

**POMP 5 CAREGIVER PROGRAM SUPPORT AND ASSESSMENT SURVEY
MAIL SURVEY
June 9, 2004**

We are conducting a survey to find out how we can better assist with the needs of caregivers and seniors being served by [INSERT AGENCY'S NAME]. Our records show that you have received caregiver support services from [INSERT AGENCY'S NAME] to help you take care of an elderly person. We would like to know if these caregiver support services have been helpful.

Are you still the caregiver for an elderly person age 60 years of age or older?

Yes 1

Please continue.

No 2

**Please return this survey in the enclosed envelope.
Thank you for your time.**

CONTINUE HERE: Before you begin the caregiver survey, we want you to know that:

Your participation is voluntary and very important to the success of this study.

Your answers to the questions will be kept confidential to the full extent of the law and will be used only for the purpose of this study.

Your eligibility for services will not be affected by (1) your decision to participate in this survey or not, (2) any answers you give, or (3) anything at all related to this survey.

Please continue on the next page.

Office Use Only:	1 of 28
Type of Administration [check]: Telephone <input type="checkbox"/> Mail <input type="checkbox"/> Interview Date: _____	
Result Code: _____ Caregiver Enrollment Date: _____ Caregiver ID: _____	

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1. What is your relationship to the person you are caring for? Are you his or her ...

Please choose only one answer.

- Husband 1
- Wife..... 2
- Son 3
- Son-in-Law 4
- Daughter 5
- Daughter-in-Law 6
- Father 7
- Mother..... 8
- Brother 9
- Sister 10
- Granddaughter 11
- Grandson 12
- Niece 13
- Nephew 14
- Other relative [Not a relative mentioned above]..... 15
(Relation: _____)
- Friend or Neighbor or Another Person 16

Please continue on the next page.

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2. The following are several activities that some people need help with. When the person you are caring for performs or is involved in these activities, how often do you help with ...

	All the time or Most of the time	Sometimes	Rarely or Never
A.) Activities like dressing, eating, bathing, or getting to the bathroom?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
B.) Medical needs such as taking medicine or changing bandages?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
C.) Keeping track of bills, checks, or other financial matters?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
D.) Preparing meals, doing laundry, or cleaning the house?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
E.) Going shopping or to the doctor's office?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
F.) Arranging for care or services provided by others?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

If you have answered all parts of question 2 as "Rarely or Never," please tell us what kind of care you provide for the person you are caring for in the space below. If you are not providing any kind of care, write "None" on a line below.

IF YOU DO NOT PROVIDE ANY CARE, please return the survey in the enclosed envelope. Thank you for your time.

IF YOU DO PROVIDE CARE, please continue on the next page.

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The next questions are about the services that you are receiving from [AGENCY'S NAME] and/or other agencies. We are interested in your experiences with services during the last year.

3. Have you received **Respite Care**, which allows you, the caregiver, a brief period of rest or relief while temporary care is provided to the person you are caring for, either in your home or someplace else?

Yes 1 [Please go to Q.3A.]

No 2 [Please go to Q.4.]

3A. To what extent have the **Respite Care Services** you have received helped you as a caregiver?

Please check only one answer

They helped a lot,..... 1

They helped a little,..... 2

They didn't help, or 3

They made things worse?..... 4

4. Has someone, such as your case worker, case manager, or other AAA staff person, **helped you or given you information** to connect you to the services and resources that you need as a caregiver?

Yes 1 [Please go to Q.4A.]

No 2 [Please go to Q.5.]

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4A. To what extent has the **help or information** you have received helped you connect to the services and resources that you need as a caregiver?

Please check only one answer

- They helped a lot,..... 1
- They helped a little,..... 2
- They didn't help, or 3
- They made things worse?..... 4

5. Have you received **caregiver training or education**, including counseling or support groups, to help you make decisions and solve problems in your role as a caregiver?

- Yes 1 **[Please go to Q.5A.]**
- No 2 **[Please go to Q.6.]**

5A. To what extent has the **caregiver training or education** you have received helped you as a caregiver?

Please check only one answer

- It helped a lot, 1
- It helped a little, 2
- It did not help, or..... 3
- It made things worse? 4

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6. Has the National Family Caregiver Support Program provided you with any other **Supplemental Services** to help you with the care you provide, such as home modifications, assistive technologies, or incontinence supplies?

Yes 1 [Please go to Q.6A.]

