Purple Ribbon Task Force

Survey of People With Alzheimer's Disease or Related Dementias

1. Where do you live or work?

1a. City:

		Number	Percent
Responses	Fort Myers	3	33.3
	Lehigh Acres	1	11.1
	Naples	1	11.1
	North Port	1	11.1
	Punta Gorda	1	11.1
	Sarasota	2	22.2
	Total	9	100.0

1b. County:

		Number	Percent
Responses	Charlotte	1	11.1
	Collier	1	11.1
	Lee	4	44.4
	Sarasota	3	33.3
	Total	9	100.0

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

		Number	Percent
Responses	2b. Alzheimer's disease	4	40.0%
	2c. Mild Cognitive Impairment (MCI)	2	20.0%
	2d. Frontotemporal Dementia	1	10.0%
	2f. Vascular Dementia	1	10.0%
	2g. Memory Loss	2	20.0%
	Total	10	100.0%

2. Other (please specify)

Dad with Dementia

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

		Number	Percent
Responses	Less than a year	2	22.2
	1-5 years	6	66.7
	6-10 years	1	11.1
	Total	9	100.0

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4. How challenging are the following issues for you?

4a. Getting helpful information on Alzheimer's disease and related dementias

		Number	Percent
Responses	Not Challenging	4	50.0
	A Little Challenging	2	25.0
	Somewhat Challenging	2	25.0
	Total	8	100.0

4b. Access to medical care for yourself

		Number	Percent
Responses	Not Challenging	5	62.5
	Somewhat Challenging	3	37.5
	Total	8	100.0

4c. Dealing with financial, legal and insurance issues

		Number	Percent
Responses	Not Challenging	2	28.6
	A Little Challenging	2	28.6
	Somewhat Challenging	2	28.6
	Very Challenging	1	14.3
	Total	7	100.0

4d. Access to support groups

		Number	Percent
Responses	Don't Know	1	12.5
	Not Challenging	4	50.0
	A Little Challenging	2	25.0
	Somewhat Challenging	1	12.5
	Total	8	100.0

4e. Loss of ability to drive

		Number	Percent
Responses	Don't Know	1	14.3
	Not Challenging	3	42.9
	A Little Challenging	1	14.3
	Very Challenging	2	28.6
	Total	7	100.0

4f. Paying for services

		Number	Percent
Responses	Don't Know	1	14.3
	Not Challenging	3	42.9
	Somewhat Challenging	2	28.6
	Very Challenging	1	14.3
	Total	7	100.0

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4g. Depression or anxiety

		Number	Percent
Responses	Not Challenging	1	14.3
	A Little Challenging	2	28.6
	Quite Challenging	1	14.3
	Very Challenging	3	42.9
	Total	7	100.0

4h. Changing relationships in the family

		Number	Percent
Responses	Don't Know	1	14.3
	Not Challenging	2	28.6
	A Little Challenging	1	14.3
	Somewhat Challenging	1	14.3
	Quite Challenging	2	28.6
	Total	7	100.0

4i. Communication with family and friends

		Number	Percent
Responses	Don't Know	1	14.3
	Not Challenging	3	42.9
	A Little Challenging	1	14.3
	Somewhat Challenging	1	14.3
	Quite Challenging	1	14.3
	Total	7	100.0

4j. Worrying about being a burden on others

		Number	Percent
Responses	Don't Know	1	14.3
	Not Challenging	1	14.3
	A Little Challenging	2	28.6
	Somewhat Challenging	1	14.3
	Very Challenging	2	28.6
	Total	7	100.0

4. Other (please specify)

Difficult for family to accept, but we were able to work it out. Dad was living by himself and we had to move him to Clare Bridge for assistance.
Paying for my care.

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Survey of People With Alzheimer's Disease or Related Dementias

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

		Number	Percent
Responses	5a. Internet or web-based information and training	5	25.0%
	5b. In-person support groups	5	25.0%
	5c. Community education and training	4	20.0%
	5d. Toll-free 24-hr telephone helpline	1	5.0%
	5e. One-on-one counseling	2	10.0%
	5f. Other	3	15.0%
	Total	20	100.0%

5. Other (please specify)

I was able to attend Caregiving Training. It was fantastic. I learned a lot about Alzheimer's/Dementia and was able to pass it on to my distant sisters. Very important training.

Magazines and news publications

The most important to me would be in-person support groups - on-line is not as helpful.

6. 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.

6a. Research on prevention, treatment, and clinical trials

		Number	Percent
Responses	Somewhat Important	2	25.0
	Very Important	6	75.0
	Total	8	100.0

6b. Clinical assessment, diagnosis, and testing

		Number	Percent
Responses	Quite Important	1	12.5
	Very Important	7	87.5
	Total	8	100.0

6c. Assisting families in paying for care

		Number	Percent
Responses	Quite Important	4	44.4
	Very Important	4	44.4
	Total	8	88.9

6d. Protecting people with Alzheimer's disease and related dementias

		Number	Percent
Responses	Don't Know	1	12.5
	A little Important	1	12.5
	Quite Important	2	25.0
	Very Important	4	50.0
	Total	8	100.0

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Survey of People With Alzheimer's Disease or Related Dementias

6e. Ensuring quality of care

		Number	Percent
Responses	Quite Important	3	37.5
	Very Important	5	62.5
	Total	8	100.0

6f. Education and training for caregivers

		Number	Percent
Responses	Quite Important	4	50.0
	Very Important	4	50.0
	Total	8	100.0

6g. Economic impact of Alzheimer's disease and related dementias on communities, workplaces, and citizens

		Number	Percent
Responses	Don't Know	2	25.0
	Somewhat Important	3	37.5
	Very Important	3	37.5
	Total	8	100.0

6h. Access to affordable and appropriate dementia-specific care

		Number	Percent
Responses	Don't Know	1	12.5
	Quite Important	3	37.5
	Very Important	4	50.0
	Total	8	100.0

6i. Having an educated and trained workforce on Alzheimer’s disease and related dementias

		Number	Percent
Responses	Don't Know	2	25.0
	Quite Important	1	12.5
	Very Important	5	62.5
	Total	8	100.0

6j. Transportation

		Number	Percent
Responses	Don't Know	2	25.0
	Not Important	1	12.5
	Somewhat Important	1	12.5
	Quite Important	1	12.5
	Very Important	3	37.5
	Total	8	100.0

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6k. Employment

		Number	Percent
Responses	Don't Know	2	25.0
	Not Important	1	12.5
	A little Important	1	12.5
	Somewhat Important	2	25.0
	Quite Important	1	12.5
	Very Important	1	12.5
	Total	8	100.0

6l. Tax credits for caregivers

		Number	Percent
Responses	Don't Know	2	25.0
	A little Important	1	12.5
	Somewhat Important	1	12.5
	Quite Important	1	12.5
	Very Important	3	37.5
	Total	8	100.0

6m. Access to non-dementia-specific services

		Number	Percent
Responses	Don't Know	2	25.0
	A little Important	2	25.0
	Somewhat Important	2	25.0
	Very Important	2	25.0
	Total	8	100.0

6n. Specialized care facilities

		Number	Percent
Responses	Don't Know	1	12.5
	Quite Important	2	25.0
	Very Important	5	62.5
	Total	8	100.0

6o. Emergency Management/Disaster Preparedness

		Number	Percent
Responses	Don't Know	1	12.5
	A little Important	1	12.5
	Somewhat Important	1	12.5
	Quite Important	1	12.5
	Very Important	4	50.0
	Total	8	100.0

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Survey of People With Alzheimer's Disease or Related Dementias

6p. Medical care

		Number	Percent
Responses	Don't Know	2	25.0
	Somewhat Important	1	12.5
	Quite Important	1	12.5
	Very Important	4	50.0
	Total	8	100.0

6q. Mental health/Depression

		Number	Percent
Responses	Don't Know	1	12.5
	Somewhat Important	1	12.5
	Quite Important	2	25.0
	Very Important	4	50.0
	Total	8	100.0

6r. Other

		Number	Percent
Responses	Don't Know	2	66.7
	Very Important	1	33.3
	Total	3	100.0

7. What is your gender?

		Number	Percent
Responses	Female	6	75.0
	Male	2	25.0
	Total	8	100.0

8. What is your age?

		Number	Percent
Responses	50	1	12.5
	59	1	12.5
	70	1	12.5
	71	1	12.5
	74	2	25.0
	81	1	12.5
	87	1	12.5
	Total	8	100.0

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Survey of People With Alzheimer's Disease or Related Dementias

9. What is your marital status?

		Number	Percent
Responses	Now married	5	62.5
	Widowed	1	12.5
	Divorced	2	25.0
	Total	8	100.0

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

		Number	Percent
Responses	No	8	100.0

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

		Number	Percent
Responses	11a. White	7	87.5%
	11b. Black or African American	1	12.5%
	Total	8	100.0%

12. Estimated household income

		Number	Percent
Responses	Under $25,000	2	28.6
	$25,000 - $35,999	1	14.3
	$46,000 - $55,999	3	42.9
	$86,000 and over	1	14.3
	Total	7	100.0

13. Any other comments or suggestions?

I filled this out for my Mother, she has no internet savvy?! Thanks 4 all you have conquered. I'll B @ the Oct. Walk in Punta Gorda 4 sure!!!!!

I live 1/2 the year in Florida, the rest in Mass/NH. They have more programs up north such as meetings, drop in programs (Cafes), programs for both caregivers and us - a chance to talk together and then separate, programs including activities - wish Florida would develop more programs. We LOVED the BASE program, but there was little else available. Would love to talk more when we return south in the late fall. Just attended the national Alzheimer's meeting in DC - lots of good ideas - hope some of your Florida people were there.

Please note that I am the daughter of the patient who has dementia. The patient is my father. I still feel that my answers are important to this survey.

