

Characteristics of Caregivers and Non-caregivers – Florida, 2008

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Characteristics of Caregivers and Care Recipients—Florida, 2008

These data are from the 2008 Florida Behavioral Risk Factor surveillance System (BRFSS) and are designed to provide estimates of the adult, non-institutionalized population in Florida.

Caregiving and the Caregiver Module

America's 53.4 million caregivers form an integral and frequently unrecognized part of the health care team, providing an estimated \$257 to \$389 billion in unpaid care to individuals with disabilities and chronic diseases.¹ These informal caregivers may be a family member, friend, or neighbor of a person with a disability or chronic health condition. Currently, the prevalence of caregiving and the health impacts of caregiving are not known at the state and local level. State and federal agencies, as well as private organizations are concerned about issues surrounding caregiving and could employ population-based caregiving data to design needed programs and interventions to address this increasingly important public health issue. Many community and public health groups also express interest in specific conditions as they relate to caregiving—notably cancer, Alzheimer's disease and dementia, and developmental disabilities. Thus, there is an emerging and increasing audience requiring this information. Learning more about caregivers and how their caregiving activities impact their risk of poor health outcomes will improve our understanding of how to provide support to them, in turn improving the ability of care recipients to maintain independence and experience an improved quality of life.

During the past four years, the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention (CDC) has made a systematic attempt to identify and describe caregivers as part of the total health care system, and to identify public health dimensions of caregiving. One result of this work has been the development of the Caregiver Module, a series of questions about caregivers and their experiences that can be added to the Behavioral Risk Factor Surveillance System (BRFSS).² The BRFSS is a state-based, random-digit-dialed (RDD) telephone survey of non-institutionalized U.S. adults aged 18 and older. This survey is administered by state health agencies, territories, and in the District of Columbia with assistance from the CDC.³ The Caregiver Module is designed to collect information about a population-based sample of adult caregivers who care for individuals with a disability or chronic condition regardless of the individual's age, level of need, or diagnosis. Data are weighted so that people who respond to the survey represent the entire state of Florida based on age, gender, and race.

Caregiving in Florida

According to US Census Bureau projections, the age profile of Florida will change considerably by the year 2030.⁴ In 2000, an estimated 3.6 million Floridians were under age 18, representing 22.8% of the population. By 2030, this number is expected to grow to 5.8 million people, but those under age 18 will represent a smaller percent (20.1) of Florida's population. In 2000, 17.6% of Floridians, or 2.8 million people, were age 65 or older. This age group is expected to grow to 7.8 million people, or 27.1% of Florida's population, by 2030.⁴ Because the risk of disability increases with age, it is expected that as the population ages, the need for informal caregivers will increase as well.

To study the characteristics and health of caregivers and their care recipients in the state of Florida, the thirteen question Caregiver Module was added to the 2008 Florida BRFSS (Appendix A). The 2008 Florida BRFSS not only allows for the analysis of demographic differences among caregivers and non-caregivers but also assesses health behaviors, such as exercise frequency, smoking status, and alcohol use. In addition, through the use of this module, caregivers can be compared to non-caregivers on quality of life measures such as general life satisfaction, the amount of emotional and social support received, and self-reported general health status.

During 2008, 10,217 Florida BRFSS respondents were asked, “People may provide regular care or assistance to someone who has a long-term illness or disability. During the past month, did you provide any such care or assistance to a family member or friend?” A total of 1,461 people, or 13.4% (weighted) of these respondents said “yes” to this question. These respondents were classified as caregivers and answered the remaining Caregiver Module questions about themselves and their care recipient. (Note: if the caregiver reported providing care to more than one recipient, the caregiver was asked to answer the remaining questions based on the recipient who required the most care).

Questions on the Caregiver Module included the age and gender of the care recipient and their relationship to the caregiver. Module questions also assessed the major health problem of the care recipient, and up to two areas in which the care recipient required the most assistance. Other questions asked the caregiver how long they have provided care for the recipient, the average number of hours per week they provided care, how far they lived from their care recipient, and their greatest difficulty faced as a caregiver. Finally, the caregiver was asked whether she had any concerns about the care recipient’s memory or thinking, whether memory or thinking problems interfered with the care recipient’s daily activities or quality of life, and whether the care recipient’s memory or thinking had ever been formally evaluated by a health care professional.