No 2 **If you have not received any of the services asked about in Questions 3, 4, 5, and 6, please return the survey in the enclosed envelope.**

Otherwise, if you have received at least one of the services in Questions 3, 4, 5, and 6, please continue with the survey.

- 6A. To what extent have the **Supplemental Services** you have received helped you as a caregiver?

Please check only one answer

They helped a lot,..... 1

They helped a little,..... 2

They did not help, or..... 3

They made things worse?..... 4

7. Of the caregiver services provided, which **one service** was the most helpful?

Please check only one answer

Respite Care Services, 1

Help or Information connecting you
to Caregiver Support Services, 2

Caregiver Training or Education,
including Counseling or a Support Group, or..... 3

Other Supplemental Support Services
or Assistance? 4

Please continue on the next page

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8. How have the caregiver services that have been provided affected you and your caregiving tasks?

9. Overall, to what extent have these caregiver services helped you to be a better caregiver?

Please check only one answer

- They helped a lot,..... 1
- They helped a little,..... 2
- They didn't help, or 3
- They made things worse?..... 4

10. Have these caregiver services enabled you to provide care for the person you provide care to for a longer time than would have been possible without these services?

Please check only one answer

- Yes, definitely, 1
- Yes, I think so, 2
- No, I don't think so, or 3
- No, definitely not? 4

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11. Overall, how would you rate the caregiver support services that have been provided?

Please check only one answer

- Excellent, 1
- Very good,..... 2
- Good,..... 3
- Fair, or..... 4
- Poor? 5

The next questions are about your employment.

12. What is your current employment status?

Please check only one answer

- Working full time,..... 1 [Please go to Q.13.]
- Working part time, 2 [Please go to Q.13.]
- Retired, or 3 [Please go to Q.12A.]
- Not working? 4 [Please go to Q.12A.]

12A. Did your caregiving responsibilities cause you to quit work or retire early?

- Yes 1 [Please go to Q.16.]
- No 2 [Please go to Q.16.]

13. Has providing care for the person you care for interfered with your job?

- Yes 1 [Please go to Q.13A.]
- No 2 [Please go to Q.16.]

Please continue on the next page.

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13A. How frequently has providing care for the person you care for interfered with your job?

Please check only one answer

- Always or usually, 1 [Please go to Q.14.]
- Sometimes, 2 [Please go to Q.14.]
- Rarely or never? 3 [Please go to Q.16.]

14. Because of providing care for the person you care for, have you ...

- | | <u>YES</u> | <u>NO</u> |
|--|----------------------------|----------------------------|
| A. Taken a less demanding job. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| B. Changed from full time to part-time work. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| C. Reduced your official working hours. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| D. Lost some of your employment fringe benefits. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| E. Had time conflicts between working and caregiving. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| F. Used your vacation time to provide care. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| G. Taken a leave of absence to provide care. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| H. Lost a promotion..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| I. Worked less than your normal number of hours last month because of providing care for the person you care for | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| J. Anything else? [What? _____] | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |

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15. To what extent have caregiver support services helped alleviate these work difficulties?

Please check only one answer

- They helped a lot,..... 1
- They helped a little,..... 2
- They didn't help, or 3
- They made things worse?..... 4

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16. Please check how frequently each of the following happens: Always or usually, Sometimes, or Rarely or never.

	Always or Usually	Sometimes	Rarely or Never	Does Not Apply
A.) As a caregiver, how often do you feel that you are helping the person you care for?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/>
B.) As a caregiver, how often do you feel that you are helping your family by caring for the person you care for?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/>
C.) How often does being a caregiver provide you with a sense of accomplishment?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/>
D.) How often does providing care for the person you care for give you the satisfaction of caring for someone who cared for you?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/>
E.) How often do you feel that the person you care for appreciates the care that you are providing for them?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/>
F.) How often does being a caregiver for the person you care for provide companionship for you?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/>
G.) Anything else? (What?: _____)?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/>

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If you answered “Rarely or Never” or “Does Not Apply” to all parts of Question 16, please go to Question 18.

Otherwise, please answer Question 17.

17. In your experience as a caregiver, what would you say is the **one most positive aspect** of caregiving?

Please check only one answer

- Helping your care recipient,..... 1
- Helping your other family members,..... 2
- Feeling a sense of accomplishment,..... 3
- Caring for someone who cared for you,..... 4
- Being appreciated, 5
- Providing companionship for you?..... 6
- Other? (What?: _____) 7
- No Positive Aspects 8

18. In your experience as a caregiver, how often do you feel that...

	Always or Usually	Sometimes	Rarely or Never	Does Not Apply
A.) Caregiving creates a financial burden for you?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/>
B.) You do not have enough time for yourself?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/>
C.) You do not have enough time for your family?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/>
D.) Caregiving negatively affects your health?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/>
E.) Caregiving conflicts with your social life?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/>
F.) You are stressed?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/>
G.) Anything else? (What?: _____)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/>

Please continue on the next page.

