address in the next few years? Please rate the importance of the following possible issues that Florida might address.

Answer Options	Not Important	A Little Important	Some-what Important	Quite Important	Very Important	Don't Know	Rating Average	Response Count
Research on prevention, treatment, and clinical trials	5.1%	2.6%	7.7%	17.9%	66.7%	0.0%	4.38	39
Clinical assessment, diagnosis, and testing	0.0%	2.6%	5.3%	36.8%	52.6%	2.6%	4.32	38
Assisting families in paying for care	0.0%	0.0%	12.2%	17.1%	70.7%	0.0%	4.59	41
Protecting people with Alzheimer's disease and related dementias	0.0%	7.5%	10.0%	27.5%	55.0%	0.0%	4.30	40
Ensuring quality of care	0.0%	0.0%	2.5%	20.0%	77.5%	0.0%	4.75	40
Education and training for caregivers	0.0%	2.6%	2.6%	30.8%	64.1%	0.0%	4.56	39
Economic impact of Alzheimer's disease and related dementias on communities, workplaces, and citizens	0.0%	7.3%	7.3%	22.0%	63.4%	0.0%	4.41	41
Access to affordable and appropriate dementia-specific care	0.0%	0.0%	2.5%	12.5%	85.0%	0.0%	4.83	40
Having an educated and trained workforce on Alzheimer's disease and related dementias	0.0%	2.5%	7.5%	20.0%	70.0%	0.0%	4.58	40
Transportation	0.0%	4.9%	17.1%	26.8%	51.2%	0.0%	4.24	41
Employment	7.7%	12.8%	17.9%	25.6%	33.3%	2.6%	3.56	39
Tax credits for caregivers	0.0%	7.5%	12.5%	17.5%	62.5%	0.0%	4.35	40
Access to non-dementia-specific services	0.0%	17.5%	20.0%	22.5%	37.5%	2.5%	3.73	40
Specialized care facilities	2.5%	0.0%	17.5%	20.0%	60.0%	0.0%	4.35	40
Emergency Management/ Disaster Preparedness	0.0%	15.0%	17.5%	17.5%	47.5%	2.5%	3.90	40
Medical care	0.0%	2.6%	20.5%	33.3%	43.6%	0.0%	4.18	39
Mental health/ Depression	0.0%	0.0%	15.4%	17.9%	66.7%	0.0%	4.51	39
Other (please specify below)	0.0%	0.0%	0.0%	0.0%	50.0%	50.0%	2.50	10

APPENDIX B: Survey Instruments

Survey for People with Alzheimer's Disease or Related Dementia

We need your help. Your personal experiences will help inform the creation of a Florida state plan to address the growing public health impact of Alzheimer's disease and related dementias. Your ideas and insights will help the state identify the needs of individuals with Alzheimer's disease or related dementias and their caregivers.

This survey is being conducted by the Florida Purple Ribbon Task Force, which is a project of knowledgeable leaders, appointed by the Governor, the President of the Florida Senate, and the Speaker of the Florida House of Representatives, who are concerned about the impact of Alzheimer's disease on our communities and want to address the needs of Florida's citizens.

Thank you for sharing your ideas and advice!

Please tell us about yourself

1. Where do you live or work?

City:

County:

State:

2. Have you been diagnosed with a specific condition? (Check all that apply.)

- ☐ I have not been diagnosed
- ☐ Alzheimer's disease
- ☐ Mild Cognitive Impairment (MCI)
- ☐ Frontotemporal Dementia
- ☐ Lewy Body Dementia
- ☐ Vascular Dementia
- ☐ Memory Loss
- ☐ Dementia
- ☐ Stroke
- ☐ Parkinson's Disease
- ☐ Don't know
- ☐ Other (please specify below)

Other (please specify)

3. How long have you been dealing with this problem or condition?

- ☐ Less than a year
- ☐ 1-5 years
- ☐ 6-10 years
- ☐ Over 10 years

Please tell us about your experience with memory difficulties

4. How challenging are the following issues for you?

	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know
Getting helpful information on Alzheimer's disease and related dementias	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to medical care for yourself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dealing with financial, legal and insurance issues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to support groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Loss of ability to drive	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Paying for services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Depression or anxiety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Changing relationships in the family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Communication with family and friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worrying about being a burden on others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

Creating a State Plan - Public Awareness

5. What ways of getting information about Alzheimer's disease and related dementias would be most helpful to you? (Check all that apply.)

- ☐ Internet or web-based information and training
- ☐ In-person support groups
- ☐ Community education and training
- ☐ Toll-free 24-hr telephone helpline
- ☐ One-on-one counseling
- ☐ Other (please specify below)

Other (please specify)

Creating a State Plan - Critical Issues

6. In your opinion, what are the most critical issues the state government in Florida should address in the next few years? Please rate the importance of the following possible issues that Florida might address.