Purple Ribbon Task Force

Survey of Family Caregivers of People With Alzheimer's Disease and Related Dementias

1. Where do you live or work?

1a. City:

		Number	Percent
Responses	Bonita Springs	4	8.9
	Cape Coral	2	4.4
	Englewood	2	4.4
	Fort Myers	9	20.0
	Lehigh Acres	2	4.4
	Longboat Key	2	4.4
	Naples	9	20.0
	North Port	2	4.4
	Osprey	1	2.2
	Port Charlotte	1	2.2
	Punta Gorda	1	2.2
	Sarasota	5	11.1
	St. James City	1	2.2
	Venice	4	8.9
	Total	45	100.0

1b. County:

		Number	Percent
Responses	Charlotte	2	4.4
	Collier	9	20.0
	Lee	18	40.0
	Sarasota	16	35.6
	Total	45	100.0

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

		Number	Percent
Responses	1-3 years	15	33.3
	4-7 years	15	33.3
	8-11 years	9	20.0
	Over 12 years	6	13.3
	Total	45	100.0

3. Are you the primary caregiver?

		Number	Percent
Responses	Yes	39	90.7
	No	4	9.3
	Total	43	100.0

4. Do you consider yourself a long distance caregiver?

		Number	Percent
Responses	Yes	4	8.9
	No	41	91.1
	Total	45	100.0

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

		Number	Percent
Responses	Yes	12	26.7
	No	33	73.3
	Total	45	100.0

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

		Number	Percent
Responses	Yes	9	20.0
	No	36	80.0
	Total	45	100.0

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

		Number	Percent
Responses	Spouse	26	59.1
	Adult child	11	25.0
	Significant partner	1	2.3
	Other (please specify below)	6	13.6
	Total	44	100.0

7. Other (please specify)

Daughter
Daughter-in-law
Mother
Parent
Parents

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

		Number	Percent
Responses	Female	22	50.0
	Male	22	50.0
	Total	44	100.0

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

		Number	Percent
Responses	55-64	1	2.3
	65-74	9	20.9
	75-84	17	39.5
	85-94	15	34.9
	95 or older	1	2.3
	Total	43	100.0

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

		Number	Percent
Responses	Alone in their own home	1	2.3
	In their own home, with others	2	4.7
	In your home	26	60.5
	Assisted living facility	6	14.0
	Nursing home	7	16.3
	Other (please specify below)	1	2.3
	Total	43	100.0

10. Other (please specify)

In our home
We live with my son and grandson.

11. What is the diagnosis of the person you are caring for?

		Number	Percent
Responses	11b. Alzheimer's disease	31	44.9%
	11d. Frontotemporal Dementia	4	5.8%
	11e. Lewy Body Dementia	3	4.3%
	11f. Vascular Dementia	6	8.7%
	11g. Memory Loss	8	11.6%
	11h. Dementia	13	18.8%
	11i. Stroke	3	4.3%
	11j. Parkinson's disease	1	1.4%
	Total	69	100.0%

11. Other (please specify)

Severe vertigo, COPD

12. Who diagnosed the person you are caring for?

		Number	Percent
Responses	Family doctor/Primary care physician	7	15.9
	Neurologist	23	52.3
	Geriatrician	3	6.8
	(Florida) Memory Disorder Clinic	5	11.4
	Other (please specify below)	6	13.6
	Total	44	100.0

12. Other (please specify)

Family doctor diagnosed MCI. Neuropsychologist did extensive testing twice several years apart. Was under care by Neuropsychiatrist who specialized in AD.
Mayo Clinic, Rochester, MN
Neuropsychologist
Please note that I cared for my spouse in NJ
Psychiatrist
U Penn Memory Center
V.A. Psychiatrist

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

13a. Taking care of himself/herself, such as eating, dressing, or bathing

		Number	Percent
Responses	No Help	3	7.1
	A Little Help	6	14.3
	Some Help	12	28.6
	Quite a Bit of Help	6	14.3
	A Lot of Help	15	35.7
	Total	42	100.0

13b. Taking care of his/her residence or personal living spaces, such as cleaning, managing money, or preparing meals

		Number	Percent
Responses	No Help	2	4.8
	A Little Help	1	2.4
	Some Help	4	9.5
	Quite a Bit of Help	4	9.5
	A Lot of Help	31	73.8
	Total	42	100.0

13c. Communicating with others

		Number	Percent
Responses	No Help	7	16.7
	A Little Help	7	16.7
	Some Help	11	26.2
	Quite a Bit of Help	5	11.9
	A Lot of Help	12	28.6
	Total	42	100.0

13d. Seeing or hearing

		Number	Percent
Responses	No Help	14	33.3
	A Little Help	7	16.7
	Some Help	13	31.0
	Quite a Bit of Help	3	7.1
	A Lot of Help	5	11.9
	Total	42	100.0

13e. Moving around within the house

		Number	Percent
Responses	No Help	13	31.7
	A Little Help	6	14.6
	Some Help	9	22.0
	Quite a Bit of Help	6	14.6
	A Lot of Help	7	17.1
	Total	41	100.0

13f. Transportation outside of the home

		Number	Percent
Responses	No Help	2	4.9
	A Little Help	5	12.2
	Some Help	2	4.9
	Quite a Bit of Help	1	2.4
	A Lot of Help	31	75.6
	Total	41	100.0

13g. Getting along with people

		Number	Percent
Responses	No Help	13	31.7
	A Little Help	10	24.4
	Some Help	9	22.0
	Quite a Bit of Help	3	7.3
	A Lot of Help	6	14.6
	Total	41	100.0

13h. Relieving/decreasing anxiety or depression

		Number	Percent
Responses	No Help	4	9.8
	A Little Help	6	14.6
	Some Help	10	24.4
	Quite a Bit of Help	10	24.4
	A Lot of Help	11	26.8
	Total	41	100.0

13. Other

		Number	Percent
Responses	Quite a Bit of Help	1	50.0
	A Lot of Help	1	50.0
	Total	2	100.0

13. Other (please specify)

Disorientation and confusion

Incontinence and taking insulin and other Rx medications

My spouse is completely dependent on the aides in her assisted living facility. She has been in a wheel chair for over 2 and 1/2 years and cannot speak.

14. Average number of hours per week providing care

		Number	Percent
Responses	4	2	5.1
	10	2	5.1
	14	2	5.1
	15	2	5.1
	20	1	2.6
	24	2	5.1
	25	2	5.1
	30	1	2.6
	35	1	2.6
	40	2	5.1
	50	1	2.6
	60	3	7.7
	70	2	5.1
	80	1	2.6
	84	1	2.6
	85	1	2.6
	110	1	2.6
	112	1	2.6
	120	1	2.6
	133	1	2.6
	150	1	2.6
	160	2	5.1
	162	1	2.6
	168	4	10.3
	180	1	2.6
	Total	39	100.0

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

		Number	Percent
Responses	Yes	27	67.5
	No	13	32.5
	Total	40	100.0

16. If yes, who helps you with your caregiving responsibilities?

		Number	Percent
Responses	16a. Spouse	6	16.7%
	16b. Adult child	4	11.1%
	16c. Sibling	2	5.6%
	16e. Friend	1	2.8%
	16f. Relative (aunt/uncle/cousin)	1	2.8%
	16g. Paid help	13	36.1%
	16. Other	9	25.0%
	Total	36	100.0%

16. Other (please specify)

Adult day care
Assisted living staff
Friendship Center from 9AM to 3:30PM
No help, family lives long distance and can not afford paid help
Nursing Home Staff
Respite care from JCFS
Respite from Church
Staff at nursing home

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

		Number	Percent
Responses	Adult child	1	2.6%
	Adult son	1	2.6%
	Aides	1	2.6%
	Assisted living staff	1	2.6%
	Can be left alone or I pay someone	1	2.6%
	Caregiver always present	1	2.6%
	Day Care	1	2.6%
	Friends and neighbors	2	5.3%
	Geriatric care manager	1	2.6%
	Hopefully my husband	1	2.6%
	Me	1	2.6%
	N/A	1	2.6%
	Neighbor	1	2.6%
	Never absent	1	2.6%
	Next door neighbor - this is extremely rare	1	2.6%
	No one	1	2.6%
	No one, I don't leave him alone for more than 2 hours at a time and try to run errands when he is asleep.	1	2.6%
	Not very often	1	2.6%
	Nursing home staff	6	15.8%
	Our son and his family	1	2.6%
	Paid help	4	10.5%
	Paid help comes 2 times/week; 4 hrs/day	1	2.6%
	Person from Just Like Family	1	2.6%
	Respite	1	2.6%
	Sister	1	2.6%
	Son	1	2.6%
	Spouse	3	7.9%
	Total	38	100.0%

18. How challenging the following issues affecting the person with Alzheimer's disease or related dementia have been for you and your family.

18a. Loss of ability to drive

		Number	Percent
Responses	Not Challenging	10	27.8
	A Little Challenging	3	8.3
	Somewhat Challenging	5	13.9
	Quite Challenging	8	22.2
	Very Challenging	10	27.8
	Total	36	100.0

18b. Depression or anxiety of the person with Alzheimer's disease or related dementia

		Number	Percent
Responses	Not Challenging	5	12.2
	A Little Challenging	5	12.2
	Somewhat Challenging	11	26.8
	Quite Challenging	6	14.6
	Very Challenging	14	34.1
	Total	41	100.0

18c. Difficult behaviors

		Number	Percent
Responses	Not Challenging	5	12.5
	A Little Challenging	9	22.5
	Somewhat Challenging	9	22.5
	Quite Challenging	8	20.0
	Very Challenging	9	22.5
	Total	40	100.0

18d. Wandering or safety

		Number	Percent
Responses	Not Challenging	11	33.3
	A Little Challenging	9	27.3
	Somewhat Challenging	5	15.2
	Quite Challenging	4	12.1
	Very Challenging	4	12.1
	Total	33	100.0

18e. Becoming a financial burden

		Number	Percent
Responses	Not Challenging	17	45.9
	A Little Challenging	5	13.5
	Somewhat Challenging	5	13.5
	Quite Challenging	2	5.4
	Very Challenging	8	21.6
	Total	37	100.0

18f. Losing control over lifestyle

		Number	Percent
Responses	Not Challenging	1	2.6
	A Little Challenging	7	17.9
	Somewhat Challenging	6	15.4
	Quite Challenging	8	20.5
	Very Challenging	17	43.6
	Total	39	100.0

18. Other (please specify)

Diabetic, no longer able to comprehend insulin dosing or taking other Rx medications, unable to understand he is incontinent.
Dual diagnosis: bipolar disorder
Loss of companionship
Loss of husband's companionship
Sad, alone
Toileting, bathing, providing a social & stimulating environment while also managing care.
Very frustrating to not be able to communicate.

