

POMP 4 CAREGIVER SUPPORT AND SATISFACTION SURVEY MAIL SURVEY

April 21, 2003

Thank you for your participation in this very important study. The results will be used to better understand the needs of caregivers. All of your responses will be kept strictly confidential. No one's answers will be identified with their name, and your eligibility for service will in no way be affected by any answers you provide.

Please check the appropriate response category or write in your response where necessary.

What is today's date? ___/___/___ (month/day/year)

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

- Husband 1
- Wife 2
- Son 3
- Daughter 4
- Father 5
- Mother 6
- Brother 7
- Sister 8
- Other relative 9
- [Not a relative mentioned above]*
- (SPECIFY: _____)*
- Friend or neighbor 10
- Another person 11
- [Not a relative, friend, or neighbor]*
- (SPECIFY: _____)*

2) Do you live in the same house with the person you are providing care for?

- Yes (*Skip to Question 3*) 1
- No 2

2A) (**IF NO**) How far away do you live?

- Less than 20 minutes away 1
- Between 20 and 60 minutes away 2
- Between 1 and 2 hours away 3
- More than two hours away 4

Office Use Only:

1 of 14

Type of Administration [check]: Telephone Mail Interview Date: _____

Client ID: _____ Client Enrollment Date: _____ Caregiver ID: _____

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3) Below is a list of several activities that some people need help with. Please indicate if you have helped the person you are providing care for with any of these in the past month:
(**Check all that apply.**) Have you...

- A. Helped him/her dress, eat, bathe, or get to the bathroom? 1
- B. Helped with medical needs such as taking medicine or changing bandages? 1
- C. Helped him/her keep track of bills, checks, or other financial matters? 1
- D. Helped by preparing meals, doing laundry, or cleaning the house? 1
- E. Helped by taking him/her shopping or to the doctor's office? 1
- F. Helped to coordinate care or services 1
- G. Offered telephone reassurance or other regular contact 1
- OR -
- H. None of the above 1

IF "NONE OF THE ABOVE": What kind of care do you provide for the person you are providing care for? (*If you don't provide any kind of care for this person, write "NONE."*)

NOTE: IF YOU DON'T PROVIDE CARE OF ANY KIND FOR THIS PERSON, PLEASE DO NOT ANSWER ANY OTHER QUESTIONS.

PLEASE MAIL THIS QUESTIONNAIRE BACK TO [AGENCY NAME] IN THE ENVELOPE PROVIDED.

THANK YOU VERY MUCH FOR YOUR TIME AND COOPERATION.

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On this page are some questions about the services that you and/or the person you are providing care for are receiving from [AGENCY'S NAME] and/or other agencies. We are interested in your experiences with services during the last 6 months.

- *Please complete each row for each service type, before moving onto next row. Place a CHECKMARK (✓) in the appropriate box.*
- *Indicate if either you (the caregiver) or the person to whom you provide care (the client) received the indicated service. (Y = Yes, N= No, DK = Don't know)*
- *If YES, please answer Part B, "Who receives this service?" (CG = Caregiver)*
- *Follow with Part C, a rating of each service.*
- *Do this for each service type.*

A. Do you or the person you are providing care for receive the following service?				B. Who receives this service?			C. How would you rate the quality of this service?						
	Y	N	DK	Client	CG	Both	Excellent	Very Good	Good	Fair	Poor	DK	
4) In-Home Respite Care Services													
5) Adult Daycare (Center-provided daycare)													
6) Case Management													
7) Homemaker Service													
8) Home Health Aide													
9) Home Delivered Meals													
10) Chore Service													
11) Transportation Service (includes Assisted Transportation)													
12) Information about services													
13) Assistance with access to services													
14) Individual Caregiver Counseling													
15) Caregiver Training or Education													
16) Caregiver Support Groups													
17) Other services or assistance (not listed above)													
A. SPECIFY: _____													
B. SPECIFY: _____													

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18) In addition to the kinds or amounts of services that you and/or the person you are providing care for are now receiving, what additional or new kinds of **help** would be valuable to you as a caregiver? (*Read list and check all that apply.*)

- A. Help with housekeeping 1
- B. Help with shopping 1
- C. Help with transportation, getting places 1
- D. Help with making meals 1
- E. Help with bathing, dressing, grooming, toileting, feeding, other personal care 1
- F. Help with medicines (administering medicine, monitoring side effects, etc.)..... 1
- G. Help with getting other family members involved in caring for the person you are providing care for..... 1
- H. Financial support, tax break, stipend, government subsidy 1
- I. In-home respite care for the person you are providing care for..... 1
- J. Adult daycare for the person you are providing care for 1
- K. Money management assistance or financial advice 1
- L. Other (*SPECIFY:* _____) 1
- OR -
- M. No additional help needed 1