	Not Important	A little Important	Somewhat Important	Quite Important	Very Important	Don't Know
Research on prevention, treatment, and clinical trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clinical assessment, diagnosis, and testing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assisting families in paying for care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Protecting people with Alzheimer's disease and related dementias	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ensuring quality of care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Education and training for caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Economic impact of Alzheimer's disease and related dementias on communities, workplaces, and citizens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to affordable and appropriate dementia-specific care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having an educated and trained workforce on Alzheimer's disease and related dementias	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transportation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tax credits for caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to non-dementia-specific services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specialized care facilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Emergency management/ Disaster preparedness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental health/ Depression	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

Please help us by providing some background information

The following section will help us better understand your survey responses. All responses provided are anonymous and you can skip any question you do not wish to answer, but we appreciate any answers you are willing to provide.

7. What is your gender?

- ☐ Female
- ☐ Male

8. What is your age?

9. What is your marital status?

- ☐ Now married
- ☐ Partnered
- ☐ Widowed
- ☐ Divorced
- ☐ Separated
- ☐ Never married
- ☐ Don't know

10. Are you of Hispanic, Latino, or Spanish origin?

- ☐ No
- ☐ Yes

11. What is your race? (Check all that apply.)

- ☐ White
- ☐ Black or African American
- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ Other (please specify below)

Other (please specify)

12. Please estimate your household income.

- ☐ Under \$25,000
- ☐ \$25,000 - \$35,999
- ☐ \$36,000 - \$45,999
- ☐ \$46,000 - \$55,999
- ☐ \$56,000 - \$65,999
- ☐ \$66,000 - \$75,999
- ☐ \$76,000 - \$85,999
- ☐ \$86,000 and over

THANK YOU!

Thank you for taking the time to fill out this survey. Your responses will help efforts to address the impact of Alzheimer's disease and related dementias on Florida's citizens.

You can follow the work of the Purple Ribbon Task Force at the website below:

http://elderaffairs.state.fl.us/doea/purple_ribbon.php

Please feel free to make any comments that you believe will help us in understanding the needs of people with Alzheimer's disease and related dementias.

13. Any other comments or suggestions?



This survey was created by the Purple Ribbon Task Force of Florida, but has been based in large part upon surveys conducted by the State Plan for Alzheimer's Disease in Oregon (SPADO) Task Force.

Survey for Family Caregivers

We need your help. Your ideas and experience as a current or former family caregiver will help inform the creation of a Florida state plan to address the growing public health impact of Alzheimer's disease and related dementias. Your insights will help the state identify the needs of individuals with Alzheimer's disease or related dementias and their caregivers.

This survey is being conducted by the Florida Purple Ribbon Task Force, which is a project of knowledgeable leaders, appointed by the Governor, the President of the Florida Senate, and the Speaker of the Florida House of Representatives, who are concerned about the impact of Alzheimer's disease on our communities and want to address the needs of Florida's citizens.

Thank you for sharing your ideas and advice!

Please tell us about yourself and your caregiving situation

1. Where do you live or work?

City:

County:

State:

2. How many years have you been caregiving for the person with Alzheimer's disease or related dementia?

- ☐ Newly diagnosed
- ☐ 1-3 years
- ☐ 4-7 years
- ☐ 8-11 years
- ☐ Over 12 years

3. Are you the primary caregiver?

- ☐ Yes
- ☐ No

4. Do you consider yourself a long distance caregiver?

- ☐ Yes
- ☐ No

5. Are you part of the "sandwich generation," caring for younger loved ones such as children, and elder parents or other elder family members?

- ☐ Yes
- ☐ No

6. Have you taken care of more than one person with Alzheimer's disease or related dementia?

- ☐ Yes
- ☐ No

Please tell us about the person you are caring for

7. What is your relationship to the person you are caring for?

- ☐ Spouse
- ☐ Adult child
- ☐ Significant partner
- ☐ Sibling
- ☐ Friend
- ☐ Grandchild
- ☐ Other (please specify below)

Other (please specify)

8. What is the gender of the person you are caring for?

- ☐ Female
- ☐ Male

9. What is the age of the person you are caring for?

- ☐ 35-44
- ☐ 45-54
- ☐ 55-64
- ☐ 65-74
- ☐ 75-84
- ☐ 85-94
- ☐ 95 or older

10. Where does the person you are caring for live?

- ☐ Alone in their own home
- ☐ In their own home, with others
- ☐ In your home
- ☐ Assisted living facility
- ☐ Nursing home
- ☐ Other (please specify below)

Other (please specify)

11. What is the diagnosis of the person you are caring for? (Check all that apply.)

- ☐ Not diagnosed
- ☐ Alzheimer's Disease
- ☐ Mild Cognitive Impairment
- ☐ Frontotemporal Dementia
- ☐ Lewy Body Dementia
- ☐ Vascular Dementia
- ☐ Memory loss
- ☐ Dementia
- ☐ Stroke
- ☐ Parkinson's Disease
- ☐ Don't know
- ☐ Other (please specify below)

Other (please specify)

12. Who diagnosed the person you are caring for?

- ☐ Family doctor/Primary care physician
- ☐ Neurologist
- ☐ Geriatrician
- ☐ (Florida) Memory Disorder Clinic
- ☐ Don't know
- ☐ Other (please specify below)

Other (please specify)

What kind of help does the person you are caring for need?