19. How challenging are (or have been) the following issues to you as a caregiver?

19a. Getting helpful information on Alzheimer's disease and related dementias

		Number	Percent
Responses	Not Challenging	17	42.5
	A Little Challenging	10	25.0
	Somewhat Challenging	12	30.0
	Quite Challenging	1	2.5
	Total	40	100.0

19b. Getting information about community resources

		Number	Percent
Responses	Not Challenging	11	28.2
	A Little Challenging	10	25.6
	Somewhat Challenging	9	23.1
	Quite Challenging	7	17.9
	Very Challenging	2	5.1
	Total	39	100.0

19c. Access to medical care for yourself

		Number	Percent
Responses	Not Challenging	23	62.2
	A Little Challenging	7	18.9
	Somewhat Challenging	4	10.8
	Quite Challenging	2	5.4
	Very Challenging	1	2.7
	Total	37	100.0

19d. Access to medical care for your family member with Alzheimer's disease or related dementia

		Number	Percent
Responses	Not Challenging	17	44.7
	A Little Challenging	13	34.2
	Somewhat Challenging	4	10.5
	Quite Challenging	3	7.9
	Very Challenging	1	2.6
	Total	38	100.0

19e. Dealing with financial, legal, and insurance issues

		Number	Percent
Responses	Not Challenging	8	20.5
	A Little Challenging	12	30.8
	Somewhat Challenging	8	20.5
	Quite Challenging	6	15.4
	Very Challenging	5	12.8
	Total	39	100.0

19f. Access to support groups

		Number	Percent
Responses	Not Challenging	17	50.0
	A Little Challenging	9	26.5
	Somewhat Challenging	2	5.9
	Quite Challenging	4	11.8
	Very Challenging	2	5.9
	Total	34	100.0

19g. Access to respite care, adult day care, and other services

		Number	Percent
Responses	Not Challenging	9	32.1
	A Little Challenging	6	21.4
	Somewhat Challenging	4	14.3
	Quite Challenging	3	10.7
	Very Challenging	6	21.4
	Total	28	100.0

19h. Paying for services

		Number	Percent
Responses	Not Challenging	13	38.2
	A Little Challenging	5	14.7
	Somewhat Challenging	4	11.8
	Quite Challenging	5	14.7
	Very Challenging	7	20.6
	Total	34	100.0

19i. Changing relationships in the family

		Number	Percent
Responses	Not Challenging	7	21.2
	A Little Challenging	5	15.2
	Somewhat Challenging	7	21.2
	Quite Challenging	4	12.1
	Very Challenging	10	30.3
	Total	33	100.0

19j. Communication with the person with Alzheimer's disease or related dementia

		Number	Percent
Responses	Not Challenging	2	5.9
	A Little Challenging	5	14.7
	Somewhat Challenging	10	29.4
	Quite Challenging	8	23.5
	Very Challenging	9	26.5
	Total	34	100.0

19k. Dying before the person with Alzheimer's disease or related dementia

		Number	Percent
Responses	Not Challenging	6	23.1
	A Little Challenging	4	15.4
	Somewhat Challenging	2	7.7
	Quite Challenging	5	19.2
	Very Challenging	9	34.6
	Total	26	100.0

19l. Losing control of lifestyle

		Number	Percent
Responses	Not Challenging	3	8.8
	A Little Challenging	3	8.8
	Somewhat Challenging	8	23.5
	Quite Challenging	5	14.7
	Very Challenging	15	44.1
	Total	34	100.0

19m. Loss of employment

		Number	Percent
Responses	Not Challenging	12	52.2
	A Little Challenging	1	4.3
	Somewhat Challenging	1	4.3
	Quite Challenging	4	17.4
	Very Challenging	5	21.7
	Total	23	100.0

19n. Getting an appropriate diagnosis

		Number	Percent
Responses	Not Challenging	18	54.5
	A Little Challenging	3	9.1
	Somewhat Challenging	6	18.2
	Quite Challenging	2	6.1
	Very Challenging	4	12.1
	Total	33	100.0

19. Other (please specify)

After extensive testing, I have a diagnosis for my husband but no one to help manage the disease. Feel very much alone and on my own with how to cope and manage his care.

Finding resources appropriate for dual diagnosis - dementia and bipolar disorder

Two prior primary caregivers have died in the past 3 years & I believe it was at least partially due to stress related caring for my father.

20. Difficulties you may have faced as a caregiver.

20a. Creates a financial burden

		Number	Percent
Responses	Strongly Agree	13	35.1
	Agree	12	32.4
	Neither Agree or Disagree	4	10.8
	Disagree	4	10.8
	Strongly Disagree	4	10.8
	Total	37	100.0

20b. Doesn't leave enough time for yourself

		Number	Percent
Responses	Strongly Agree	15	38.5
	Agree	18	46.2
	Neither Agree or Disagree	5	12.8
	Disagree	1	2.6
	Total	39	100.0

20c. Doesn't leave enough time for your family

		Number	Percent
Responses	Strongly Agree	13	39.4
	Agree	10	30.3
	Neither Agree or Disagree	7	21.2
	Disagree	3	9.1
	Total	33	100.0

20d. Interferes with your work

		Number	Percent
Responses	Strongly Agree	6	26.1
	Agree	12	52.2
	Neither Agree or Disagree	4	17.4
	Disagree	1	4.3
	Total	23	100.0

20e. Creates anxiety or depression

		Number	Percent
Responses	Strongly Agree	15	40.5
	Agree	15	40.5
	Neither Agree or Disagree	6	16.2
	Strongly Disagree	1	2.7
	Total	37	100.0

20f. Feeling resentful

		Number	Percent
Responses	Strongly Agree	7	18.4
	Agree	10	26.3
	Neither Agree or Disagree	10	26.3
	Disagree	8	21.1
	Strongly Disagree	3	7.9
	Total	38	100.0

20g. Creates or aggravates health problems

		Number	Percent
Responses	Strongly Agree	8	21.1
	Agree	18	47.4
	Neither Agree or Disagree	7	18.4
	Disagree	3	7.9
	Strongly Disagree	2	5.3
	Total	38	100.0

20h. Affects family relationships

		Number	Percent
Responses	Strongly Agree	6	16.2
	Agree	17	45.9
	Neither Agree or Disagree	5	13.5
	Disagree	7	18.9
	Strongly Disagree	2	5.4
	Total	37	100.0

20i. Interferes with employment/loss of employment

		Number	Percent
Responses	Strongly Agree	8	42.1
	Agree	6	31.6
	Neither Agree or Disagree	3	15.8
	Disagree	2	10.5
	Total	19	100.0

20j. Difficult behaviors

		Number	Percent
Responses	Strongly Agree	12	32.4
	Agree	19	51.4
	Neither Agree or Disagree	4	10.8
	Disagree	2	5.4
	Total	37	100.0

20k. Wandering or safety

		Number	Percent
Responses	Strongly Agree	5	17.2
	Agree	16	55.2
	Neither Agree or Disagree	4	13.8
	Disagree	1	3.4
	Strongly Disagree	3	10.3
	Total	29	100.0

20l. Understanding the disease

		Number	Percent
Responses	Strongly Agree	7	19.4
	Agree	16	44.4
	Neither Agree or Disagree	6	16.7
	Disagree	4	11.1
	Strongly Disagree	3	8.3
	Total	36	100.0

20. Other (please specify)

Loss of friends
Managing incontinence, diabetes and other health issue and properly taking Rx medications.

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

		Number	Percent
Responses	21a. Financial assistance	11	12.5%
	21b. Transportation	8	9.1%
	21c. Education and training for caregivers	6	6.8%
	21d. Legal advice	9	10.2%
	21e. Medical care	10	11.4%
	21f. Respite	22	25.0%
	21g. Meals	4	4.5%
	21h. Personal care	12	13.6%
	21. Other	6	6.8%
	Total	88	100.0%

21. Other (please specify)

All of the above
Cannot keep him at home, needs 24 hour care
Companion care so I can run errands, do my doctor appointments, etc. without having to worry about leaving him home alone. Support with light housekeeping, yard work as I am exhausted and have arthritis so am in a lot of pain most days.
Is not at home
Need a day care option
None at this time
Not applicable; she is in a nursing home
Was unable to care for at home had to be in an Alzheimer unit
With dementia and bipolar disorder, she cannot be at home
Would have to make home wheelchair accessible.

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.)

		Number	Percent
Responses	22a. No, I do not have a plan or other preparations	17	41.5%
	22b. Yes, I have a written plan	5	12.2%
	22c. Yes, I have a survival kit	10	24.4%
	22d. Yes, I have registered with my county for a Special Needs Shelter	3	7.3%
	22. Other	6	14.6%
	Total	41	100.0%

22. Other (please specify)

Assisted living facility has emergency evacuation plans (3)
Have a planned place to go
Moving to another area
Never thought of this problem.
Nursing home will take care of my husband. I may go with family. No definite plan.
Patient is deceased
The facility had a plan
The nursing home has a plan.

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.)

		Number	Percent
Responses	23a. Internet or web-based information and training	29	21.8%
	23b. In-person support groups	27	20.3%
	23c. Community education and training	17	12.8%
	23d. Toll-free 24-hr telephone helpline	15	11.3%
	23e. Case management	14	10.5%
	23f. Seminars	14	10.5%
	23g. One-on-one counseling	15	11.3%
	23. Other	2	1.5%
	Total	133	100.0%

23. Other (please specify)

I am an RN so I am pretty well informed.

I attend weekly support group meetings.

It is too late for my father--he can't see, can't walk, can't communicate, feed, bathe or dress himself.

Training for medical community. Most doctors and office staff are clueless with respect to dealing with patients and dementias. For example when my husband has a surgical procedure, I have to beg and plead to be allowed to stay with him until the procedure starts. I explain that he can sign and comprehend but can't remember and yet they continue to insist upon asking him questions outside of my presence and therefore don't always get accurate information. Also no sensitivity when he is around and they talk about him as if he wasn't present, very degrading and humiliating to him and usually triggers an anger response.

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

		Number	Percent
Responses	24a. Home health	14	8.9%
	24b. Personal care/Bath assistance	10	6.3%
	24c. Homemaker/Housekeeper	6	3.8%
	24d. Counseling	6	3.8%
	24e. Case management	4	2.5%
	24f. Adult day services	12	7.6%
	24g. Respite	6	3.8%
	24h. Hospice	7	4.4%
	24i. Aging and Disability Resource Center	1	.6%
	24j. Area Agency on Aging	4	2.5%
	24k. Education	10	6.3%
	24l. Research/Clinical trials	3	1.9%
	24m. Support Groups	19	12.0%
	24n. Telephone reassurance	6	3.8%
	24o.Personal emergency response systems	1	.6%
	24p. Wanderguards/Project Lifesaver	4	2.5%
	24q. Meals on Wheels	2	1.3%
	24r. On-line support through professional or informal groups (for example, Facebook)	9	5.7%
	24s. On-line research/Support/blogging	11	7.0%
	24t. Legal services	11	7.0%
	24u. Memory Disorder Clinic	7	4.4%
	24. Other	5	3.2%
	Total	158	100.0%

24. Other (please specify)

Assisted living facility

Resource center

Husband was a resident of memory care assisted living while medications were being regulated for 4 months.