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If you answered “Rarely or Never” or “Does Not Apply” to all parts of Question 18, please go to Question 21.

Otherwise, please answer Questions 19 and 20.

19. Which of these difficulties is **the greatest difficulty** you have faced in your caregiving?

Please check only one answer

- Creates a financial burden,..... 1
- Doesn't leave enough time for yourself,..... 2
- Doesn't leave enough time for your family, 3
- Interferes with your work,..... 4
- Creates or aggravates health problems, 5
- Affects your family relationships, or 6
- Creates stress?..... 7
- Any other difficulty?
(What?: _____) 8

20. To what extent have the **Caregiver Support Services** you have received helped alleviate these difficulties?

Please check only one answer

- They helped a lot,..... 1
- They helped a little,..... 2
- They didn't help, or 3
- They made things worse?..... 4

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21. Do you have any kind of health problem, physical condition, or disability that affects the kind or amount of care that you can provide to the person you care for

Yes 1 [Please go to Q.21A.]

No 2 [Please go to Q.23.]

21A. What is that problem, condition, or disability?

Please check all that apply to you.

Physical

1. Back problems and other joint problems/ Arthritis..... 1

Illness

2. Heart problems / High Blood Pressure /
Hypertension / Stroke. 1

3. Diabetes..... 1

4. Allergies/Asthma/Other breathing and lung problems. ... 1

5. **Mental health (all).** 1

6. **Eye problems.** 1

7. **Other (Please write in the space provided)**..... 1

Other conditions or disabilities:

22. Have your caregiving activities created or worsened any of these problems, conditions, or disabilities?

Yes 1

No 2

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The next questions are about the person for whom you provide care.

23. How long have you been caring for the person you care for?

Number of Months

Number of Years

24. How far away do you live from the person for whom you provide care? Do you live...

Please check only one answer

In the same house,..... 1 [Please go to Q.26.]

Less than 20 minutes away, 2 [Please go to Q.25.]

Between 20 and 60 minutes away,..... 3 [Please go to Q.25.]

Between 1 and 2 hours away, or 4 [Please go to Q.25.]

More than two hours away? 5 [Please go to Q.25.]

25. Does the person you care for live alone?

Yes 1

No 2

26. Can the person you care for be left alone?

Please check only one answer

He/she can be left alone, 1

He/she needs someone there at least part of the day, or 2

He/she needs someone there all or nearly all the time? 3

Please continue on the next page.

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27. In your judgment, how many hours per day of help, care, or supervision does the person you care for need?

Number of hours per day

28. In a **typical** 24-hour **week day**, how many hours do **you** provide help, care or supervision for the person you care for in person?

Number of hours per week day

29. In a **typical** 24-hour **weekend day**, how many hours do **you** provide help, care or supervision for the person you care for in person?

Number of hours per weekend day

30. Do any agencies, family members or friends help you get **time off** or relief from the responsibility of caring for the person you care for?

Yes 1

No 2

31. Do you need more time off?

Yes 1

No 2

Please continue on the next page.

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32. Thinking about all the family members or friends who provide unpaid help, care, or supervision for the person you care for, what proportion of the care do **you** provide?

Please check only one answer

- All, 1
- Nearly all,..... 2
- More than one-half, but not nearly all, 3
- About half, 4
- More than a little, but less than one-half, or 5
- A little? 6

The next questions are about the services that **the person you care for is receiving** from [AGENCY'S NAME] and/or other agencies. We are interested in your experiences with services during the last year.