13. How much help does the person you care for need in the following areas?

	No Help	A Little Help	Some Help	Quite a Bit of Help	A Lot of Help
Taking care of himself/herself, such as eating, dressing, or bathing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taking care of his/her residence or personal living spaces, such as cleaning, managing money, or preparing meals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Communicating with others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Seeing or hearing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Moving around within the house	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transportation outside of the home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting along with people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relieving/decreasing anxiety or depression	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

Please describe your caregiving responsibilities

14. In an average week, how many hours do you provide care for this person?

Average hours per week

15. Do you have others helping you with the care of this person?

☐ Yes

☐ No

16. If yes, who helps you with your caregiving responsibilities? (Check all that apply.)

☐ Spouse

☐ Adult child

☐ Sibling

☐ In-laws

☐ Friend

☐ Relative (aunt/uncle/cousin)

☐ Paid help

☐ Other (please specify below)

Other (please specify)

17. Who provides routine assistance when the primary caregiver is absent?

Issues affecting the person you are caring for

18. Please indicate how challenging the following issues affecting the person with Alzheimer's disease or related dementia have been for you and your family. Check N/A if the topic is not applicable to you.

	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	N/A
Loss of ability to drive	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Depression or anxiety of the person with Alzheimer's disease or related dementia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficult behaviors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wandering or safety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Becoming a financial burden	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Losing control over lifestyle	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

Challenges for the Caregiver

19. Please indicate how challenging the following issues are (or have been) to you as a caregiver.

	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	N/A
Getting helpful information on Alzheimer's disease and related dementias	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting information about community resources	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to medical care for yourself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to medical care for your family member with Alzheimer's disease or related dementia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dealing with financial, legal, and insurance issues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to support groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to respite care, adult day care, and other services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Paying for services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Changing relationships in the family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Communication with the person with Alzheimer's disease or related dementia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dying before the person with Alzheimer's disease or related dementia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Losing control of lifestyle	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Loss of employment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting an appropriate diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

Difficulties for the Caregiver

20. Below is a list of difficulties you may have faced as a caregiver. Please indicate how much you agree or disagree with the following:

	Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree	N/A
Creates a financial burden	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doesn't leave enough time for yourself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doesn't leave enough time for your family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Interferes with your work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Creates anxiety or depression	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling resentful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Creates or aggravates health problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Affects family relationships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Interferes with employment/loss of employment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficult behaviors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wandering or safety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understanding the disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

Services needed to continue to live at home

21. What type of support do you need to keep the person you care for at home? (Check all that apply.)

- ☐ Financial assistance
- ☐ Transportation
- ☐ Education
- ☐ Legal advice
- ☐ Medical care
- ☐ Respite
- ☐ Meals
- ☐ Personal care
- ☐ Other (please specify below)

Other (please specify)

22. Have you made a plan or other preparations for what to do in case there is a disaster, like a hurricane? (Check all that apply.)

- ☐ No, I do not have a plan or other preparations
- ☐ Yes, I have a written plan
- ☐ Yes, I have a survival kit
- ☐ Yes, I have registered with my county for a Special Needs Shelter
- ☐ Other (please specify below)

Other (please specify)

23. What ways of getting information about Alzheimer's disease and related dementias and caregiving would be most helpful to you? (Check all that apply.)

- ☐ Internet or web-based information and training
- ☐ In-person support groups
- ☐ Community education and training
- ☐ Toll-free 24-hr telephone helpline
- ☐ Case management
- ☐ Seminars
- ☐ One-on-one counseling
- ☐ Employers
- ☐ Other (please specify below)

Other (please specify)

Services Received

24. What services have you accessed to care for the person with Alzheimer's disease or related dementia? (Check all that apply.)

- ☐ Home health
- ☐ Personal care/ Bath assistance
- ☐ Homemaker/ Housekeeper
- ☐ Counseling
- ☐ Case management
- ☐ Adult day services
- ☐ Respite
- ☐ Hospice
- ☐ Aging and Disability Resource Center
- ☐ Area Agency on Aging
- ☐ Education
- ☐ Research/ Clinical trials
- ☐ Support Groups
- ☐ Telephone reassurance
- ☐ Personal emergency response systems
- ☐ Wanderguards/ Project Lifesaver
- ☐ Meals on Wheels
- ☐ On-line support through professional or informal groups (for example, Facebook)
- ☐ On-line research/ Support/ Blogging
- ☐ Legal services
- ☐ Memory Disorder Clinic
- ☐ Other (please specify below)

Other (please specify)