I still work full time and also help my elderly parents. But, I have arranged some in home caregiver for them a couple of times a week, a dog walker for them, and a cleaning service.

Nursing home

Then assisted living and then a nursing facility with specialized Alzheimer's unit

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

		Number	Percent
Responses	25a. Private pay/Out of pocket of person	29	53.7%
	25b. Trust funds	1	1.9%
	25c. Family supported	5	9.3%
	25d. Long-term care insurance	4	7.4%
	25e. Medicaid	5	9.3%
	25f. Nursing Home Diversion Medicaid Waiver	1	1.9%
	25h. Government funding	2	3.7%
	25j. Veterans Administration	6	11.1%
	25. Other	1	1.9%
	Total	54	100.0%

25. Other (please specify)

Hospice
N/A can not afford any private pay services so do without.
Plus difference I pay for.

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

		Number	Percent
Responses	26a. I don't know where to find them	9	26.5%
	26b. I can't afford them	9	26.5%
	26d. I don't have time	6	17.6%
	26e. They are not available	4	11.8%
	26. Other	6	17.6%
	Total	34	100.0%

26. Other (please specify)

Able to take care of him now
Able to utilize resources from Alzheimer's unit
Currently Day Care is the answer. Later will have to do more research.
Difficulty accessing Medicaid system, not user friendly.
Difficulty with patient being without his primary caregiver
Have 1 year left of 4 year long term care insurance.
I have all the services that I need at this point.
My husband has no sense of self so he is not able to comprehend that he has dementia. This makes him resistive to any and all efforts to support him.

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.)

		Number	Percent
Responses	27a. Employers	17	7.7%
	27b. Hospitals	12	5.4%
	27c. Aging services and senior centers	25	11.3%
	27d. Churches and faith communities	25	11.3%
	27e. Veterans Administration	16	7.2%
	27f. Public service announcements on radio & TV	26	11.8%
	27g. Medical training schools	14	6.3%
	27h. Law enforcement	8	3.6%
	27i. Physicians	24	10.9%
	27j. Nursing schools	12	5.4%
	27k. Religious organizations	12	5.4%
	27l. Website with updated information	30	13.6%
	Total	221	100.0%

27. Other (please specify)

Direct training on the disease from Alzheimer's educators to the nursing homes that provide their care. Found most staff uniformed and poorly trained to deal with dementia patients
Local fairs, festivals, and community events.
Local/county Alzheimer's services are very important
Support groups for caretakers

28. 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.

28a. Research on prevention, treatment, and clinical trials

		Number	Percent
Responses	A Little Important	1	2.7
	Somewhat Important	4	10.8
	Quite Important	2	5.4
	Very Important	30	81.1
	Total	37	100.0

28b. Clinical assessment, diagnosis, and testing

		Number	Percent
Responses	A Little Important	1	2.7
	Somewhat Important	4	10.8
	Quite Important	6	16.2
	Very Important	26	70.3
	Total	37	100.0

28c. Assisting families in paying for care

		Number	Percent
Responses	A Little Important	1	2.7
	Somewhat Important	4	10.8
	Quite Important	8	21.6
	Very Important	24	64.9
	Total	37	100.0

28d. Protecting people with Alzheimer's disease and related dementias

		Number	Percent
Responses	Don't Know	1	2.7
	A Little Important	1	2.7
	Somewhat Important	4	10.8
	Quite Important	13	35.1
	Very Important	18	48.6
	Total	37	100.0

28e. Ensuring quality of care

		Number	Percent
Responses	Somewhat Important	2	5.4
	Quite Important	10	27.0
	Very Important	25	67.6
	Total	37	100.0

28f. Education and training for caregivers

		Number	Percent
Responses	Somewhat Important	5	13.9
	Quite Important	7	19.4
	Very Important	24	66.7
	Total	36	100.0

28g. Economic impact of Alzheimer's disease and related dementias on communities, workplaces, and citizens

		Number	Percent
Responses	A Little Important	1	2.7
	Somewhat Important	8	21.6
	Quite Important	10	27.0
	Very Important	18	48.6
	Total	37	100.0

28h. Access to affordable and appropriate dementia-specific care

		Number	Percent
Responses	Quite Important	7	18.9
	Very Important	30	81.1
	Total	37	100.0

28i. Having an educated and trained workforce on Alzheimer's disease and related dementias

		Number	Percent
Responses	Somewhat Important	3	8.6
	Quite Important	8	22.9
	Very Important	24	68.6
	Total	35	100.0

28j. Transportation

		Number	Percent
Responses	Don't Know	4	11.1
	Not Important	1	2.8
	A Little Important	2	5.6
	Somewhat Important	10	27.8
	Quite Important	11	30.6
	Very Important	8	22.2
	Total	36	100.0

28k. Employment

		Number	Percent
Responses	Don't Know	10	29.4
	Not Important	6	17.6
	A Little Important	5	14.7
	Somewhat Important	5	14.7
	Quite Important	4	11.8
	Very Important	4	11.8
	Total	34	100.0

28l. Tax credits for caregivers

		Number	Percent
Responses	Don't Know	2	5.4
	Not Important	2	5.4
	A Little Important	1	2.7
	Somewhat Important	3	8.1
	Quite Important	7	18.9
	Very Important	22	59.5
	Total	37	100.0

28m. Access to non-dementia-specific services

		Number	Percent
Responses	Don't Know	5	15.6
	Not Important	3	9.4
	A Little Important	5	15.6
	Somewhat Important	6	18.8
	Quite Important	5	15.6
	Very Important	8	25.0
	Total	32	100.0

28n. Specialized care facilities

		Number	Percent
Responses	Don't Know	1	2.7
	A Little Important	3	8.1
	Somewhat Important	2	5.4
	Quite Important	4	10.8
	Very Important	27	73.0
	Total	37	100.0

28o. Emergency Management/Disaster Preparedness

		Number	Percent
Responses	Don't Know	1	2.8
	Not Important	1	2.8
	A Little Important	2	5.6
	Somewhat Important	7	19.4
	Quite Important	13	36.1
	Very Important	12	33.3
	Total	36	100.0

28p. Medical care

		Number	Percent
Responses	Not Important	1	2.7
	A Little Important	1	2.7
	Somewhat Important	5	13.5
	Quite Important	8	21.6
	Very Important	22	59.5
	Total	37	100.0

28q. Mental health/Depression

		Number	Percent
Responses	Not Important	2	5.6
	Somewhat Important	5	13.9
	Quite Important	8	22.2
	Very Important	21	58.3
	Total	36	100.0

28. Other (please specify)

Mandate that memory care clinics offer caregiver support groups. Lee Memorial Hospital just disbanded all their caregiver support groups which just leaves the caregivers adrift with even less support than before.

29. What is your gender?

		Number	Percent
Responses	Female	30	81.1
	Male	7	18.9
	Total	37	100.0

30. What is your age?

		Number	Percent
Responses	51	2	5.7
	58	2	5.7
	59	2	5.7
	60	1	2.9
	61	2	5.7
	62	3	8.6
	63	3	8.6
	64	1	2.9
	65	2	5.7
	66	1	2.9
	67	1	2.9
	69	1	2.9
	70	1	2.9
	71	3	8.6
	72	1	2.9
	73	1	2.9
	74	1	2.9
	75	1	2.9
	76	2	5.7
	78	1	2.9
	81	1	2.9
	84	1	2.9
	88	1	2.9
	Total	35	100.0

31. What is your marital status?

		Number	Percent
Responses	Now married	29	78.4
	Partnered	3	8.1
	Widowed	1	2.7
	Separated	1	2.7
	Never married	2	5.4
	Don't know	1	2.7
	Total	37	100.0

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

		Number	Percent
Responses	No	35	94.6
	Yes	2	5.4
	Total	37	100.0

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

		Number	Percent
Responses	33a. White	36	97.3%
	33b. Black or African American	1	2.7%
	Total	37	100.0%

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

		Number	Percent
Responses	Just English	36	100.0

35. What is your highest level of education attained?

		Number	Percent
Responses	High School	10	27.0
	College	14	37.8
	Post College	13	35.1
	Total	37	100.0

36. Are you employed?

		Number	Percent
Responses	Full-time	5	13.9
	Part-time	3	8.3
	Retired	24	66.7
	Unemployed	3	8.3
	Other (please specify below)	1	2.8
	Total	36	100.0

36. Other (please specify)

Had to quit work to care for mother
Retired
Unable to work due to caregiving job.

37. Do your caregiver responsibilities affect your employment?

		Number	Percent
Responses	Yes	13	37.1
	No	22	62.9
	Total	35	100.0

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

		Number	Percent
Responses	Yes	11	68.8
	No	3	18.8
	Other (please specify below)	2	12.5
	Total	16	100.0

38. Other (please specify)

At times when Mom was alive
Had to stop working all together as my husband's health issues were declining dramatically without my being present to supervise him and taking insulin and other Rx medications.
Only as needed

39. If yes, did you leave your job?

		Number	Percent
Responses	Yes	7	41.2
	No	10	58.8
	Total	17	100.0

39. Other (please specify)

My employer works with me on my hours

40. Estimated household income

		Number	Percent
Responses	Under $25,000	3	8.8
	$25,000 - $35,999	3	8.8
	$36,000 - $45,999	5	14.7
	$46,000 - $55,999	3	8.8
	$56,000 - $65,999	2	5.9
	$66,000 - $75,999	1	2.9
	$76,000 - $85,999	4	11.8
	$86,000 and over	13	38.2
	Total	34	100.0

41. Any other comments or suggestions?

Alzheimer's is a devastating illness that requires a very concerted focus by our medical community (physicians, researchers, drug companies, government, etc.) to understand, treat and find ways to cure or prevent the disease. It reminds me of how devastating polio was until we broke the code and developed a vaccine. The economic, emotional and monetary cost will become unbearable for society unless resources are allocated to eradicating the disease.

Having a loved one afflicted with Alzheimer's and related dementias is devastating enough on a day to day basis. Without the support of a competent and caring medical community it is harder to insure quality medical care. For example my husband is diabetic but no longer understands the correlation of what he eats and the impact on him. I do my best to control what food is in the house but then have to deal with the anger and rage when he can't find what he wants to eat. Life becomes a constant tradeoff between quality of life (health, etc) and keeping the person happy. When we see new doctors and I explain my husband's condition, most have no clue what I am talking about (Frontal Temporal Dementia). I usually feel lost and alone and it is via caregiver support groups that I find the greatest support yet there are not enough support groups and those that are in place require a 30 minute drive so that just makes it harder to find the time to leave my spouse unattended while I go. Before my husband was diagnosed he pretty much destroyed our financial status and I was left to pick up the pieces by myself. I know I should take better care of my own health but that makes me feel selfish so I put my husband's needs above my own. My greatest fear is that taking care of him by myself will eventually wear me down and I might become too sick myself to be of any use to him.