Results

In order to understand the best way to target and serve the needs of caregivers, it is necessary to understand who they are. Demographic and health behavior characteristics of caregivers of people with and without memory or thinking problems are presented in Table 1. The majority of caregivers identified in the survey were women (57.9%). The mean age of both caregivers and non-caregivers was 48 years. Educational attainment was similar among caregivers and non-caregivers with 66.1% of caregivers and 62.0% of non-caregivers having some education beyond high school. Most caregivers (58.6%) and non-caregivers (57.7%) were employed. Shown in Table 1, household income was consistent throughout each income bracket distribution. Caregivers and non-caregivers have similar marital status distributions, with 61.7% of caregivers and 63.7% of non-caregivers reporting they were married or coupled. Around one-third of respondents had a child under age 18 living in the household: 32.1% of caregivers and 39.3% of non-caregivers. The most commonly reported race/ethnicity in Florida was white, non-Hispanic (64.3% of caregivers and 62.7% of non-caregivers). Non-caregivers were somewhat more likely to report Hispanic ethnicity (19.3% compared to 14.3% of caregivers). Caregivers were less likely to be veterans than non-caregivers (10.8% compared to 16.0%).

Respondents were categorized as having a disability according to the BRFSS definition of disability. If respondents answered “yes” to either of two questions: “Are you limited in any way in any activities because of physical, mental, or emotional problems,” or “Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone,” they were classified as having a disability. The prevalence of disability was higher among caregivers than among non-caregivers (27.4% and 20.1%, respectively).

Health related quality of life (HRQOL) was assessed using the following variables: physical unhealthy days in the last 30 days, mental unhealthy days in the last 30 days, general life satisfaction, emotional support, and general health status. The number of physical unhealthy days was assessed in the question: “Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?” Caregivers and non-caregivers both reported an average of 3.6 days of poor physical health in the past month. Mentally unhealthy days were assessed as: “Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?” Caregivers reported more days per month of poor mental health (5.7 days) than non-caregivers (3.3 days). Cancer was also assessed, 10% of caregivers were told by a doctor that they had cancer, compared to 8.2% of non-caregivers. Caregivers and non-caregivers reported being satisfied or very satisfied with life in general with similar frequency (92.3% and 95.1%, respectively). Respondent emotional support was assessed by the question: “How often do you get the social or emotional support you need?” Caregivers and non-caregivers reported always or usually receiving the social and emotional support needed with equal frequency (79.5%). Ratings of general health among caregivers and non-caregivers were also similar; 82.7% of caregivers and 84.9% of non-caregivers reported their general health was excellent, very good, or good. When dealing with medical costs, 21% of caregivers needed to see a doctor but could not because of cost, while 14.5% of non-caregivers reported to have the same problem.

Measures of health and health behaviors were very similar among caregivers and non-caregivers. Seventy-six percent of caregivers and 74.1% of non-caregivers reported engaging in some form of physical activity outside of work. Approximately 40% of caregivers and non-caregivers had a body mass index (BMI) in the normal range (18.5-24.9), over 30% were considered overweight (BMI of 25.0-29.9), and under 30% were obese (BMI of 30.0 or higher).

The CDC defines heavy drinking as more than two drinks per day for men and more than one drink per day for women. Nearly four percent of caregivers reported heavy alcohol consumption, as did 5.5% of non-caregivers. Binge drinking is defined as men having five or more drinks on one occasion, and women having four or more drinks on one occasion. The prevalence of binge drinking in the last 30 days was 14.5% among caregivers and 12.9% among non-caregivers. Caregivers were more likely to be current smokers than non-caregivers (21.2% compared to 17.0%).

Only caregivers age 65 and older were asked whether they had received a flu shot in the past year or a pneumonia vaccine at any time. Caregivers were slightly more likely to have

received a flu shot within the past year (68.0% compared to 63.2%) but the two groups were equally likely to have ever received the pneumonia vaccine (62.7% compared to 61.7%).