25. How were the services paid for? (Check all that apply.)

- ☐ Private pay/ Out of pocket of person
- ☐ Trust funds
- ☐ Family supported
- ☐ Long-term care insurance
- ☐ Medicaid
- ☐ Nursing Home Diversion Medicaid Waiver
- ☐ Employee Assistance Program
- ☐ Government funding
- ☐ County/ City funding
- ☐ Veterans Administration
- ☐ Other (please specify below)

Other (please specify)

26. What prevents you from receiving the services or resources you need but don't have? (Check all that apply.)

- ☐ I don't know where to find them
- ☐ I can't afford them
- ☐ I don't have transportation to use the service
- ☐ I don't have time
- ☐ They are not available
- ☐ Family dynamics - I'm a long distance caregiver
- ☐ Other (please specify below)

Other (please specify)

Creating a State Plan - Public Awareness

27. The Purple Ribbon Task Force wants to increase general awareness and understanding of Alzheimer's disease across Florida. Which of the following would be the best ways to raise public awareness of Alzheimer's disease and related dementias in your community? (Check all that apply.)

- ☐ Employers and workplaces
- ☐ Hospitals
- ☐ Aging services and senior centers
- ☐ Churches and faith communities
- ☐ Veterans Administration
- ☐ Public service announcements on radio and TV
- ☐ Medical training schools
- ☐ Law enforcement
- ☐ Physicians
- ☐ Nursing schools
- ☐ Religious organization
- ☐ Website with updated information
- ☐ Other (please specify below)

Other (please specify)

Creating a State Plan - Critical Issues

28. In your opinion, what are the most critical issues that the state government in Florida should address in the next few years? Please rate the importance of the following possible issues that Florida might address.

	Not Important	A Little Important	Somewhat Important	Quite Important	Very Important	Don't Know
Research on prevention, treatment, and clinical trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clinical assessment, diagnosis, and testing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assisting families in paying for care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Protecting people with Alzheimer's disease and related dementias	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ensuring quality of care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Education and training for caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Economic impact of Alzheimer's disease and related dementias on communities, workplaces, and citizens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to affordable and appropriate dementia-specific care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having an educated and trained workforce on Alzheimer's disease and related dementias	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transportation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tax credits for caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to non-dementia-specific services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specialized care facilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Emergency management/disaster preparedness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental health/depression	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

Please help us by providing some background information

The following section will help us better understand your survey responses. All responses provided are anonymous and you can skip any question you do not wish to answer, but we appreciate any answers you are willing to provide.

29. What is your gender?

- ☐ Female
- ☐ Male

30. What is your age?

31. What is your marital status?

- ☐ Now married
- ☐ Partnered
- ☐ Widowed
- ☐ Divorced
- ☐ Separated
- ☐ Never married
- ☐ Don't know

32. Are you of Hispanic, Latino, or Spanish origin?

- ☐ No
- ☐ Yes

33. What is your race? (Check all that apply.)

- ☐ White
- ☐ Black or African American
- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ Other (please specify below)

Other (please specify)

34. Do you speak a language other than English in your work or home life?

- ☐ Just English
- ☐ Spanish
- ☐ Russian
- ☐ Creole
- ☐ Other (please specify below)

Other (please specify)

35. What is your highest level of education attained?

- ☐ Grade School
- ☐ High School
- ☐ College
- ☐ Post College

36. Are you employed?

- ☐ Full-time
- ☐ Part-time
- ☐ Retired
- ☐ Military
- ☐ Unemployed
- ☐ Other (please specify below)

Other (please specify)

37. Do your caregiver responsibilities affect your employment?

- ☐ Yes
- ☐ No

38. If yes, did you have to cut back on your hours of work?

- ☐ Yes
- ☐ No
- ☐ Other (please specify below)

Other (please specify)

39. If yes, did you leave your job?

- ☐ Yes
- ☐ No
- ☐ Other (please specify below)

Other (please specify)

40. Please estimate your household income.

- ☐ Under \$25,000
- ☐ \$25,000 - \$35,999
- ☐ \$36,000 - \$45,999
- ☐ \$46,000 - \$55,999
- ☐ \$56,000 - \$65,999
- ☐ \$66,000 - \$75,999
- ☐ \$76,000 - \$85,999
- ☐ \$86,000 and over

THANK YOU!


Thank you for taking the time to fill out this survey. Your responses will help efforts to address the impact of Alzheimer's disease and related dementias on Florida's citizens.

You can follow the work of the Purple Ribbon Task Force at the website below:

http://elderaffairs.state.fl.us/doea/purple_ribbon.php

Please feel free to make any comments that you believe will help us in understanding the needs of people with Alzheimer's disease and related dementias.

41. Any other comments or suggestions?



This survey was created by the Purple Ribbon Task Force of Florida, but has been based in large part upon surveys conducted by the State Plan for Alzheimer's Disease in Oregon (SPADO) Task Force.

Survey for Concerned Family and Friends

We need your help. Your ideas and experiences with persons with Alzheimer's disease and related dementias will help inform the creation of a Florida state plan to address the growing public health impact of Alzheimer's disease. Your ideas and insights will help the state identify the needs of individuals with Alzheimer's disease or related dementias and their caregivers.