19) 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? (*Read list and check all that apply.*)

- A. A help line (or central place to call to find out what kind of help is available/where to get it) 1
- B. Someone to talk to/counseling services/support group 1
- C. Information about [CLIENTS' NAME]'s condition or disability 1
- D. Information about changes in laws that might affect your situation 1
- E. Help in understanding how to select a nursing home/group home/other care facility ... 1
- F. Help in understanding how to pay for nursing homes, adult day care, or other services 1
- G. Help in dealing with agencies (bureaucracies) to get services 1
- H. Other (*SPECIFY:* _____) 1
- OR -
- I. No additional information needed 1

Next, we'd like to ask you some overall questions about these services that you or the person you are providing care for are receiving from [AGENCY'S NAME] and/or other agencies.

20) Overall, how satisfied are you with the services that you and/or the person you are providing care for receives? Would you say...

- Very satisfied 1
- Somewhat satisfied 2
- Somewhat dissatisfied..... 3
- Very dissatisfied..... 4

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21) To what extent do the services that you and/or the person you are providing care for receive help you to be a better caregiver? Would you say ...

- They help a lot..... 1
- They help a little 2
- They don't help..... 3
- They make things worse 4

22) Have the services enabled you to provide care for this person for a longer time than would have been possible without these services? Would you say ...

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

23) How have the services that you have received – or that have been received by the person you are providing care for – affected you and your caregiving tasks?

Next, we are interested in your experiences as a caregiver for the person you are providing care for.

24) Do any agencies, family members or friends help you get time off or relief from the responsibility of caring for the person you are providing care for?

- Yes 1
- No (*Skip to Question 25*)..... 2

24A) About how many times per month does someone else take over for you?

|_|_|_| (number of times)

24B) When someone else takes over, about how many hours of time off do you usually get?

|_|_|_| (number of hours)

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24C) Is this enough relief for you?

- Yes (*Skip to Question 25*) 1
No..... 2

24D) How many more hours per month of time off or relief do you need?

|_|_| (number of hours per month)

25) How many other family members or friends provide unpaid care for the person you are providing care for?

|_|_| (number of family members) (*If zero, skip to Question 27*)

26) Thinking about all the family members or friends who provide unpaid care for the person you are providing care for, what proportion of the care do **you** provide? Would you say . . .

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

27) On a typical 24-hour **weekday**, how many hours do you provide care for the person you are providing care for in person? [*Weekdays are Monday through Friday*]

|_|_| (number of hours/day)

28) On a typical 24-hour **weekend day**, how many hours do you provide care for the person you are providing care for in person? [*Weekend days are Saturday and Sunday*]

|_|_| (number of hours/day)

29) What is your current employment status?

- Working full time (*Skip to Question 31*)..... 1
Working part time (*Skip to Question 31*)..... 2
Retired 3
Not working 4

30) Were you working when you started providing care for the person you are providing care for?

- Yes 1
No (*Skip to Question 32*)..... 2

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31) Because of providing care for the person you are caring for, have you:
(Check **YES** or **NO**.)

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

K1. (IF K is YES:)

How many hours of work did you miss last month?

|_|_|_| (number of hours missed last month)

- L. Has caring for the person you are providing care for affected your work in any other way? 1 2

L1. **(IF L is YES:)** How has caring for the person you are providing care for affected your work?

- OR -

- M. None of the above 1 2

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Please indicate how frequently each of the following happens. Please select one of these six responses: (1) Always or Nearly Always, (2) Quite Frequently, (3) Sometimes, (4) Rarely, (5) Never, or (6) Not Applicable N/A.

	Always or Nearly Always	Quite Frequently	Some- times	Rarely	Never	N/A
32) How often does being a caregiver for this person provide companionship for you? Would you say...	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
33) 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	<input type="checkbox"/> 6
34) How often does providing care for the person you are providing 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"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
35) As a caregiver, how often do you feel that you are helping your family by caring for the person you are providing care for? Would you say ...	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
36) How often do you feel that the person you are providing 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	<input type="checkbox"/> 6
37) Does providing care for the person you are caring for have any other positive benefits or rewards for you?						
Yes						<input type="checkbox"/> 1
No						<input type="checkbox"/> 2

37A) (**IF YES**) Please describe:

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38) In your experience as a caregiver, what would you say is the most positive aspect of caregiving? (*Check only one.*) Would you say ...

- Companionship 1
- A sense of accomplishment..... 2
- Caring for someone who cared for you..... 3
- Helping your family 4
- Being appreciated..... 5
- Other (*SPECIFY:* _____)..... 6
- None 7

Please indicate how frequently each of the following happens: Please select one of these six responses: (1) Always or Nearly Always, (2) Quite Frequently, (3) Sometimes, (4) Rarely, (5) Never, or (6) Not Applicable.

	Always or Nearly Always	Quite Frequently	Some- times	Rarely	Never	N/A
39) How often does providing care for the person you are providing care for create a financial burden for you? Would you say...	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
40) How often does caregiving leave you with not enough time for yourself?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
41) How often does caregiving leave you with not enough time for the rest of your family (or your family)?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
42) If you are working , how often does caring for the person you are providing care for interfere with your work?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
43) How often does caring for the person you are providing care for affect your relationships with the rest of your family (or your family) in a negative way? Would you say ...	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
44) How often does caregiving interfere with your personal needs for privacy?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
45) How often does caregiving create problems in your social life?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
46) How often does caregiving create stress for you?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

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47) Does providing care for the person you are caring for have any other negative effects or burdens for you?

- Yes 1
No 2

47A) (**IF YES**) Please describe:

48) Which of the following has been the biggest difficulty you have faced in caring for the person you are providing care for? (**Check only one.**)

- The financial burden 1
Not enough time for yourself 2
Not enough time for your family 3
Interferes with your work..... 4
Affects your family relationships..... 5
Interferes with your privacy..... 6
Conflicts with your social life 7
Creates stress..... 8
Other (**SPECIFY:** _____)..... 9
None 10

Next, we would like to ask you some background questions.

49) Are there any other persons for whom you provide care, such as children, parents, etc.?

- Yes 1
No (**Skip to Question 52**)..... 2

50) (**IF YES**) Who are those people? (**Check all that apply**)

- A. Husband or wife 1
B. Son(s) or daughter(s) 1
C. Father 1
D. Mother 1
E. Brother(s) or sister(s)..... 1
F. Grandson(s) or granddaughter(s) 1
G. Other relative(s) not mentioned above..... 1
H. Friend(s) or neighbor(s) 1
I. Other persons not mentioned above (**SPECIFY:** _____) 1

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51) Not counting the person you are providing care for, how many other persons are you caring for?

|_|_| (number)

52) 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 are providing care for?

Yes 1
No (*Skip to Question 54*)..... 2

52A) (*IF YES*) What is that problem, condition, or disability?

53) Have your caregiving activities created or worsened any of these problems, conditions, or disabilities?

Yes 1
No (*Skip to Question 54*)..... 2

53A) (*IF YES*) How have your caregiving activities created or worsened these problems, conditions, or disabilities?

54) How long have you been caring for the person you are providing care for?

|_|_| Months |_|_| Years

55) What is the age of the person you are providing care for?

|_|_|_| Years

56) What is the gender of the person you are providing care for?

Male 1
Female 2

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DEMOGRAPHIC INFORMATION

Finally, could you please tell us a bit about yourself? Like all of your other answers, all of this information will be kept **strictly confidential**.

D1) What is your gender?

- Male 1
Female 2

D2) What is your age?

|_|_|_| (years)

D3) What is your highest educational 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

D4) Are you Spanish, Hispanic, or Latino?

- Yes 1
No 2

D5) What is your race? (*Check all that apply.*)

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

D6) Where is your home located?

- In a City 1
In a Suburban area 2
In a Rural area 3

D7) What is your home zip code? |_|_|_|_|_|

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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
No (*Skip to Question D11*)..... 2

D9) Do you . . .

YES NO

- A. Live with your spouse? 1 2
B. Live with your children? 1 2
C. Live with other relatives? 1 2
D. Live with non relatives? 1 2

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

D11) What is your marital status?

- Now married 1
Widowed 2
Divorced 3
Separated 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 during the year 2002 above or below \$20,000?

- Below \$20,000 [*Go to Question D13*]..... 1
Above \$20,000 [*Skip to Question D14*]..... 2

[Include income from jobs, Social Security, retirement income, public assistance, and all other sources.]

D13) Which category best describes your total household annual income during the year 2002?

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

[SKIP TO END OF THE QUESTIONNAIRE]

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D14) Which category best describes your total household annual income during the year 2002?

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

PLEASE MAIL THIS QUESTIONNAIRE BACK TO [AGENCY NAME] IN THE ENVELOPE PROVIDED.

Thank you very much for your time and cooperation. Your responses will be very helpful to us.