More than one in ten Floridians surveyed reported they had fallen in the past 3 months, and caregivers and non-caregivers were equally likely to have reported a fall (12.8% and 12.7%, respectively). Respondents who reported experiencing a fall also were asked whether they sustained an injury due to the fall. Thirty-four percent of caregivers and 35.6% of non-caregivers reported an injury due to a fall in the past 3 months.

The results of the thirteen question Florida Caregiver Module based on the 1,461 identified caregivers are found in Table 2. A majority of care recipients were women (60.6%) and age 65 and older (64.4%). The mean age of care recipients was 71.1 years. Care recipients were most commonly a family member of the caregiver, with a parent or parent-in-law being the most frequently reported relationship (31.0%). Another 5.5% of caregivers provided care for a spouse or a partner, and 14.1% cared for a child or child-in-law. The most common care recipient diagnosis as reported by the caregiver was cancer (19.0%). Arthritis or rheumatism (8.3%), Alzheimer's disease or dementia (7.5%), diabetes (6.8%), heart disease (6.3%), and stroke (3.8%) completed the list of the six most common diagnoses reported.

Caregivers reported providing the most help in a variety of areas. When asked to choose up to two areas in which their care recipient needed the most help, caregivers reported moving around (31.3%) and self-care (26.5%), both representing activities of daily living, most frequently. When asked the greatest difficulty faced personally, caregivers most often said that caregiving created stress (41.3%) and caregiving created a financial burden (20.7%).

Overall, 39.8% of caregivers provided zero to eight hours of care in an average week, and 26.5% provided 40 hours of care or more in an average week. Nearly one-quarter (23.9%) of caregivers had been providing care for three months or less, while more than one-quarter (25.6%) of caregivers had provided care for more than 5 years. Caregivers tended to live with the care recipient (41.4%) or within 20 minutes of him/her (40.0%).

References

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Table 1

Table 1: Weighted demographic and health behavior characteristics of caregivers and non-caregivers, Florida Behavioral Risk Factor Surveillance System (BRFSS), 2008.

Variable	Categories	Caregivers (n = 1,461)	Non-caregivers (n = 8,756)
		Percent (95% CI)	Percent (95% CI)
Age	18-24	10.8 (5.1-16.5)	8.9 (7.1-10.8)
	25-34	16.2 (11.5-20.8)	19.2 (17.2-21.3)
	35-44	14.2 (10.9-17.5)	18.1 (16.6-19.6)
	45-54	21.3 (17.4-25.3)	17.5 (16.0-18.9)
	55-64	18.1 (15.1-21.1)	14.5 (13.3-15.6)
	65 and older	19.4 (16.4-22.4)	21.8 (20.5-23.0)
Gender (% Female)	Female	57.9 (52.3-63.6)	50.4 (48.3-52.5)
Education status	Less than high school	9.3 (6.3-12.2)	10.4 (8.9-11.9)
	High school degree or equivalent	24.6 (20.6-28.6)	27.5 (25.7-29.3)
	Some college or technical School	30.6 (25.1-36.1)	29.6 (27.7-31.6)
	College degree or higher	35.5 (30.4-40.5)	32.4 (30.6-34.3)
Employment status	Employed	58.6 (50.0-67.2)	57.7 (54.3-61.3)
	Out of work	5.7 (2.4-9.0)	6.3 (4.7-7.9)
	Homemaker	7.3 (4.9-9.7)	6.5 (5.5-7.5)
	Student	4.2 (0.6-7.8)	3.1 (1.9-4.2)
	Retired	19.3 (16.3-22.2)	21.3 (20.1-22.5)
	Unable to work	5.0 (3.0-7.0)	5.0 (4.3-5.8)
Race/ethnicity	White only, non-Hispanic	64.3 (58.4-70.2)	62.7 (60.6-64.8)
	Black only, non-Hispanic	13.4 (9.6-17.2)	11.3 (9.9-12.7)
	Other only, non-Hispanic	6.1 (3.3-8.8)	5.7 (4.5-6.9)
	Multiracial, non-Hispanic	1.9 (0.2-3.5)	1.0 (0.5-1.5)
	Hispanic	14.3 (8.4-20.3)	19.3 (17.3-21.3)