This survey is being conducted by the Florida Purple Ribbon Task Force, which is a project of knowledgeable leaders, appointed by the Governor, the President of the Florida Senate, and the Speaker of the Florida House of Representatives, who are concerned about the impact of Alzheimer's disease on our communities and want to address the needs of Florida's citizens.

Thank you for sharing your ideas and advice!

Please tell us about yourself

1. Where do you live or work?

City:

County:

State:

2. What is your involvement or relationship to those with Alzheimer's disease and related dementias and their families? (Check all that apply.)

- ☐ Family
- ☐ Friend
- ☐ Neighbor
- ☐ Co-worker
- ☐ Other (please specify below)

Other (please specify)

3. If you provide support to someone with Alzheimer's disease or related dementia or their family, please indicate approximately how many hours per week of help you provide.

Average hours per week

Challenges for Families

4. How challenging do you feel the following issues are for families involved with Alzheimer's disease and related dementias and caregiving?

	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know
Getting helpful information on Alzheimer's disease and related dementias	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting information about community resources	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caregivers feeling depressed or anxious	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caregivers feeling resentful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to medical care for caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to medical care for people with Alzheimer's disease and related dementias	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dealing with financial, legal, and insurance issues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to support groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to respite care, adult day care, and other services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Paying for services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Changing relationships in the family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Communication with the person with Alzheimer's disease or related dementia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Becoming a financial burden on children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dying before the person with Alzheimer's disease or related dementia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Losing control of lifestyle	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Loss of employment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting an appropriate diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understanding the disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

Challenges for Individuals

5. How challenging do you feel the following issues are for individuals with Alzheimer's disease and related dementias and their families?

	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know
Loss of ability to drive	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Depression or anxiety of the person with Alzheimer's disease or related dementia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficult behaviors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wandering or safety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Becoming a financial burden	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Losing control over lifestyle	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

Creating a State Plan - Public Awareness

6. The Alzheimer's Purple Ribbon Task Force wants to increase general awareness and understanding of Alzheimer's disease across Florida. Which of the following would be best ways to raise public awareness of Alzheimer's disease and related dementias in your community? (Check all that apply.)

- ☐ Employers and workplaces
- ☐ Hospitals
- ☐ Aging services and senior centers
- ☐ Churches and faith communities
- ☐ Veterans Administration
- ☐ Public service announcements on radio and TV
- ☐ Medical training schools
- ☐ Law enforcement
- ☐ Physicians
- ☐ Nursing schools
- ☐ Religious organization
- ☐ Website with updated information
- ☐ Other (please specify below)

Other (please specify)

Creating a State Plan - Critical Issues

7. In your opinion, what are the most critical issues the state government in Florida should address in the next few years? Please rate the importance of the following possible issues that Florida might address.

	Not Important	A Little Important	Somewhat Important	Quite Important	Very Important	Don't Know
Research on prevention, treatment, and clinical trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clinical assessment, diagnosis, and testing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assisting families in paying for care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Protecting people with Alzheimer's disease and related dementias	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ensuring quality of care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Education and training for caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Economic impact of Alzheimer's disease and related dementias on communities, workplaces, and citizens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to affordable and appropriate dementia-specific care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having an educated and trained workforce on Alzheimer's disease and related dementias	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transportation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tax credits for caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to non-dementia-specific services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specialized care facilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Emergency Management/ Disaster Preparedness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental health/ Depression	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

Please help us by providing some background information

The following section will help us better understand your survey responses. All responses provided are anonymous and you can skip any question you do not wish to answer, but we appreciate any answers you are willing to provide.

8. What is your gender?

- ☐ Female
- ☐ Male

9. What is your age?

10. Are you of Hispanic, Latino, or Spanish origin?

- ☐ No
- ☐ Yes

11. What is your race? (Check all that apply.)

- ☐ White
- ☐ Black or African American
- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ Other (please specify below)

Other (please specify)

THANK YOU!

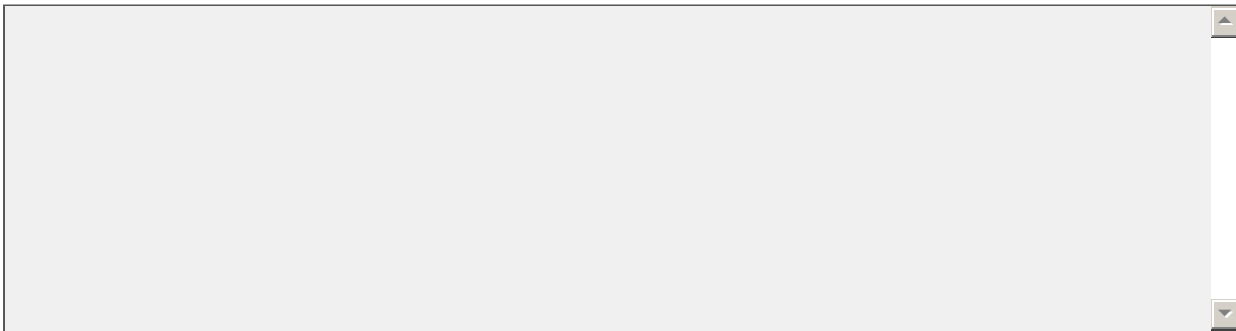
Thank you for taking the time to fill out this survey. Your responses will help efforts to address the impact of Alzheimer's disease and related dementias on Florida's citizens.