33. Does the person you care for receive the following service?

	Yes	No
A.) Adult Daycare (Center-provided daycare)?	<input type="checkbox"/> 1	<input type="checkbox"/> 2
B.) Case Management?	<input type="checkbox"/> 1	<input type="checkbox"/> 2
C.) Homemaker Service?	<input type="checkbox"/> 1	<input type="checkbox"/> 2
D.) Home Health Aide?	<input type="checkbox"/> 1	<input type="checkbox"/> 2
E.) Home Delivered Meals?	<input type="checkbox"/> 1	<input type="checkbox"/> 2
F.) Chore Service?	<input type="checkbox"/> 1	<input type="checkbox"/> 2
G.) Transportation Service (includes Assisted Transportation)?	<input type="checkbox"/> 1	<input type="checkbox"/> 2
H.) Information about services?	<input type="checkbox"/> 1	<input type="checkbox"/> 2
I.) Other services or assistance (not listed above)?		
1. Which service? _____	<input type="checkbox"/> 1	<input type="checkbox"/> 2
2. Which service?: _____	<input type="checkbox"/> 1	<input type="checkbox"/> 2

Please continue on the next page.

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If the person you care for does not receive any of the services in Question 33, please go to Question 37.

Otherwise, please answer questions 34, 35, and 36.

34. Overall, how would you rate the services that the person you care for receives?

Please check only one answer

- Excellent, 1
- Very good,..... 2
- Good,..... 3
- Fair, or..... 4
- Poor? 5

35. Have the services received by the person you care for enabled you to provide care for a longer time than would have been possible without these services?

Please check only one answer

- Yes, definitely, 1
- Yes, I think so, 2
- No, I don't think so, or..... 3
- No, definitely not? 4

Please continue on the next page.

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36. Thinking **only** about the services that the person you care for received, how have the services that he or she received affected you and your caregiving tasks?

37. In your judgment, if the services that you and the person you care for have received had **not** been available, would he or she be living in a different place now?

Yes 1 [Please go to Q.37A.]

No 2 [Please go to Q.38.]

37A. Where would the person you care for be living?

Please check only one answer

In your home, 1

In the home of another family member or friend, 2

In an assisted living facility, or 3

In a nursing home? 4

Some other situation?
(Please specify?: _____) 5

Please continue on the next page.

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38. In addition to the kinds or amounts of services the person you care for is now receiving, what additional or **new kinds of help** would be valuable to you as a caregiver? How about...

	<u>YES</u>	<u>NO</u>
A. Help with housekeeping,	<input type="checkbox"/> 1	<input type="checkbox"/> 2
B. Help with shopping,	<input type="checkbox"/> 1	<input type="checkbox"/> 2
C. Help with transportation, getting places,	<input type="checkbox"/> 1	<input type="checkbox"/> 2
D. Help with making meals,	<input type="checkbox"/> 1	<input type="checkbox"/> 2
E. Help with bathing, dressing, grooming, toileting, feeding, other personal care,	<input type="checkbox"/> 1	<input type="checkbox"/> 2
F. Help with medicines (administering medicine, monitoring side effects, etc.),	<input type="checkbox"/> 1	<input type="checkbox"/> 2
G. Help with getting other family members involved in caring for the person you care for,	<input type="checkbox"/> 1	<input type="checkbox"/> 2
H. Financial support, tax break, stipend, government subsidy,	<input type="checkbox"/> 1	<input type="checkbox"/> 2
I. In-home respite care for the person you care for,	<input type="checkbox"/> 1	<input type="checkbox"/> 2
J. Adult daycare for the person you care for, or	<input type="checkbox"/> 1	<input type="checkbox"/> 2
K. Money management assistance or financial advice,	<input type="checkbox"/> 1	<input type="checkbox"/> 2
L. Any other type of help? (What? _____)	<input type="checkbox"/> 1	<input type="checkbox"/> 2
- OR -		
M. No additional help needed?	<input type="checkbox"/> 1	<input type="checkbox"/> 2

Please continue on the next page.

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39. In addition to the kinds or amounts of information that you already have, what additional or new kinds of information would be valuable to you as a caregiver? How about...

	<u>YES</u>		<u>NO</u>
A. A help line (or central place to call to find out what kind of help is available and where to get it),	<input type="checkbox"/>	1	<input type="checkbox"/> 2
B. Someone to talk to or counseling services or support group,	<input type="checkbox"/>	1	<input type="checkbox"/> 2
C. Information about the condition or disability for the person for whom you provide care,	<input type="checkbox"/>	1	<input type="checkbox"/> 2
D. Information about changes in laws that might affect your situation,	<input type="checkbox"/>	1	<input type="checkbox"/> 2
E. Help in understanding how to select a nursing home or group home or other care facility,	<input type="checkbox"/>	1	<input type="checkbox"/> 2
F. Help in understanding how to pay for nursing homes, adult day care, or other services,	<input type="checkbox"/>	1	<input type="checkbox"/> 2
G. Help in dealing with agencies (bureaucracies) to get services, or	<input type="checkbox"/>	1	<input type="checkbox"/> 2
H. Any other information? (What? _____)	<input type="checkbox"/>	1	<input type="checkbox"/> 2
- OR -			
I. No additional information needed?	<input type="checkbox"/>	1	<input type="checkbox"/> 2

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We are interested in knowing more about the demographic characteristics of people receiving these services. We would appreciate it if you would answer the following questions. All this information will be kept confidential to the full extent of the law.