I am a Certified Financial Planner and long ago purchased long term care for my husband and myself so at this time costs for my husband's care are covered by his long-term care contract and my employer provided health care policy (which is primary to Medicare). Due to our planning and education levels we will be OK. However, I know we are in the minority. I feel that more financial education in our schools which should include cost of health and LTC is VERY important. Dementias are a huge problem, but vehicle accidents, MS, cancer, and other health conditions also create caregiver needs and costs.

I cannot state enough how important the local/count Alzheimer's Association has been to help me better understand the disease and the resources available to me as a caregiver. Specifically Sarasota and Charlotte counties in Florida.

I think it is important that people not affected by dementia understand the real economic impact of this disease. Not only is my husband no longer able to work, but I have also been forced to give up my job in order to take care of him. I am no longer able to contribute to my retirement and fear that I may become a burden in my later years. am also so sad that I am not able to do the work outside my home that I have been trained to do.

I think it's outrageous that a person with Alzheimer's must give up everything they have accumulated in order to qualify for Medicaid when going into a nursing home. His PPO does not consider Alzheimer's a disease and would not help with any of the in home care that we so desperately needed to be able to keep Dad at home. We, as a family, could not afford to put children through college and pay for his in home care, nor could I afford to quit my job to provide the care. Please spend what ever is required to stop the progression of this terribly debilitating disease as the number of people with this terrible disease is increasing at an alarming rate!

It is frustrating to not see more progress in the attempt to find a cure or medication to improve the condition.

My husband is in a nursing home. I feel that one of the most important things that must be done is be sure there is enough staffing to properly care for the residents. No matter how many laws are written or how much staff is educated, care suffers if the nurses and CNAs are overworked. This is more important than a tasty menu, entertainment, or anything else in my opinion. If there is adequate staff, the rest happens. If Medicaid or Medicare reimbursement goes down, the quality of care suffers. After letting the facility get rundown, cutting out all the frills, taking the expensive food off the menu, there is nothing left except cutting staffing.

Need a cure!!!!!

Resources and information for caregivers would be good, where do you go for help and most important is financial help when person with disease needs it. Caregivers have enough strain with caregiving not to mention financial burden. We need some time off to have a life for ourselves but cannot afford facility to care for person with the problem. It would be nice to have Medicare or Medicaid available to pitch in for caregivers to take some time off from caregiving burdens and to allow caregivers to get away for their own mental health and relationship with spouse.

Services for those with dementia and a psychiatric disorder are nearly impossible to find. I've had to make compromises on quality of care to find an ALF that would take my mother-in-law. I put so many hours into ensuring she gets the specialized help she needs. I have not found any service providers, other than her neurologist and one ALF in Sarasota who can handle her needs.

Though my husband does not drive, I see many other drivers who should not be on the roads and I would like to see more public transportation and education about taking the keys away from someone with dementia. Perhaps PSA's like the ones the state is doing about texting would raise awareness of the dangers of driving with dementia.

Purple Ribbon Task Force

Survey of Concerned Family and Friends of People With Alzheimer's Disease and Related Dementias

1. Where do you live or work?

1a. City:

		Number	Percent
Responses	Bonita Springs	1	7.1
	Fort Myers	5	35.7
	Fort Myers Beach	1	7.1
	Marco Island	1	7.1
	Naples	1	7.1
	Naples Park	1	7.1
	Osprey	1	7.1
	Punta Gorda	2	14.3
	Sarasota	1	7.1
	Total	14	100.0

1b. County:

		Number	Percent
Responses	Charlotte	1	7.1
	Collier	3	21.4
	Lee	8	57.1
	Sarasota	2	14.3
	Total	14	100.0

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

		Number	Percent
Responses	2a. Family	12	66.7%
	2b. Friend	6	33.3%
	Total	18	100.0%

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.

		Number	Percent
Responses	0	1	14.3
	2	1	14.3
	3	1	14.3
	4	1	14.3
	20	3	42.9
	Total	7	100.0

Purple Ribbon Task Force

Survey of Concerned Family and Friends of People With Alzheimer's Disease and Related Dementias

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

4a. Getting helpful information on Alzheimer's disease and related dementias

		Number	Percent
Responses	Not Challenging	4	30.8
	A Little Challenging	3	23.1
	Somewhat Challenging	5	38.5
	Very Challenging	1	7.7
	Total	13	100.0

4b. Getting information about community resources

		Number	Percent
Responses	Not Challenging	1	7.7
	A Little Challenging	4	30.8
	Somewhat Challenging	5	38.5
	Quite Challenging	2	15.4
	Very Challenging	1	7.7
	Total	13	100.0

4c. Caregivers feeling depressed or anxious

		Number	Percent
Responses	Don't Know	1	7.7
	A Little Challenging	1	7.7
	Somewhat Challenging	2	15.4
	Quite Challenging	4	30.8
	Very Challenging	5	38.5
	Total	13	100.0

4d. Caregivers feeling resentful

		Number	Percent
Responses	Don't Know	1	7.7
	Not Challenging	2	15.4
	A Little Challenging	1	7.7
	Somewhat Challenging	2	15.4
	Quite Challenging	2	15.4
	Very Challenging	5	38.5
	Total	13	100.0

4e. Access to medical care for caregivers

		Number	Percent
Responses	A Little Challenging	3	23.1
	Somewhat Challenging	4	30.8
	Quite Challenging	4	30.8
	Very Challenging	2	15.4
	Total	13	100.0

4f. Access to medical care for people with Alzheimer's disease and related dementias

		Number	Percent
Responses	A Little Challenging	6	46.2
	Quite Challenging	5	38.5
	Very Challenging	2	15.4
	Total	13	100.0

4g. Dealing with financial, legal, and insurance issues

		Number	Percent
Responses	Not Challenging	1	7.7
	A Little Challenging	1	7.7
	Somewhat Challenging	3	23.1
	Quite Challenging	3	23.1
	Very Challenging	5	38.5
	Total	13	100.0

4h. Access to support groups

		Number	Percent
Responses	Don't Know	1	7.7
	Not Challenging	3	23.1
	A Little Challenging	3	23.1
	Somewhat Challenging	2	15.4
	Quite Challenging	2	15.4
	Very Challenging	2	15.4
	Total	13	100.0

4i. Access to respite care, adult day care, and other services

		Number	Percent
Responses	Don't Know	1	7.7
	Not Challenging	1	7.7
	A Little Challenging	3	23.1
	Somewhat Challenging	4	30.8
	Quite Challenging	2	15.4
	Very Challenging	2	15.4
	Total	13	100.0

4j. Paying for services

		Number	Percent
Responses	Not Challenging	2	15.4
	A Little Challenging	1	7.7
	Somewhat Challenging	2	15.4
	Quite Challenging	2	15.4
	Very Challenging	6	46.2
	Total	13	100.0

Purple Ribbon Task Force

Survey of Concerned Family and Friends of People With Alzheimer's Disease and Related Dementias

4k. Changing relationships in the family

		Number	Percent
Responses	A Little Challenging	2	15.4
	Somewhat Challenging	1	7.7
	Quite Challenging	4	30.8
	Very Challenging	6	46.2
	Total	13	100.0

4l. Communication with the person with Alzheimer's disease or related dementia

		Number	Percent
Responses	Not Challenging	1	7.7
	Somewhat Challenging	2	15.4
	Quite Challenging	4	30.8
	Very Challenging	6	46.2
	Total	13	100.0

4m. Becoming a financial burden on children

		Number	Percent
Responses	Don't Know	3	25.0
	Not Challenging	1	8.3
	A Little Challenging	1	8.3
	Somewhat Challenging	2	16.7
	Very Challenging	5	41.7
	Total	12	100.0

4n. Dying before the person with Alzheimer's disease or related dementia

		Number	Percent
Responses	Don't Know	2	16.7
	A Little Challenging	1	8.3
	Somewhat Challenging	3	25.0
	Quite Challenging	3	25.0
	Very Challenging	3	25.0
	Total	12	100.0

4o. Losing control of lifestyle

		Number	Percent
Responses	Don't Know	1	7.7
	A Little Challenging	2	15.4
	Somewhat Challenging	3	23.1
	Quite Challenging	4	30.8
	Very Challenging	3	23.1
	Total	13	100.0

4p. Loss of employment

		Number	Percent
Responses	Don't Know	4	30.8
	Not Challenging	4	30.8
	A Little Challenging	1	7.7
	Somewhat Challenging	1	7.7
	Quite Challenging	1	7.7
	Very Challenging	2	15.4
	Total	13	100.0

4q. Getting an appropriate diagnosis

		Number	Percent
Responses	Don't Know	2	15.4
	Not Challenging	2	15.4
	A Little Challenging	2	15.4
	Quite Challenging	5	38.5
	Very Challenging	2	15.4
	Total	13	100.0

4r. Understanding the disease

		Number	Percent
Responses	Don't Know	1	7.7
	A Little Challenging	2	15.4
	Somewhat Challenging	8	61.5
	Quite Challenging	1	7.7
	Very Challenging	1	7.7
	Total	13	100.0

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

5a. Loss of ability to drive

		Number	Percent
Responses	Don't Know	1	7.7
	Not Challenging	1	7.7
	A Little Challenging	2	15.4
	Somewhat Challenging	1	7.7
	Quite Challenging	2	15.4
	Very Challenging	6	46.2
	Total	13	100.0

5b. Depression or anxiety of the person with Alzheimer's disease or related dementia

		Number	Percent
Responses	A Little Challenging	1	7.7
	Somewhat Challenging	1	7.7
	Quite Challenging	5	38.5
	Very Challenging	6	46.2
	Total	13	100.0

5c. Difficult behaviors

		Number	Percent
Responses	Somewhat Challenging	4	30.8
	Quite Challenging	3	23.1
	Very Challenging	6	46.2
	Total	13	100.0

5d. Wandering or safety

		Number	Percent
Responses	A Little Challenging	1	7.7
	Somewhat Challenging	2	15.4
	Quite Challenging	4	30.8
	Very Challenging	6	46.2
	Total	13	100.0

5e. Becoming a financial burden

		Number	Percent
Responses	Don't Know	1	7.7
	Not Challenging	3	23.1
	A Little Challenging	1	7.7
	Very Challenging	8	61.5
	Total	13	100.0

5f. Losing control over lifestyle

		Number	Percent
Responses	Don't Know	1	7.7
	A Little Challenging	1	7.7
	Somewhat Challenging	4	30.8
	Quite Challenging	2	15.4
	Very Challenging	5	38.5
	Total	13	100.0

6. 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.)