You can follow the work of the Purple Ribbon Task Force at the website below:

http://elderaffairs.state.fl.us/doea/purple_ribbon.php

Please feel free to make any comments that you believe will help us in understanding the needs of people with Alzheimer's disease and related dementias.

12. Any other comments or suggestions?



This survey was created by the Purple Ribbon Task Force of Florida, but has been based in large part upon surveys conducted by the State Plan for Alzheimer's Disease in Oregon (SPADO) Task Force.

Survey for Healthcare Providers and Paid Caregivers

We need your help. Your ideas and experience in providing care for persons with Alzheimer's disease and related dementias will help inform the creation of a Florida state plan to address the growing public health impact of Alzheimer's disease. Your ideas and insights will help the state identify the needs of individuals with Alzheimer's disease or related dementias and their caregivers.

This survey is being conducted by the Florida Purple Ribbon Task Force, which is a project of knowledgeable leaders, appointed by the Governor, the President of the Florida Senate, and the Speaker of the Florida House of Representatives, who are concerned about the impact of Alzheimer's disease on our communities and want to address the needs of Florida's citizens.

Thank you for sharing your ideas and advice!

Please tell us about yourself

1. Where do you live or work?

City:

County:

State:

2. How long have you been providing care for persons with Alzheimer's disease and related dementias?

- ☐ 0-5 years
- ☐ 6-10 years
- ☐ 11-15 years
- ☐ 16-20 years
- ☐ 21-25 years
- ☐ Over 25 years

3. What kind of training certification or license do you have? (Check all that apply.)

- ☐ No specific training or certification
- ☐ CNA
- ☐ LPN
- ☐ RN
- ☐ NP
- ☐ PA
- ☐ MD/DO
- ☐ MSW/LCSW
- ☐ Other (please specify below)

Other certification or license

Please tell us about your work

4. In what kind of setting do you work? (Check all that apply.)

- ☐ Adult day care facility
- ☐ Adult family care home
- ☐ Assisted living facility
- ☐ Community health center
- ☐ Hospice
- ☐ Hospital
- ☐ Memory Disorder Clinic
- ☐ Nursing facility
- ☐ Physician's office
- ☐ Private residence
- ☐ Other (please specify below)

Other (please specify)

5. Do you, or does your facility/agency, provide cognitive assessment or screening?

- ☐ Yes
- ☐ No
- ☐ Unsure/Don't know
- ☐ Other (please specify below)

Other (please specify)

6. What type of services do you provide to people with Alzheimer's disease and related dementias? (Check all that apply.)

- ☐ Home health
- ☐ Personal care/ Bath assistance
- ☐ Homemaker/ Housekeeper
- ☐ Counseling
- ☐ Case management
- ☐ Adult day services
- ☐ Respite
- ☐ Hospice
- ☐ Education
- ☐ Research/ Clinical trials
- ☐ Support groups
- ☐ Telephone reassurance
- ☐ Personal emergency response systems
- ☐ Wanderguards/ Project Lifesaver
- ☐ Meals on Wheels
- ☐ On-line support through professional or informal groups (for example, Facebook)
- ☐ On-line research/ Support/ Blogging
- ☐ Legal services
- ☐ Other (please specify below)

Other (please specify)

7. How do you, or does your facility/ agency, advertise? (Check all that apply.)

- ☐ Newspaper
- ☐ On-line/website
- ☐ Facebook
- ☐ Newsletters
- ☐ Don't know
- ☐ Other (please specify below)

Other (please specify)

Challenges for Families

8. How challenging do you feel the following issues are for families involved with Alzheimer's disease and related dementias and caregiving?

	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know
Getting helpful information on Alzheimer's disease and related dementias	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting information on community resources	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caregivers feeling depressed or anxious	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caregivers feeling resentful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to medical care for caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to medical care for people with Alzheimer's disease and related dementias	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dealing with financial, legal, and insurance issues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to support groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to respite care, adult day care, and other services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Paying for services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Changing relationships in the family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Communication with the person with Alzheimer's disease or related dementia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dying before the person with Alzheimer's disease or related dementia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Losing control of lifestyle	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Loss of employment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting an appropriate diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understanding the disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

Challenges for Individuals

9. How challenging do you feel the following issues are for individuals with Alzheimer's disease or related dementia and their families?

