

POMP Final: Caregiver Services Survey Instrument

(Mail Version)

This survey is about the caregiver services that you receive. We are interested in the length of time you have received caregiver services and whether the caregiver services have been helpful. Your answers will help us make sure that the services meet your needs. Participation in the survey is voluntary and you may skip any question. Your answers will be kept confidential and will not influence the services that you receive.

CR1. Are you still caring for a person age 60 years or older?

Yes..... 1 → GO TO CR2
No..... 2

CR1a. What happened to change your caregiving situation? Check all that apply.

- a. The person you care for died 1
 - b. The person you care for was placed in a nursing home 2
 - c. The person you care for was placed in an assisted living facility 3
 - d. The person you care for was placed in a family type group home (family care home) 4
 - e. The person you care for is getting help temporarily from a different caregiver 5
 - f. The person you care for has a different permanent caregiving arrangement 6
 - g. The person you care for got better and no longer needs help..... 7
 - h. The needs of the person you care for exceed your capacity to help..... 8
 - i. Your health status has declined 9
 - j. Your employment status has changed 10
 - k. Your family situation has changed 11
 - l. Other reason 91
- Please describe: _____

END SURVEY

Office Use Only:

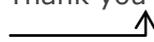
Client ID: _____

Service Enrollment Date: _____

Date of Survey Administration: _____

CR2. When was the last time you received caregiver support services?

- | | | | |
|---|--------------------------|---|---|
| Today or yesterday | <input type="checkbox"/> | 1 | Thank you, but the focus of this survey is on people who have used the service within the past year. Thank you for your time. |
| More than 1 day, but not more than a week ago | <input type="checkbox"/> | 2 | |
| More than 1 week, but not more than a month ago | <input type="checkbox"/> | 3 | |
| More than 1 month ago..... | <input type="checkbox"/> | 4 | |
| Over 1 year ago | <input type="checkbox"/> | 5 | |



CR3. How long have you been receiving caregiver services?

- | | | |
|--|--------------------------|---|
| 6 months or less | <input type="checkbox"/> | 1 |
| More than 6 months, but less than 1 year | <input type="checkbox"/> | 2 |
| At least 1 year, but less than 2 years..... | <input type="checkbox"/> | 3 |
| 2 to 5 years..... | <input type="checkbox"/> | 4 |
| More than 5 years | <input type="checkbox"/> | 5 |

CR4. What is your relationship to the person you care for? Are you his or her ...

- | | | |
|--|--------------------------|----|
| Husband | <input type="checkbox"/> | 1 |
| Wife | <input type="checkbox"/> | 2 |
| Domestic partner | <input type="checkbox"/> | 3 |
| Father..... | <input type="checkbox"/> | 4 |
| Mother..... | <input type="checkbox"/> | 5 |
| Grandfather | <input type="checkbox"/> | 6 |
| Grandmother | <input type="checkbox"/> | 7 |
| Brother | <input type="checkbox"/> | 8 |
| Sister | <input type="checkbox"/> | 9 |
| Uncle..... | <input type="checkbox"/> | 10 |
| Aunt | <input type="checkbox"/> | 11 |
| Son | <input type="checkbox"/> | 12 |
| Son-in-Law..... | <input type="checkbox"/> | 13 |
| Daughter..... | <input type="checkbox"/> | 14 |
| Daughter-in-Law | <input type="checkbox"/> | 15 |
| Other relative (not mentioned above) | <input type="checkbox"/> | 16 |
| Friend or neighbor or another person..... | <input type="checkbox"/> | 17 |

CR5. Has someone from the agency helped you or given you information to connect you to the services and resources that you need as a caregiver?

- | | | |
|----------|--------------------------|---|
| Yes..... | <input type="checkbox"/> | 1 |
| No..... | <input type="checkbox"/> | 2 |

CR6. Have you received respite care, which allows you a brief break while temporary care is provided, either in your home or someplace else?

Yes..... 1
No..... 2

CR7. Have you received caregiver training or education, including participation in support groups, to help you make decisions and solve problems in your role as a caregiver?

Yes..... 1
No..... 2

CR8. Has the agency provided you with any supplemental services to help you provide care, such as home modifications, nutritional supplements such as Ensure or Boost, assistive devices such as canes or walkers, personal emergency response system, specialized equipment such as sleep apnea machines or hospital beds, stipends, etc.?

Yes..... 1
No..... 2

CR9. Of the caregiver services you received, which one service was the most helpful? Check only one.