40. What is the age of the person for whom you provide care?

Number of years old |__|__|__|

41. What is the gender of the person for whom you provide care?

Male 1

Female 2

42. How many other persons total are you caring for, not counting the person for whom you provide care?

Number of other person for whom you care |__|__|

If you **do not** take care of anyone else, please go to question 43 on the next page.

If you **do** take care of others, please answer Question 42A on the next page.

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42A. Who are those people?

Please check all that apply.

- 1. Husband or wife 1
- 2. Son(s) or daughter(s) 1
- 3. Father 1
- 4. Mother 1
- 5. Brother(s) or sister(s) 1
- 6. Grandson(s) or granddaughter(s) 1
- 7. Other relative(s) not mentioned above..... 1
- 8. Friend(s) or neighbor(s) 1
- 9. Other persons not mentioned above
(Who?: _____) 1

D1. What is your gender?

- Male 1
- Female..... 2

D2. What is your age?

Number of years old

Please continue on the next page.

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D3. What is your highest educational level?

Please check only one answer.

- Less than high school diploma,..... 1
- High school diploma or GED, 2
- Some college, including Associate's degree, 3
- Bachelor's degree, or 4
- Some post-graduate work or advanced degree?..... 5

D4. Are you Spanish, Hispanic or Latino?

- Yes 1
- No 2

D5. What is your race?

Please check all that apply.

- A. White or Caucasian,..... 1
- B. Black or African-American,..... 1
- C. Asian, 1
- D. American Indian or Alaska Native, or 1
- E. Native Hawaiian or Other Pacific Islander? 1
- F. Other (Other race: _____)..... 1

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D6. Where is your home located?

Please check only one answer.

- In a City,..... 1
 In a Suburban Area, or 2
 In a Rural area? 3

D7. What is your home zip code?

5 Digit Zip Code

D8. We'd like to ask about the persons who live in this household. Does anyone else live with you in this household?

- Yes 1 **[Please go to Q.D9.]**
 No 2 **[Please go to Q.D11.]**

D9. Do you...

- | | Yes | No |
|-------------------------------|----------------------------|----------------------------|
| A. Live with your spouse? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| B. Live with your children? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| C. Live with other relatives? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| D. Live with non-relatives? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |

D10. Including yourself, how many people live in your household?

Number of people in your household

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D11. What is your marital status?

Please check only one answer.

- Now married, 1
- Widowed, 2
- Divorced, 3
- Separated, or 4
- Never Married? 5

D12. Thinking about the total combined income from all sources for all persons in this household, was your total household annual income for the past 12 months \$20,000 or less or more than \$20,000?

Total combine household income includes income from jobs, Social Security, retirement income, public assistance, and all other sources.

- \$20,000 OR LESS, OR 1 [Please go to Q.D13.]
- MORE THAN \$20,000 2 [Please go to Q.D14.]

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D13. Which category best describes your total household annual income for the last 12 months?

Please check only one answer.

- \$10,000 or less, 1
- \$10,001-\$15,000, or 2
- \$15,001 - \$20,000? 3

D14. Which category best describes your total household annual income for the last 12 months?

Please check only one answer.

- \$20,001 - \$25,000, 1
- \$25,001 - \$30,000, 2
- \$30,001-\$35,000, 3
- \$35,001 - \$40,000, or 4
- Over \$40,000?..... 5

Thank you very much for your time and information. Your responses will be very helpful to our study.

Please see the next page.

**POMP 5 CAREGIVER PROGRAM SUPPORT AND ASSESSMENT SURVEY
MAIL SURVEY
June 9, 2004**

If you would like more information on services available to caregivers, please give us your address:

Please note that this page will be separated from all other pages of this interview so that your name will not be associated with any of the answers that you have given to us.

First Name

Last Name

Street Number and Address

City

State

Zip Code

You may also contact us directly using the following information:

[INSERT AREA AGENCY NAME AND FULL CONTACT INFORMATION HERE]

Please return this survey in the enclosed envelope. THANK YOU VERY MUCH.