Table 1 continued Variable	Categories	Caregivers (n = 1,461)	Non- caregivers (n = 8,756)
Marital status	Married/Coupled	61.7 (56.0-67.3)	63.7 (61.7-65.7)
	Divorced/Widowed/Separated	20.4 (16.6-24.1)	20.3 (18.9-21.6)
	Never married	17.9 (12.0-23.8)	16.0 (14.1-17.9)
Veteran status	Respondent is a veteran	10.8 (8.1-13.5)	16.0 (14.6-17.5)
Disability status	Respondent has a disability	27.4 (23.1-31.8)	20.1 (18.6-21.5)
General life satisfaction	Very Satisfied/Satisfied	92.3 (89.8-94.9)	95.1 (94.3-95.9)
Emotional support	Always or usually receive support needed	79.5 (75.5-83.5)	79.5 (77.8-81.1)
General health	Excellent, very good, or good	82.7 (79.0-85.9)	84.9 (83.6-86.2)
Physical activity	Engage in physical activity outside of work	76.5 (72.3-80.7)	74.1 (72.2-75.9)
Body Mass Index (BMI)	Neither overweight nor obese	40.9 (35.2-46.5)	39.4 (37.3-41.5)
	Overweight	31.3 (26.7-35.9)	35.5 (33.5-37.4)
	Obese	27.8 (23.3-32.3)	25.1 (23.2-27.0)
Smoking status	Current Smoker	21.2 (17.1-25.2)	17.0 (15.5-18.5)
	Former Smoker	24.3 (20.5-28.1)	26.2 (24.5-27.8)
	Never Smoked	54.5 (49.3-59.7)	56.8 (54.8-58.8)
Alcohol consumption	Heavy drinkers (adult men having more than two drinks per day and adult women having more than one drink per day)	3.5 (2.3-4.7)	5.5 (4.6-6.3)
Binge drinking	Binge drinkers (Men having five or more drinks on one occasion, women having four or more drinks on one occasion)	14.5 (10.2-18.8)	12.9 (11.4-14.5)
Flu shot	Adults age 65+ who have had flu shot within the past year	68.0 (60.9-75.1)	63.2 (60.5-65.9)
Pneumonia vaccine	Adults age 65+ who have ever had a pneumonia vaccination	62.7 (55.1-70.2)	61.7 (59.0-64.3)
Fall experience	Respondent has fallen within the past 3 months	12.8 (10.1-15.5)	12.7 (11.3-14.0)
Fall-related injury	Among respondents who fell in the past 3 months, those who were injured	34.0 (23.5-44.4)	35.6 (30.5-40.7)
Household Income	Less than \$10,000	2.7 (0.7-4.7)	3.7 (2.9-4.5)
	\$10,000-\$20,000	14.0 (10.4-17.7)	11.8 (10.5-13.2)

	\$20,000-\$35,000	20.9 (17.0-24.9)	23.9 (22.0-25.7)
	\$35,000-\$50,000	17.8 (17.0-24.9)	14.9 (13.4-16.3)
	\$50,000-\$75,000	16.6 (12.2-21.0)	17.9 (16.2-19.7)
	More than \$75,000	27.9 (22.7-33.1)	27.8 (25.8-29.7)
Children in Household	At least one child under age 18 lives in household	32.1 (27.3-37.0)	39.3 (37.2-41.4)
Medical Costs	Needed to see a doctor but could not because of cost	21.0 (16.8-25.2)	14.5 (13.0-16.0)
Cancer	Respondent ever told by a doctor that they had cancer	10.0 (7.7-12.0)	8.2 (7.3-9.0)

Table 2**Table 2: Weighted caregiving experience characteristics, Florida Behavioral Risk Factor Surveillance System (BRFSS), 2008.**