Help or information connecting you to services and resources 1
Respite Care Services 2
Caregiver Training or Education, including Counseling or a Support Group, or 3
Other Supplemental Support Services or Assistance 4
Specify: _____

CR10. As a result of the caregiver services, do you...

| | <u>Yes</u> | <u>No</u> |
|---|----------------------------|----------------------------|
| a. Have more time for personal activities..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| b. Feel less stress | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| c. Have a clearer understanding of how to get the services you and the person you care for need.... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| d. Know more about the condition or illness of the person you care for | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| e. Feel more confident in providing care to the person you care for | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |

CR11. Would the person you care for have been able to continue to live in the same home if caregiver services had not been provided?

Yes..... 1 → GO TO CR12
No..... 2 → GO TO CR11a

CR11a. Where would the person you care for be living? Check only one answer.

In your (caregiver's) home 1
In the home of another family member or friend 2
In an assisted living facility..... 3
In a nursing home 4
The person you care for would have died..... 5
Other 91
Describe: _____

CR12. Thinking about the caregiver services that you have received, how would you rate these services? Would you say...

Excellent 1
Very good 2
Good 3
Fair 4
Poor 5

CR13. Would you recommend these services to a friend?

Yes..... 1
No..... 2

CR14. Have the caregiver services enabled you to provide care for a longer period of time than would have been possible without these services?

Yes..... 1
No..... 2

CR15. In general, would you say that the caregiver service has helped you?

Yes..... 1 → GO TO CR15a
No..... 2 → GO TO CR16

CR15a. How has the caregiver service helped you?

CR16. Do you have any recommendations to improve the caregiver service?

Yes..... ₁ → GO TO CR16a
No..... ₂

CR16a. What recommendations do you have for improving the service?

Thank you very much for your time and cooperation. Your answers are very important to us in improving the caregiver services.

Module A: Care Provided

In this section of the survey, we would like to obtain some basic information about how much care you provide for the person you care for.

CRA1. How long have you been caring for this person?

|__|__| Years |__|__| Months

CRA2. Thinking about all the family members or friends who provide help, care, or supervision for the person you care for, what proportion of the care do you provide during a typical week? Check only one.
Would you say...

- Less than one-quarter..... 1
- About one-quarter..... 2
- About one-half..... 3
- About three-quarters..... 4
- All or almost all of the care..... 5

CRA3. Does the person you care for live with you?

- Yes..... 1 → GO TO CRA5
- No..... 2

CRA4. Does the person you care for live alone?

- Yes..... 1 → Thank you.
This concludes
Module A.
- No..... 2

Module B: Burdens and Rewards of Caregiving

The next group of questions ask about the rewards and burdens you may feel as a caregiver.

CRB1. The following questions ask about the positive aspects of caregiving and give you some choices for answers. Please choose the answer that best tells how you feel.

| | <u>Always</u> | <u>Usually</u> | <u>Some- times</u> | <u>Rarely</u> | <u>Never</u> |
|--|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| a. As a caregiver, how often do you feel that you are helping the person you care for continue to live at home..... | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ |
| b. How often does being a caregiver for the person you care for give you the joy of spending time with someone you care about..... | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ |
| 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"/> ₄ | <input type="checkbox"/> ₅ |
| d. How often does providing care for the person you care for give you the satisfaction of knowing that they are receiving the care and attention they need ... | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ |
| 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"/> ₄ | <input type="checkbox"/> ₅ |
| f. As a caregiver, how often do you feel you are fulfilling your duty by caring for the person you care for | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ |

CRB2. In your experience as a caregiver, what is the one most positive aspect of caregiving? Check only one.

- Helping the person you care for live at home 1
- Spending time with someone you care about 2
- Feeling a sense of accomplishment 3
- Satisfaction that care and attention are received 4
- Being appreciated, or 5
- Fulfilling a duty 6
- None 7

CRB3. Now we would like to ask you about potential difficulties you may face in caring for the person you care for. Please respond to each of the following questions with one of the options provided. In your experience as a caregiver, how often do you feel that ...

| | <u>Always</u> | <u>Usually</u> | <u>Some- times</u> | <u>Rarely</u> | <u>Never</u> |
|--|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| a. Caregiving creates a financial burden for you | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| b. Caregiving does not leave you enough time for yourself..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| c. Caregiving does not leave enough time for your family..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| d. Caregiving interferes with your work | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| e. Caregiving negatively affects your health | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| f. Caregiving conflicts with your social life | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| g. Caregiving causes you stress..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

CRB4. What is the greatest difficulty you have faced in your caregiving? Check only one.