	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know
Loss of ability to drive	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Depression or anxiety of the person with Alzheimer's disease or related dementia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficult behaviors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wandering or safety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Becoming a financial burden	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Losing control over lifestyle	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

Creating a State Plan - Public Awareness

10. The Purple Ribbon Task Force wants to increase general awareness and understanding of Alzheimer's disease across Florida. Which of the following would be the best ways to raise public awareness of Alzheimer's disease and related dementias in your community? (Check all that apply.)

- ☐ Employers and workplaces
- ☐ Hospitals
- ☐ Aging services and senior centers
- ☐ Churches and faith communities
- ☐ Veterans Administration
- ☐ Public service announcements on radio and TV
- ☐ Medical training schools
- ☐ Law enforcement
- ☐ Physicians
- ☐ Nursing schools
- ☐ Religious organization
- ☐ Website with updated information
- ☐ Other (please specify below)

Other (please specify)

Creating a State Plan - Issues of the Newly Diagnosed

11. How important is it for Florida to address the following issues relating to identifying and meeting the needs of newly diagnosed individuals with Alzheimer's disease and related dementias?

	Not Important	A Little Important	Somewhat Important	Quite Important	Very Important	Don't Know
Increase public awareness of Alzheimer's disease and related dementias	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Promote annual cognitive assessment/ screening for older adults	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Improve access to information and resources for newly diagnosed individuals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>					

Creating a State Plan - Critical Issues

12. In your opinion, what are the most critical issues that the state government of Florida should address in the next few years? Please rate the importance of the following possible issues that Florida might address.

	Not Important	A Little Important	Somewhat Important	Quite Important	Very Important	Don't Know
Research on prevention, treatment, and clinical trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clinical assessment, diagnosis, and testing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assisting families in paying for care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Protecting people with Alzheimer's disease and related dementias	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ensuring quality of care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Education and training for caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Economic impact of Alzheimer's disease and related dementias on communities, workplaces, and citizens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to affordable and appropriate dementia-specific care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having an educated and trained workforce on Alzheimer's disease and related dementias	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transportation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tax credits for caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to non-dementia-specific services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specialized care facilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Emergency Management/Disaster Preparedness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental health/depression	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

Please help us by providing some background information

The following section will help us better understand your survey responses. All responses provided are anonymous and you can skip any question you do not wish to answer, but we appreciate any answers you are willing to provide.

13. What is your gender?

- ☐ Female
- ☐ Male

14. What is your age?

15. Are you of Hispanic, Latino, or Spanish origin?

- ☐ No
- ☐ Yes

16. What is your race? (Check all that apply.)

- ☐ White
- ☐ Black or African American
- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ Other (please specify below)

Other (please specify)

17. Do you speak a language other than English in your work or home life?

- ☐ Just English
- ☐ Spanish
- ☐ Russian
- ☐ Creole
- ☐ Other (please specify below)

Other (please specify)

THANK YOU!

Thank you for taking the time to fill out this survey. Your responses will help efforts to address the impact of Alzheimer's disease and related dementias on Florida's citizens.

You can follow the work of the Purple Ribbon Task Force at the website below:

http://elderaffairs.state.fl.us/doea/purple_ribbon.php

Please feel free to make any comments that you believe will help us in understanding the needs of people with Alzheimer's disease and related dementias.

18. Any other comments or suggestions?



This survey was created by the Purple Ribbon Task Force of Florida, but has been based in large part upon surveys conducted by the State Plan for Alzheimer's Disease in Oregon (SPADO) Task Force.

Survey for Policy, Legal, Educational, and Other Professionals

We need your help. Your ideas and experience will help inform the creation of a Florida state plan to address the growing public health impact of Alzheimer's disease and related dementias. Your ideas and insights will help the state identify the needs of individuals with Alzheimer's disease or related dementias and their caregivers.

This survey is being conducted by the Florida Purple Ribbon Task Force, which is a project of knowledgeable leaders, appointed by the Governor, the President of the Florida Senate, and the Speaker of the Florida House of Representatives, who are concerned about the impact of Alzheimer's disease on our communities and want to address the needs of Florida's citizens.

Thank you for sharing your ideas and advice!

Please tell us about yourself

1. Where do you live or work?

City:

County:

State:

2. Please indicate the category that fits you best.

- ☐ Case manager
- ☐ Elected official
- ☐ Ombudsman
- ☐ Advocate
- ☐ Educator, trainer, or academic
- ☐ Legal or financial professional
- ☐ Public safety or law enforcement
- ☐ State or county government coordination/regulation of care and services
- ☐ Other (please specify below)

Other (please specify)

3. Do you have personal experience as a primary caregiver for someone with Alzheimer's disease and related dementias?

- ☐ Yes
- ☐ No

Challenges for Families

4. How challenging do you feel the following issues are for families involved with Alzheimer's disease and related dementias and caregiving?

	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know
Getting helpful information on Alzheimer's disease and related dementias	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting information about community resources	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caregivers feeling depressed or anxious	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caregivers feeling resentful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to medical care for caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to medical care for people with Alzheimer's disease and related dementias	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dealing with financial, legal, and insurance issues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to support groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to respite care, adult day care, and other services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Paying for services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Changing relationships in the family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Communication with the person with Alzheimer's disease or related dementia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Becoming a financial burden on children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dying before the person with Alzheimer's disease or related dementia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Losing control of lifestyle	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Loss of employment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting an appropriate diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understanding the disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

Challenges for Individuals

5. How challenging do you feel the following issues are for individuals with Alzheimer's disease or related dementia and their families?

	Not Challenging	A Little Challenging	Somewhat Challenging	Quite Challenging	Very Challenging	Don't Know
Loss of ability to drive	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Depression or anxiety of the person with Alzheimer's disease or related dementia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficult behaviors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wandering or safety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Becoming a financial burden	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Losing control over lifestyle	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

Creating a State Plan - Public Awareness

6. The Purple Ribbon Task Force wants to increase general awareness and understanding of Alzheimer's disease across Florida. Which of the following would be best ways of raising public awareness of Alzheimer's disease and related dementias in your community? (Check all that apply.)

- ☐ Employers and workplaces
- ☐ Hospitals
- ☐ Aging services and senior centers
- ☐ Churches and faith communities
- ☐ Veterans Administration
- ☐ Public service announcements on radio & TV
- ☐ Medical training schools
- ☐ Law enforcement
- ☐ Physicians
- ☐ Nursing schools
- ☐ Religious organizations
- ☐ Website with updated information
- ☐ Other (please specify below)

Other (please specify)

Creating a State Plan - Critical Issues

7. In your opinion, what are the most critical issues that the state government in Florida should address in the next few years? Please rate the importance of the following possible issues that Florida might address.

	Not Important	A Little Important	Somewhat Important	Quite Important	Very Important	Don't Know
Research on prevention, treatment, and clinical trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clinical assessment, diagnosis, and testing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assisting families in paying for care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Protecting people with Alzheimer's disease and related dementias	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ensuring quality of care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Education and training for caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Economic impact of Alzheimer's disease and related dementias on communities, workplaces, and citizens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to affordable and appropriate dementia-specific care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having an educated and trained workforce on Alzheimer's disease and related dementias	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transportation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tax credits for caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to non-dementia-specific services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specialized care facilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Emergency Management/ Disaster Preparedness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental health/ Depression	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

Please help us by providing some background information

The following section will help us better understand your survey responses. All responses provided are anonymous and you can skip any question you do not wish to answer, but we appreciate any answers you are willing to provide.

8. What is your gender?

- ☐ Female
- ☐ Male

9. What is your age?

10. Are you of Hispanic, Latino or Spanish origin?

- ☐ No
- ☐ Yes
- ☐ Don't know

11. What is your race? (Check all that apply.)

- ☐ White
- ☐ Black or African American
- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ Other (please specify below)

Other (please specify)

THANK YOU!

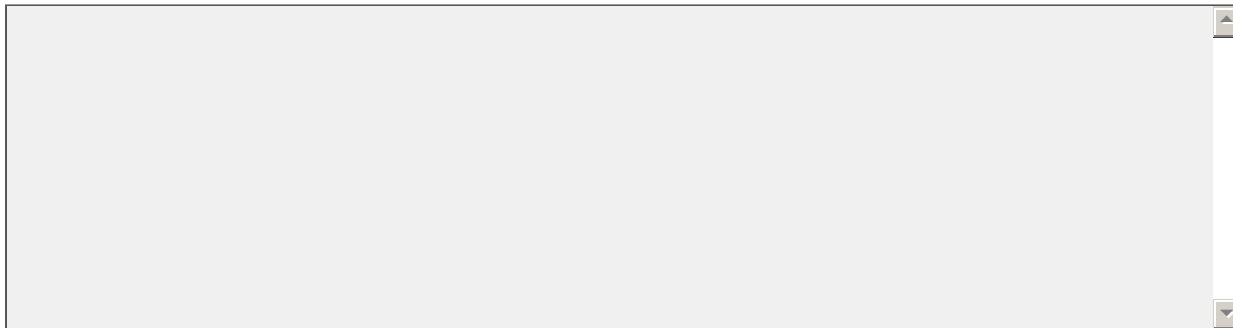
Thank you for taking the time to fill out this survey. Your responses will help efforts to address the impact of Alzheimer's disease and related dementias on Florida's citizens.

You can follow the work of the Purple Ribbon Task Force at the website below:

http://elderaffairs.state.fl.us/doea/purple_ribbon.php

Please feel free to make any comments that you believe will help us in understanding the needs of people with Alzheimer's disease and other related dementias.

12. Any other comments or suggestions?



This survey was created by the Purple Ribbon Task Force of Florida, but has been based in large part upon surveys conducted by the State Plan for Alzheimer's Disease in Oregon (SPADO) Task Force.