		Number	Percent
Responses	6a. Employers	9	9.7%
	6b. Hospitals	6	6.5%
	6c. Aging services and senior centers	8	8.6%
	6d. Churches and faith communities	10	10.8%
	6e. Veterans Administration	5	5.4%
	6f. Public service announcements on radio & TV	12	12.9%
	6g. Medical training schools	6	6.5%
	6h. Law enforcement	7	7.5%
	6i. Physicians	8	8.6%
	6j. Nursing schools	5	5.4%
	6k. Religious organizations	9	9.7%
	6l. Website with updated information	8	8.6%
	Total	93	100.0%

6. Other (please specify)

I just wanted to take the time to state my family lives in New Hampshire, not Florida.

7. What are the most critical issues the state government in Florida should address in the next few years?

7a. Research on prevention, treatment, and clinical trials

		Number	Percent
Responses	Somewhat Important	1	9.1
	Quite Important	2	18.2
	Very Important	8	72.7
	Total	11	100.0

7b. Clinical assessment, diagnosis, and testing

		Number	Percent
Responses	A Little Important	1	9.1
	Somewhat Important	2	18.2
	Quite Important	2	18.2
	Very Important	6	54.5
	Total	11	100.0

7c. Assisting families in paying for care

		Number	Percent
Responses	A Little Important	1	9.1
	Somewhat Important	3	27.3
	Quite Important	1	9.1
	Very Important	6	54.5
	Total	11	100.0

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Survey of Concerned Family and Friends of People With Alzheimer's Disease and Related Dementias

7d. Protecting people with Alzheimer's disease and related dementias

		Number	Percent
Responses	Somewhat Important	4	36.4
	Quite Important	1	9.1
	Very Important	6	54.5
	Total	11	100.0

7e. Ensuring quality of care

		Number	Percent
Responses	A Little Important	1	9.1
	Somewhat Important	1	9.1
	Quite Important	3	27.3
	Very Important	6	54.5
	Total	11	100.0

7f. Education and training for caregivers

		Number	Percent
Responses	Somewhat Important	1	9.1
	Quite Important	2	18.2
	Very Important	8	72.7
	Total	11	100.0

7g. Economic impact of Alzheimer's disease and related dementias on communities, workplaces, and citizens

		Number	Percent
Responses	Don't Know	1	9.1
	Somewhat Important	3	27.3
	Quite Important	1	9.1
	Very Important	6	54.5
	Total	11	100.0

7h. Access to affordable and appropriate dementia-specific care

		Number	Percent
Responses	Somewhat Important	2	18.2
	Quite Important	3	27.3
	Very Important	6	54.5
	Total	11	100.0

7i. Having an educated and trained workforce on Alzheimer's disease and related dementias

		Number	Percent
Responses	Somewhat Important	1	9.1
	Quite Important	4	36.4
	Very Important	6	54.5
	Total	11	100.0

Purple Ribbon Task Force

Survey of Concerned Family and Friends of People With Alzheimer's Disease and Related Dementias

7j. Transportation

		Number	Percent
Responses	A Little Important	2	18.2
	Somewhat Important	4	36.4
	Quite Important	1	9.1
	Very Important	4	36.4
	Total	11	100.0

7k. Employment

		Number	Percent
Responses	Don't Know	1	9.1
	Not Important	2	18.2
	A Little Important	2	18.2
	Somewhat Important	2	18.2
	Quite Important	2	18.2
	Very Important	2	18.2
	Total	11	100.0

7l. Tax credits for caregivers

		Number	Percent
Responses	Not Important	1	9.1
	A Little Important	1	9.1
	Somewhat Important	1	9.1
	Quite Important	2	18.2
	Very Important	6	54.5
	Total	11	100.0

7m. Access to non-dementia-specific services

		Number	Percent
Responses	Don't Know	1	9.1
	Not Important	1	9.1
	A Little Important	1	9.1
	Somewhat Important	5	45.5
	Very Important	3	27.3
	Total	11	100.0

7n. Specialized care facilities

		Number	Percent
Responses	A Little Important	2	18.2
	Somewhat Important	1	9.1
	Quite Important	1	9.1
	Very Important	7	63.6
	Total	11	100.0

Purple Ribbon Task Force

Survey of Concerned Family and Friends of People With Alzheimer's Disease and Related Dementias

7o. Emergency Management/Disaster Preparedness

		Number	Percent
Responses	Don't Know	1	9.1
	A Little Important	1	9.1
	Somewhat Important	4	36.4
	Quite Important	3	27.3
	Very Important	2	18.2
	Total	11	100.0

7p. Medical care

		Number	Percent
Responses	A Little Important	1	10.0
	Somewhat Important	3	30.0
	Quite Important	2	20.0
	Very Important	4	40.0
	Total	10	100.0

7q. Mental health/Depression

		Number	Percent
Responses	Somewhat Important	2	18.2
	Quite Important	3	27.3
	Very Important	6	54.5
	Total	11	100.0

8. What is your gender?

		Number	Percent
Responses	Female	9	81.8
	Male	2	18.2
	Total	11	100.0

9. What is your age?

		Number	Percent
Responses	41	1	9.1
	46	1	9.1
	52	1	9.1
	58	1	9.1
	59	1	9.1
	60	1	9.1
	61	1	9.1
	65	1	9.1
	68	1	9.1
	71	2	18.2
	Total	11	100.0

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

		Number	Percent
Responses	No	11	100.0

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

		Number	Percent
Responses	11a. White	11	100.0%

12. Any other comments or suggestions?

Please help my father. I'm a teacher. I find myself teaching children all day and then coming home to teach a child who used to teach me.

Purple Ribbon Task Force

Survey of Healthcare Providers and Paid Caregivers

1. Where do you live or work?

1a. City:

		Number	Percent
Responses	Bonita Springs	1	6.3
	Cape Coral	1	6.3
	Fort Myers	3	18.8
	Ft. Myers	1	6.3
	Marco Island	1	6.3
	Naples	4	25.0
	Port Charlotte	1	6.3
	Sarasota	3	18.8
	Venice	1	6.3
	Total	16	100.0

1b. County:

		Number	Percent
Responses	Charlotte	1	6.3
	Collier	5	31.3
	Lee	6	37.5
	Sarasota	4	25.0
	Total	16	100.0

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

		Number	Percent
Responses	0-5 years	2	12.5
	6-10 years	2	12.5
	11-15 years	2	12.5
	16-20 years	4	25.0
	21-25 years	2	12.5
	Over 25 years	4	25.0
	Total	16	100.0

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

		Number	Percent
Responses	3a. No specific training or certification	2	11.1%
	3b. CAN	1	5.6%
	3c. LPN	2	11.1%
	3d. RN	4	22.2%
	3e. NP	2	11.1%
	3i. Other	7	38.9%
	Total	18	100.0%

Purple Ribbon Task Force

Survey of Healthcare Providers and Paid Caregivers

3. Other (please specify)

Activity Director
Adult day care center license
Alzheimer training provided by Alzheimer's Association, degree in gerontology, certified dementia practitioner, certified activity director, previous CNA
BA, MBA
Certified Senior Advisor, and also Alzheimer's Training through Senior Helpers
Core Training, CEU.
Level one and on the job training
Neuropsychologist
Nursing Home Administrator
R.N.,Ph.D.

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

		Number	Percent
Responses	4a. Adult day care facility	2	9.1%
	4b. Adult family care home	1	4.5%
	4c. Assisted living facility	6	27.3%
	4e. Hospice	1	4.5%
	4f. Hospitals	1	4.5%
	4g. Memory Disorder Clinic	1	4.5%
	4h. Nursing facility	1	4.5%
	4i. Physician's office	2	9.1%
	4j. Private residence	4	18.2%
	4k. Other	3	13.6%
	Total	22	100.0%

4. Other (please specify)

Case management - HCBS
Home Health Agency
Home Health/Caregivers support group
Retirement Community

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

		Number	Percent
Responses	Yes	10	62.5
	No	6	37.5
	Total	16	100.0

5. Other (please specify)

Patient was assessed by private neurologist

Purple Ribbon Task Force

Survey of Healthcare Providers and Paid Caregivers

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

		Number	Percent
Responses	6a. Home health	7	7.9%
	6b. Personal care/Bath assistance	10	11.2%
	6c. Homemaker/Housekeeper	7	7.9%
	6d. Counseling	7	7.9%
	6e. Case management	4	4.5%
	6f. Adult day services	5	5.6%
	6g. Respite	9	10.1%
	6h. Hospice	4	4.5%
	6i. Education	7	7.9%
	6j. Research/Clinical trials	2	2.2%
	6k. Support groups	8	9.0%
	6l. Telephone reassurance	6	6.7%
	6m. Personal emergency response systems	3	3.4%
	6n. Wanderguards/Project Lifesaver	2	2.2%
	6o. Meals on Wheels	2	2.2%
	6p. On-line support through professional or informal groups (for example, Facebook)	2	2.2%
	6q. On-line research/Support/Blogging	1	1.1%
	6s. Other	3	3.4%
	Total	89	100.0%

6. Other (please specify)

Assessment
Information and referral to all of the above and more

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

		Number	Percent
Responses	7a. Newspaper	10	25.6%
	7b. On-line/website	14	35.9%
	7c. Facebook	4	10.3%
	7d. Newsletters	8	20.5%
	7f. Other	3	7.7%
	Total	39	100.0%

7. Other (specify)

Brochures, public presentations
Phone book, magazines, senior blue book
Senior center
TV
Word of mouth

Purple Ribbon Task Force

Survey of Healthcare Providers and Paid Caregivers

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

8a. Getting helpful information on Alzheimer's disease and related dementias

		Number	Percent
Responses	Not Challenging	3	18.8
	A Little Challenging	4	25.0
	Somewhat Challenging	2	12.5
	Quite Challenging	6	37.5
	Very Challenging	1	6.3
	Total	16	100.0

8b. Getting information on community resources

		Number	Percent
Responses	A Little Challenging	3	18.8
	Somewhat Challenging	3	18.8
	Quite Challenging	7	43.8
	Very Challenging	3	18.8
	Total	16	100.0

8c. Caregivers feeling depressed or anxious

		Number	Percent
Responses	Somewhat Challenging	1	6.3
	Quite Challenging	6	37.5
	Very Challenging	9	56.3
	Total	16	100.0

8d. Caregivers feeling resentful

		Number	Percent
Responses	A Little Challenging	2	12.5
	Somewhat Challenging	2	12.5
	Quite Challenging	9	56.3
	Very Challenging	3	18.8
	Total	16	100.0

8e. Access to medical care for caregivers

		Number	Percent
Responses	Don't Know	1	6.3
	Not Challenging	1	6.3
	A Little Challenging	3	18.8
	Somewhat Challenging	3	18.8
	Quite Challenging	6	37.5
	Very Challenging	2	12.5
	Total	16	100.0

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Survey of Healthcare Providers and Paid Caregivers

8f. Access to medical care for people with Alzheimer's disease and related dementias

		Number	Percent
Responses	A Little Challenging	3	18.8
	Somewhat Challenging	5	31.3
	Quite Challenging	3	18.8
	Very Challenging	5	31.3
	Total	16	100.0

8g. Dealing with financial, legal, and insurance issues

		Number	Percent
Responses	Don't Know	1	6.3
	A Little Challenging	1	6.3
	Somewhat Challenging	1	6.3
	Quite Challenging	4	25.0
	Very Challenging	9	56.3
	Total	16	100.0

8h. Access to support groups

		Number	Percent
Responses	Not Challenging	3	18.8
	A Little Challenging	3	18.8
	Somewhat Challenging	2	12.5
	Quite Challenging	7	43.8
	Very Challenging	1	6.3
	Total	16	100.0

8i. Access to respite care, adult day care, and other services

		Number	Percent
Responses	Not Challenging	2	12.5
	A Little Challenging	1	6.3
	Somewhat Challenging	2	12.5
	Quite Challenging	8	50.0
	Very Challenging	3	18.8
	Total	16	100.0

8j. Paying for services

		Number	Percent
Responses	A Little Challenging	1	6.7
	Somewhat Challenging	1	6.7
	Quite Challenging	5	33.3
	Very Challenging	8	53.3
	Total	15	100.0

Purple Ribbon Task Force

Survey of Healthcare Providers and Paid Caregivers

8k. Changing relationships in the family

		Number	Percent
Responses	Don't Know	1	7.1
	Somewhat Challenging	1	7.1
	Quite Challenging	3	21.4
	Very Challenging	9	64.3
	Total	14	100.0

8l. Communication with the person with Alzheimer's disease or related dementia

		Number	Percent
Responses	A Little Challenging	1	6.3
	Somewhat Challenging	1	6.3
	Quite Challenging	6	37.5
	Very Challenging	8	50.0
	Total	16	100.0

8m. Dying before the person with Alzheimer's disease or related dementia

		Number	Percent
Responses	Don't Know	2	12.5
	A Little Challenging	1	6.3
	Somewhat Challenging	2	12.5
	Quite Challenging	6	37.5
	Very Challenging	5	31.3
	Total	16	100.0

8n. Losing control of lifestyle

		Number	Percent
Responses	Don't Know	2	12.5
	A Little Challenging	1	6.3
	Somewhat Challenging	2	12.5
	Quite Challenging	4	25.0
	Very Challenging	7	43.8
	Total	16	100.0

8o. Loss of employment

		Number	Percent
Responses	Don't Know	4	25.0
	A Little Challenging	2	12.5
	Somewhat Challenging	1	6.3
	Quite Challenging	5	31.3
	Very Challenging	4	25.0
	Total	16	100.0

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Survey of Healthcare Providers and Paid Caregivers

8p. Getting an appropriate diagnosis

		Number	Percent
Responses	Don't Know	1	6.7
	A Little Challenging	1	6.7
	Somewhat Challenging	5	33.3
	Quite Challenging	2	13.3
	Very Challenging	6	40.0
	Total	15	100.0

8q. Understanding the disease

		Number	Percent
Responses	A Little Challenging	1	6.3
	Somewhat Challenging	3	18.8
	Quite Challenging	6	37.5
	Very Challenging	6	37.5
	Total	16	100.0

8r. Other

		Number	Percent
Responses	Don't Know	1	20.0
	Very Challenging	4	80.0
	Total	5	100.0

8. Other (please specify)

Getting access to services when personal funds expire
Grief
Willingness to seek and accept diagnosis, communication with out of town family (so they know the true needs)

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

9a. Loss of ability to drive

		Number	Percent
Responses	Don't Know	1	6.3
	Somewhat Challenging	2	12.5
	Quite Challenging	7	43.8
	Very Challenging	6	37.5
	Total	16	100.0

9b. Depression or anxiety of the person with Alzheimer's disease or related dementia

		Number	Percent
Responses	Somewhat Challenging	2	12.5
	Quite Challenging	6	37.5
	Very Challenging	8	50.0
	Total	16	100.0

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Survey of Healthcare Providers and Paid Caregivers

9c. Difficult behaviors

		Number	Percent
Responses	Quite Challenging	4	25.0
	Very Challenging	12	75.0
	Total	16	100.0

9d. Wandering or safety

		Number	Percent
Responses	Somewhat Challenging	1	6.3
	Quite Challenging	7	43.8
	Very Challenging	8	50.0
	Total	16	100.0

9e. Becoming a financial burden

		Number	Percent
Responses	Don't Know	1	6.3
	A Little Challenging	1	6.3
	Somewhat Challenging	3	18.8
	Quite Challenging	6	37.5
	Very Challenging	5	31.3
	Total	16	100.0

9f. Losing control over lifestyle

		Number	Percent
Responses	Somewhat Challenging	2	14.3
	Quite Challenging	6	42.9
	Very Challenging	6	42.9
	Total	14	100.0

9g. Other

		Number	Percent
Responses	Don't Know	1	33.3
	Very Challenging	2	66.7
	Total	3	100.0

9. Other (please specify)

Independence
Losing their identity
Question is confusing - loss of driving big problem for AD person - but if they have difficult behaviors - it's very difficult for those around them?

Purple Ribbon Task Force

Survey of Healthcare Providers and Paid Caregivers

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 ADRD in your community? (Check all that apply.)

		Number	Percent
Responses	10a. Employers	11	8.0%
	10b. Hospitals	9	6.5%
	10c. Aging services and senior centers	13	9.4%
	10d. Churches and faith communities	12	8.7%
	10e. Veterans Administration	11	8.0%
	10f. Public service announcements on radio & TV	14	10.1%
	10g. Medical training schools	7	5.1%
	10h.Law enforcement	11	8.0%
	10i. Physicians	14	10.1%
	10j. Nursing schools	11	8.0%
	10k. Religious organizations	9	6.5%
	10l. Website with updated information	12	8.7%
	10m. Other	4	2.9%
	Total	138	100.0%

10. Other (please specify)

Any way that information gets to families needing help. The family usually comes to us in a crisis, either financial o emotional
Most seniors still read the newspaper - so advertisement in local papers important
Need to get the reassurance and support service information to where people live, work and worship - need to educate line clinical staff - don't focus on the disease - focus on support
Social media

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?

11a. Increase public awareness of Alzheimer's disease and related dementias

		Number	Percent
Responses	Quite Important	7	46.7
	Very Important	8	53.3
	Total	15	100.0

11b. Promote annual cognitive assessment/ screening for older adults

		Number	Percent
Responses	Don't Know	1	6.7
	Somewhat Important	2	13.3
	Quite Important	1	6.7
	Very Important	11	73.3
	Total	15	100.0

11c. Improve access to information and resources for newly diagnosed individuals

		Number	Percent
Responses	Somewhat Important	1	6.7
	Quite Important	4	26.7
	Very Important	10	66.7
	Total	15	100.0

11d. Other

		Number	Percent
Responses	Don't Know	1	100.0

11. Other (please specify)

Increase awareness of dementia, care and safety - don't focus on the diagnostic label - focus on the care and support
Support for families and caregivers

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.

12a. Research on prevention, treatment, and clinical trials

		Number	Percent
Responses	Somewhat Important	2	13.3
	Quite Important	3	20.0
	Very Important	10	66.7
	Total	15	100.0

12b. Clinical assessment, diagnosis, and testing

		Number	Percent
Responses	Somewhat Important	1	6.7
	Quite Important	7	46.7
	Very Important	7	46.7
	Total	15	100.0

12c. Assisting families in paying for care

		Number	Percent
Responses	A Little Important	1	6.7
	Somewhat Important	1	6.7
	Quite Important	3	20.0
	Very Important	10	66.7
	Total	15	100.0

12d. Protecting people with Alzheimer's disease and related dementias

		Number	Percent
Responses	A Little Important	1	6.7
	Somewhat Important	2	13.3
	Quite Important	5	33.3
	Very Important	7	46.7
	Total	15	100.0

12e. Ensuring quality of care

		Number	Percent
Responses	Somewhat Important	1	6.7
	Quite Important	5	33.3
	Very Important	9	60.0
	Total	15	100.0

Purple Ribbon Task Force

Survey of Healthcare Providers and Paid Caregivers

12f. Education and training for caregivers

		Number	Percent
Responses	Quite Important	7	46.7
	Very Important	8	53.3
	Total	15	100.0

12g. Economic impact of Alzheimer's disease and related dementias on communities, workplaces, and citizens

		Number	Percent
Responses	Somewhat Important	2	13.3
	Quite Important	4	26.7
	Very Important	9	60.0
	Total	15	100.0

12h. Access to affordable and appropriate dementia-specific care

		Number	Percent
Responses	Somewhat Important	1	7.1
	Quite Important	3	21.4
	Very Important	10	71.4
	Total	14	100.0

12i. Having an educated and trained workforce on Alzheimer’s disease and related dementias

		Number	Percent
Responses	Somewhat Important	2	13.3
	Quite Important	4	26.7
	Very Important	9	60.0
	Total	15	100.0

12j. Transportation

		Number	Percent
Responses	A Little Important	1	7.1
	Somewhat Important	3	21.4
	Quite Important	2	14.3
	Very Important	8	57.1
	Total	14	100.0

12k. Employment

		Number	Percent
Responses	Don't Know	1	7.1
	Not Important	1	7.1
	A Little Important	1	7.1
	Somewhat Important	4	28.6
	Quite Important	4	28.6
	Very Important	3	21.4
	Total	14	100.0

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12l. Tax credits for caregivers

		Number	Percent
Responses	A Little Important	1	6.7
	Somewhat Important	4	26.7
	Quite Important	2	13.3
	Very Important	8	53.3
	Total	15	100.0

12m. Access to non-dementia-specific services

		Number	Percent
Responses	A Little Important	2	13.3
	Somewhat Important	2	13.3
	Quite Important	8	53.3
	Very Important	3	20.0
	Total	15	100.0

12n. Specialized care facilities

		Number	Percent
Responses	Don't Know	1	6.7
	A Little Important	1	6.7
	Somewhat Important	3	20.0
	Quite Important	6	40.0
	Very Important	4	26.7
	Total	15	100.0

12o. Emergency Management/Disaster Preparedness

		Number	Percent
Responses	A Little Important	1	6.7
	Somewhat Important	2	13.3
	Quite Important	5	33.3
	Very Important	7	46.7
	Total	15	100.0

12p. Medical care

		Number	Percent
Responses	Somewhat Important	1	6.7
	Quite Important	7	46.7
	Very Important	7	46.7
	Total	15	100.0

12q. Mental health/Depression

		Number	Percent
Responses	Quite Important	6	46.2
	Very Important	7	53.8
	Total	13	100.0

12r. Other

		Number	Percent
Responses	Don't Know	1	100.0

12. Other (please specify)

Counseling for families, patients and caregivers

13. What is your gender?

		Number	Percent
Responses	Female	12	80.0
	Male	3	20.0
	Total	15	100.0

14. What is your age?

		Number	Percent
Responses	43	1	6.7
	44	1	6.7
	49	1	6.7
	50	2	13.3
	52	2	13.3
	54	1	6.7
	55	3	20.0
	60	1	6.7
	64	1	6.7
	65	1	6.7
	70	1	6.7
	Total	15	100.0

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

		Number	Percent
Responses	No	13	86.7
	Yes	2	13.3
	Total	15	100.0

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

		Number	Percent
Responses	16a. White	14	100.0%

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

		Number	Percent
Responses	Just English	13	86.7
	Spanish	1	6.7
	Other (please specify below)	1	6.7
	Total	15	100.0

17. Other (please specify)

Farsi

18. Any other comments or suggestions?

The increase in Alzheimer's disease is alarming and so research and review is essential. Thank you for your interest and concern.

The largest problem I see today is the lack of affordable care. I'm in the home health business, and mainly, only the very well off people are able to afford care for their loved one. There is an extreme lack of coverage via insurance and Medicare to care for patients with AD. Most memory care units aren't able to provide individualized care to keep patients engaged in life, quickly increasing the progression of the disease.

The waiting lists for services should be addressed. the cost of HCBS is much cheaper than NH care. Families are in crisis and need immediate help in order to maintain family members at home and retain their own employment. Transportation issues should be addressed. There can be many HCBS but unless someone can get to them and afford the cost to get there, it will not work.

Purple Ribbon Task Force

Survey of Policy, Legal, Education and Other Professionals

1. Where do you live or work?

1a. City:

		Number	Percent
Responses	Fort Myers	2	66.7
	Sarasota	1	33.3
	Total	3	100.0

1b. County:

		Number	Percent
Responses	Lee	2	66.7
	Sarasota	1	33.3
	Total	3	100.0

2. Please indicate the category that fits you best.

		Number	Percent
Responses	Educator, trainer, or academic	2	66.7
	Public safety or law enforcement	1	33.3
	Total	3	100.0

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

		Number	Percent
Responses	No	3	100.0

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

4a. Getting helpful information on Alzheimer's disease and related dementias

		Number	Percent
Responses	A Little Challenging	1	33.3
	Somewhat Challenging	2	66.7
	Total	3	100.0

4b. Getting information about community resources

		Number	Percent
Responses	Somewhat Challenging	1	33.3
	Quite Challenging	1	33.3
	Very Challenging	1	33.3
	Total	3	100.0

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4c. Caregivers feeling depressed or anxious

		Number	Percent
Responses	Quite Challenging	3	100.0

4d. Caregivers feeling resentful

		Number	Percent
Responses	Somewhat Challenging	1	33.3
	Quite Challenging	2	66.7
	Total	3	100.0

4e. Access to medical care for caregivers

		Number	Percent
Responses	A Little Challenging	1	33.3
	Quite Challenging	1	33.3
	Very Challenging	1	33.3
	Total	3	100.0

4f. Access to medical care for people with Alzheimer's disease and related dementias

		Number	Percent
Responses	Somewhat Challenging	1	33.3
	Very Challenging	2	66.7
	Total	3	100.0

4g. Dealing with financial, legal, and insurance issues

		Number	Percent
Responses	Quite Challenging	2	66.7
	Very Challenging	1	33.3
	Total	3	100.0

4h. Access to support groups

		Number	Percent
Responses	A Little Challenging	1	33.3
	Quite Challenging	2	66.7
	Total	3	100.0

4i. Access to respite care, adult day care, and other services

		Number	Percent
Responses	Somewhat Challenging	1	33.3
	Quite Challenging	1	33.3
	Very Challenging	1	33.3
	Total	3	100.0

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4j. Paying for services

		Number	Percent
Responses	Somewhat Challenging	1	33.3
	Very Challenging	2	66.7
	Total	3	100.0

4k. Changing relationships in the family

		Number	Percent
Responses	Somewhat Challenging	1	33.3
	Quite Challenging	2	66.7
	Total	3	100.0

4l. Communication with the person with Alzheimer's disease or related dementia

		Number	Percent
Responses	Somewhat Challenging	1	33.3
	Quite Challenging	2	66.7
	Total	3	100.0

4m. Becoming a financial burden on children

		Number	Percent
Responses	Somewhat Challenging	1	33.3
	Very Challenging	2	66.7
	Total	3	100.0

4n. Dying before the person with Alzheimer's disease or related dementia

		Number	Percent
Responses	Quite Challenging	2	66.7
	Very Challenging	1	33.3
	Total	3	100.0

4o. Losing control of lifestyle

		Number	Percent
Responses	Quite Challenging	2	66.7
	Very Challenging	1	33.3
	Total	3	100.0

4p. Loss of employment

		Number	Percent
Responses	Somewhat Challenging	1	33.3
	Quite Challenging	2	66.7
	Total	3	100.0

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4q. Getting an appropriate diagnosis

		Number	Percent
Responses	Somewhat Challenging	1	33.3
	Very Challenging	2	66.7
	Total	3	100.0

4r. Understanding the disease

		Number	Percent
Responses	Somewhat Challenging	2	66.7
	Very Challenging	1	33.3
	Total	3	100.0

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

5a. Loss of ability to drive

		Number	Percent
Responses	Quite Challenging	1	33.3
	Very Challenging	2	66.7
	Total	3	100.0

5b. Depression or anxiety of the person with Alzheimer's disease or related dementia

		Number	Percent
Responses	Quite Challenging	1	33.3
	Very Challenging	2	66.7
	Total	3	100.0

5c. Difficult behaviors

		Number	Percent
Responses	Quite Challenging	1	33.3
	Very Challenging	2	66.7
	Total	3	100.0

5d. Wandering or safety

		Number	Percent
Responses	Very Challenging	3	100.0

5e. Becoming a financial burden

		Number	Percent
Responses	Quite Challenging	2	66.7
	Very Challenging	1	33.3
	Total	3	100.0

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5f. Losing control over lifestyle

		Number	Percent
Responses	Quite Challenging	2	66.7
	Very Challenging	1	33.3
	Total	3	100.0

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 ADRD in your community? (Check all that apply.)

		Number	Percent
Responses	6a. Employers	2	10.0%
	6c. Aging services and senior centers	2	10.0%
	6d. Churches and faith communities	1	5.0%
	6f. Public service announcements on radio & TV	2	10.0%
	6g. Medical training schools	3	15.0%
	6h. Law enforcement	2	10.0%
	6i. Physicians	2	10.0%
	6j. Nursing schools	3	15.0%
	6k. Religious organizations	1	5.0%
	6l. Website with updated information	2	10.0%
	Total	20	100.0%

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.

7a. Research on prevention, treatment, and clinical trials

		Number	Percent
Responses	Quite Important	1	33.3
	Very Important	2	66.7
	Total	3	100.0

7b. Clinical assessment, diagnosis, and testing

		Number	Percent
Responses	Quite Important	1	33.3
	Very Important	2	66.7
	Total	3	100.0

7c. Assisting families in paying for care

		Number	Percent
Responses	Quite Important	1	33.3
	Very Important	2	66.7
	Total	3	100.0

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7d. Protecting people with Alzheimer's disease and related dementias

		Number	Percent
Responses	Quite Important	2	66.7
	Very Important	1	33.3
	Total	3	100.0

7e. Ensuring quality of care

		Number	Percent
Responses	Very Important	3	100.0

7f. Education and training for caregivers

		Number	Percent
Responses	Very Important	3	100.0

7g. Economic impact of Alzheimer's disease and related dementias on communities, workplaces, and citizens

		Number	Percent
Responses	Quite Important	1	33.3
	Very Important	2	66.7
	Total	3	100.0

7h. Access to affordable and appropriate dementia-specific care

		Number	Percent
Responses	Very Important	3	100.0

7i. Having an educated and trained workforce on Alzheimer's disease and related dementias

		Number	Percent
Responses	Very Important	3	100.0

7j. Transportation

		Number	Percent
Responses	Quite Important	2	66.7
	Very Important	1	33.3
	Total	3	100.0

7k. Employment

		Number	Percent
Responses	A Little Important	1	33.3
	Quite Important	1	33.3
	Very Important	1	33.3
	Total	3	100.0

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7l. Tax credits for caregivers

		Number	Percent
Responses	Very Important	3	100.0

7m. Access to non-dementia-specific services

		Number	Percent
Responses	Quite Important	2	66.7
	Very Important	1	33.3
	Total	3	100.0

7n. Specialized care facilities

		Number	Percent
Responses	Very Important	3	100.0

7o. Emergency Management/Disaster Preparedness

		Number	Percent
Responses	Somewhat Important	1	33.3
	Quite Important	1	33.3
	Very Important	1	33.3
	Total	3	100.0

7p. Medical care

		Number	Percent
Responses	Quite Important	2	66.7
	Very Important	1	33.3
	Total	3	100.0

7q. Mental health/Depression

		Number	Percent
Responses	Very Important	3	100.0

8. What is your gender?

		Number	Percent
Responses	Female	3	100.0

9. What is your age?

		Number	Percent
Responses	44	1	33.3
	53	1	33.3
	71	1	33.3
	Total	3	100.0

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Survey of Policy, Legal, Education and Other Professionals

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

		Number	Percent
Responses	No	3	100.0

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

		Number	Percent
Responses	11a. White	3	100.0%

12. Any other comments or suggestions?

Make sure there is advocacy for this population to assist with funding for therapy, respite care for families and quality day programs so families can continue to address their daily needs.