Would you say caregiving:

- 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 problems with your health..... 5
- Conflicts with your social life..... 6
- Creates stress..... 7

Module C: Impact on Employment

CRC1. Have you ever been employed?

Yes..... ₁
No..... ₂

→ Thank you.
This concludes
Module C.

CRC2. What is your current employment status? Are you ...

Working full time..... ₁
Working part time ₂
Retired..... ₃
Not working..... ₄

} GO TO CRC3

CRC2a. Did your caregiving responsibilities cause you to quit work or retire early?

Yes..... ₁
No..... ₂

→ Thank you.
This concludes
Module C.

CRC3. Has providing care for the person you care for ever interfered with your employment?

Yes..... ₁
No..... ₂

→ Thank you.
This concludes
Module C.

CRC4. Because of providing care for the person you care for, have you ...
Check all that apply.

- | | <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 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |
| j. Other | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 |

Describe: _____

Module D: Health of Caregiver

CRD1. 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
No..... 2

→ Thank you.
This concludes
Module D.

CRD1a. What is that problem, condition, or disability? Check all that apply.

- 1. Back problems and other joint problems/Arthritis 1
 - 2. Heart problems/High Blood Pressure/Hypertension/Stroke .. 2
 - 3. Diabetes 3
 - 4. Allergies/Asthma/Other breathing/Lung problems 4
 - 5. Mental health (anxiety, fear, depression,
emotional problems)..... 5
 - 6. Eye problems..... 6
 - 7. Other..... 91
- Describe: _____

CRD2. Have your caregiving activities created or worsened any of these conditions, problems, or disabilities?

Yes..... 1
No..... 2

Module E: Demographics

We are interested in knowing more about the demographic characteristics of our clients. We would appreciate if you would answer a few questions about yourself. All this information will be kept confidential.

CRE1. What is your sex?

- Male 1
Female 2

CRE2. In what year were you born?

|__|__|__|__| Year

CRE3. What is your highest education level?

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

CRE4. Are you Spanish, Hispanic, or Latino?

- Yes 1
No 2

CRE5. What is your race? Check all that apply.

- a. American Indian or Alaskan Native 1
b. Asian 2
c. Black or African-American 3
d. White/Caucasian 4
e. Native Hawaiian/Other Pacific Islander 5
f. Other race 6
Describe: _____

CRE6. What is your marital status?

- Now married..... 1
- Widowed 2
- Divorced 3
- Separated 4
- Never married 5

CRE7. Where is your home located? Would you say...

- In a city 1
- In a suburban area 2
- In a rural area 3

CRE8. How many people live in your household, including yourself?

|__|__| Number of Household Members

CRE9. How many persons total are you caring for, not counting the person you care for?

|__|__| Number of Persons

CRE10. Thinking about the total combined income from all sources for all persons in this household, was your total household annual income during the past year above or below \$20,000? (IF NEEDED: including income from jobs, Social Security, retirement income, public assistance, and all other sources)

- Below \$20,000..... 1 → GO TO CRE11
- Above \$20,000 2 → GO TO CRE12

CRE11. Which category best describes your total household annual income during the past year?

- \$10,000 or less..... 1
 - \$10,001 to \$15,000..... 2
 - \$15,001 to \$20,000..... 3
- } GO TO CRE13

CRE12. Which category best describes your total household annual income during the past year?

- \$20,001 to \$30,000..... 1
- \$30,001 to \$40,000..... 2
- \$40,001 to \$50,000..... 3
- Over \$50,000 4

CRE13. What is the sex of the person you care for?

- Male 1
- Female 2

CRE14. What is the age of the person you care for?

|__|__|__| Years

Module F: Health and Physical Functioning of the Person You Care For

CRF1. Does the person you care for have difficulty getting around inside the home?

Yes..... ₁
No..... ₂ → GO TO CRF2

CRF1a. Does the person you care for need the help of another person to perform this activity?

Yes ₁
No ₂

CRF2. Does the person you care for have difficulty going outside the home, for example to shop or visit a doctor's office?

Yes..... ₁
No..... ₂ → GO TO CRF3

CRF2a. Does the person you care for need the help of another person to perform this activity?

Yes ₁
No ₂

CRF3. Does the person you care for have difficulty getting in or out of bed or a chair?

Yes..... ₁
No..... ₂ → GO TO CRF4

CRF3a. Does the person you care for need the help of another person to perform this activity?