Variable	Category	Prevalence (95% CI)
Care recipient gender	Female	60.6 (55.2-66.0)
Care recipient age	0-5	0.6 (0.0-1.6)
	6-17	1.7 (0.6-2.9)
	18-34	5.64% (3.5-7.8)
	35-44	5.9 (3.8-8.0)
	45-54	8.4 (5.3-11.5)
	55-64	13.3 (9.6-17.0)
	65-74	21.5 (16.4-26.5)
	75-84	20.8 (16.5,25.1)
	85+	22.2 (18.1-26.2)
Care recipient's relationship to caregiver	Parent or Parent-in-law	31.0 (26.1-35.8)
	Friend	7.9 (5.2-10.5)
	Spouse or Partner	5.5 (3.3-7.6)
	Child or Child-in-law	14.1 (11.4-16.9)
	Sibling or Sibling-in-law	4.6 (3.1-6.1)
	Grandparent	8.4 (3.9,13.0)
	Neighbor	1.1 (0.0-2.2)
	Client or patient	6.3 (3.6-9.0)
	Other family member	21.2 (16.4-25.9)
* Care recipient's major health problem	Cancer	19.0 (14.7-23.2)
	Heart disease	6.3 (4.3-8.2)
	Alzheimer's disease or dementia	7.5 (5.4-9.7)
	Stroke	3.8 (2.2-5.5)
	Arthritis/Rheumatism	8.3 (3.2-13.4)
	Diabetes	6.8

		(4.2-9.3)
Areas in which care recipient needs most help (respondent could choose up to 2)	Learning, remembering, confusion	16.3 (12.6-20.2)
	Seeing or hearing	5.4 (2.8-8.1)
	Self-care	26.5 (21.5-31.6)
	Communicating with others	6.0 (3.8-8.2)
	Moving around	31.3 (25.1-37.5)
	Getting along with people	2.8 (1.3-4.3)
	Feeling anxious or depressed	11.5 (8.0-15.1)
Greatest difficulty faced by caregiver (respondent could choose up to 2)	Financial burden	20.7 (15.6-26.0)
	Not enough time for him/herself	15.1 (11.2-19.0)
	Not enough time for family	6.3 (3.5-9.1)
	Interferes with work	7.4 (4.4-10.5)
	Creates or aggravates health problems	2.6 (0.8-4.5)
	Affects family relationships	2.1 (1.1-3.1)
	Creates stress	41.3 (34.1-48.5)
	Other Difficulty	4.4 (2.4-6.4)
Care recipient's distance from caregiver	Same house	41.4 (35.8-47.0)
	Less than 20 minutes away	40.0 (34.6-45.4)
	20-60 minutes away	10.4 (7.6-13.1)
	1-2 hours away	1.6 (0.8-2.3)
	More than 2 hours away	6.6 (4.6-8.7)
Hours of care provided per week	0-8	39.8 (35.6-45.0)
	9-19	18.6 (14.2-22.9)
	20-39	15.1 (11.7-18.4)
	40+	26.5 (21.7-31.4)
Length of care	0-3 months	23.9 (19.6-28.3)
	4-12 months	23.5 (18.0-29.0)
	13-24 months	8.2 (6.1-10.4)

	25-60 months	18.7 (14.8-22.5)
	More than 5 years	25.6 (21.0-30.3)

* Note: ___% of respondents (n=) of responses were classified as “other” for this question. The results presented here are based only on the respondents with categorized responses (n=).

Appendix A

Caregiver Module – 2008 Florida BRFSS

FL3.1 People may provide regular care or assistance to someone who has a long-term illness or disability. During the past month, did you provide any such care or assistance to a family member or friend?
IF NEEDED: If recipient has died in the past 30 days, say “I’m so sorry to hear of your loss” and go to the next section.

- 1 Yes
- 2 No [Go to next module]
- 7 Don't know / Not sure [Go to next module]
- 9 Refused [Go to next module]

FL3.2 What age is the person to whom you are giving care?
IF NEEDED: If more than one, ask, “What is the age of the person to whom you gave the most care in the past 30 days?”

- ___ Age in years [0-115]
- 998 Don't know
- 999 Refused

FL3.3 What is the gender of the person you are caring for?

- 1 Male
- 2 Female
- 7 Don't know / Not sure
- 9 Refused

FL3.4 (Program for gender based on response to question FL3.3) What is his/her relationship to you? For example is he/she your (mother/daughter or father/son)?

DO NOT READ ANSWER CHOICES. Let the respondent name the relationship, but probe to fit if it isn't clear. PROBE for relationship – If more than one, ask “What is the relationship of the person to whom you gave the most care in the past 30 days?”

IF NEEDED – If more than one relationship applies, say “I can only record ONE answer choice”, or something similar to ensure respondent chooses only one option.

- 1 Parent
- 2 Parent-in-law
- 3 Child
- 4 Spouse
- 5 Sibling
- 6 Grandparent
- 7 Grandchild
- 8 Other Relative
- 9 Friend or client
- 77 Don't Know / Not Sure
- 99 Refused

FL3.5 What do you think or what has a doctor said is the major health problem that your ____ {Insert response question FL3.4} has?

CHECK ONE CONDITION ONLY. DO NOT READ ANSWER CHOICES.

- | | |
|-----------------------------------|-------------------------------------|
| 1 ADD/ADHD | 15 Hearing problems (deafness) |
| 2 AIDS/HIV | 16 Heart disease |
| 3 Alzheimer's Disease or dementia | 17 Hypertension/high blood pressure |
| 4 Anxiety or emotional problems | 18 Lung disease/emphysema |
| 5 Arthritis/rheumatism | 19 Multiple Sclerosis |
| 6 Asthma | 20 Muscular Dystrophy |
| 7 Cancer | 21 Osteoporosis |
| 8 Cerebral Palsy | 22 Parkinson's |
| 9 Chromosomal anomaly | 23 Spinal Cord Injury (SCI) |
| 10 Depression | 24 Stroke |
| 11 Down's syndrome | 25 Traumatic Brain Injury (TBI) |
| 12 Developmental delays | 26 Other: |
| Specify _____ | |
| 13 Diabetes | 77 Don't know/Not sure |
| 14 Eye/vision problem (blindness) | 99 Refused |

FL3.6 Which TWO of the following areas does your ____ {Insert response question FL3.4} most need your help?

PLEASE READ ANSWER CHOICES 1-7. CHECK UP TO TWO. MULTIPLE RESPONSE.

- 1 Learning, remembering, & confusion;
 - 2 Seeing or hearing;
 - 3 Taking care of oneself, such as eating, dressing, bathing, or toileting;
 - 4 Communicating with others;
 - 5 Moving around;
 - 6 Getting along with people;
- or
- 7 Feeling anxious or depressed
- Please do not read:
- 77 Don't Know
 - 99 Refused

FL3.7 For how long have you provided care for your ____ {Insert response question FL3.4}?

DO NOT READ. Code using respondent's unit of time.

- 1 __ Days
- 2 __ Weeks
- 3 __ Months
- 4 __ Years
- 7 Don't know/Not sure
- 9 Refused

FL3.8 In an average week, how many hours do you provide care for your ____ {Insert response question FL3.4} because of his/her long-term illness or disability?

DO NOT READ

- __ Hours per week
- 77 Don't Know
- 99 Refused

FL3.9 I am going to read a list of difficulties you may have faced as a caregiver. Please indicate which TWO of the following is the greatest difficulty you have faced in your caregiving:
PLEASE READ ANSWER CHOICES 1-8. CHECK UP TO TWO

- 1 Caregiving creates a financial burden;
 - 2 Caregiving doesn't leave enough time for yourself;
 - 3 Caregiving doesn't leave enough time for your family;
 - 4 Caregiving interferes with your work;
 - 5 Caregiving creates or aggravates health problems;
 - 6 Caregiving affects your family relationships;
 - 7 Caregiving creates stress;
 - or
 - 8 Another difficulty
- Please do not read:**
77 Don't know/Not sure
99 Refused

FL3.10 How far away do you live from your ____ {Insert response question FL3.4}? Do you live...
PLEASE READ ANSWER CHOICES 1-5.

- 1 In the same house
- 2 Less than 20 minutes away
- 3 Between 20 & 60 minutes away
- 4 Between 1 & 2 hours away,
- or
- 5 More than two hours away?
- 7 Don't know/Not sure
- 9 Refused

FL3.11 Do you have concerns about your ____ {Insert response question FL3.4}'s memory or thinking?

- 1 Yes
- 2 No
- 7 Don't know / Not sure
- 9 Refused

FL3.12 Does your ____ {Insert response question FL3.4}'s memory or thinking interfere with everyday activities or quality of life?

- 1 Yes
- 2 No
- 7 Don't know / Not sure
- 9 Refused

FL3.13 Has a physician or other health care professional ever evaluated your relative's memory or thinking problems?

- 1 Yes
- 2 No
- 7 Don't know / Not sure
- 9 Refused