Yes ₁
No ₂

CRF4. Does the person you care for have difficulty when taking a bath or shower?

Yes..... ₁
No..... ₂ → GO TO CRF5

CRF4a. Does the person you care for need the help of another person to perform this activity?

Yes 1
No 2

CRF5. Does the person you care for have difficulty when dressing?

Yes 1
No 2 → GO TO CRF6

CRF5a. Does the person you care for need the help of another person to perform this activity?

Yes 1
No 2

CRF6. Does the person you care for have difficulty when walking?

Yes 1
No 2 → GO TO CRF7

CRF6a. Does the person you care for need the help of another person to perform this activity?

Yes 1
No 2

CRF7. Does the person you care for have difficulty eating?

Yes 1
No 2 → GO TO CRF8

CRF7a. Does the person you care for need the help of another person to perform this activity?

Yes 1
No 2

CRF8. Does the person you care for have difficulty using the toilet or getting to the toilet?

Yes..... ₁
No..... ₂ → GO TO CRF9

CRF8a. Does the person you care for need the help of another person to perform this activity?

Yes..... ₁
No..... ₂

CRF9. Does the person you care for have difficulty keeping track of money or bills?

Yes..... ₁
No..... ₂ → GO TO CRF10

CRF9a. Does the person you care for need the help of another person to perform this activity?

Yes..... ₁
No..... ₂

CRF10. Does the person you care for have difficulty preparing meals?

Yes..... ₁
No..... ₂ → GO TO CRF11

CRF10a. Does the person you care for need the help of another person to perform this activity?

Yes..... ₁
No..... ₂

CRF11. Does the person you care for have difficulty doing light housework, such as washing dishes or sweeping a floor?

Yes..... ₁
No..... ₂ → GO TO CRF12

CRF11a. Does the person you care for need the help of another person to perform this activity?

Yes 1
No 2

CRF12. Does the person you care for have difficulty doing heavy housework, such as scrubbing floors or washing windows?

Yes 1
No 2 → GO TO CRF13

CRF12a. Does the person you care for need the help of another person to perform this activity?

Yes 1
No 2

CRF13. Does the person you care for have difficulty taking the right amount of prescribed medicine at the right time?

Yes 1
No 2 → GO TO CRF14

CRF13a. Does the person you care for need the help of another person to perform this activity?

Yes 1
No 2

CRF14. Does the person you care for have difficulty using the telephone?

Yes 1
No 2 → GO TO CRF15

CRF14a. Does the person you care for need the help of another person to perform this activity?

Yes 1
No 2

CRF15. Does the person you care for have difficulty driving an automobile?

Yes 1
No 2

Module G: Service and Information Needs

The next two questions ask you to think about what additional services and information may be helpful to you as a caregiver.

CRG1. In addition to the kinds and amounts of services you are receiving, (and the services that the person you care for is receiving), what additional or new kinds of **help** would be valuable to you as a caregiver?

- | | <u>Yes</u> | <u>No</u> |
|--|---------------------------------------|---------------------------------------|
| a. Housekeeping assistance for the person you care for. | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| b. Shopping assistance for the person you care for | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| c. Transportation assistance for the person you care for .. | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| d. Assistance in making meals for the person you care for | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| e. Assistance in bathing, dressing, grooming, toileting, feeding, and other personal care for the person you care for..... | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| f. Adult daycare for the person you care for..... | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| g. Assistance in getting other family members involved in caring for the person you care for | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| h. Assistance in administering and monitoring side effects of medicine for the person you care for, etc. .. | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| i. In-home respite care | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| j. Help with money management and financial advice..... | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| k. Other services | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |

Describe: _____

- | | | |
|------------------------------------|---------------------------------------|---------------------------------------|
| l. No additional help needed | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
|------------------------------------|---------------------------------------|---------------------------------------|

CRG2. What additional or new kinds of **information** would be valuable to you as a caregiver? Check yes or no for each one.

- | | <u>Yes</u> | <u>No</u> |
|---|---------------------------------------|---------------------------------------|
| a. A help line/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/counseling services or support groups | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| c. Information about how to care for the condition or disability of the person you care for..... | <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. Information about how to select a nursing home, group home, assisted living facility, or other care facility | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| f. Information on how to pay for nursing homes, assisted living facilities, adult day care, and other services..... | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| g. Information on how to deal with agencies (bureaucracies) to get services | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| h. Information on health insurance and/or long-term care insurance | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| i. Other information not listed above | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| Describe: _____ _____ | | |
| j. No additional information needed | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |