

FAMILY CAREGIVER SURVEY

Have you been a family caregiver?
Are you currently caring for a family member or friend?
Will you have caregiving responsibilities in the future?

We want to hear from YOU!
We need to hear from YOU!

**Please take a moment and complete this questionnaire
and return it to us.**

Sponsored by
Central Coast Commission for
Senior Citizens,
Area Agency on Aging

August- September 2004

Central Coast Commission for Senior Citizens
Area Agency on Aging
528 S. Broadway, Santa Maria, CA 93454
805.925.9554 Phone
email seniors@KCBX.net

We are interested in learning about the recent, current and future caregiving responsibilities of people in our community. Family caregivers are an important component in the ability of older persons to maintain their independence and live in their home and community. Even if you have no caretaking responsibilities for an older adult over the age of 60 at this time, we would like your help in planning programs to make the lives of current and future caregivers easier. We are seeking your input; so PLEASE take a few minutes to complete and return this survey.

SECTION I ABOUT YOUPage 3

Please tell us a little about yourself whether or not you currently have caregiving responsibilities.

SECTION II ADULT AND OLDER ADULT CAREGIVER NEEDSPage 4

Complete Section II if you provide care or supervision for one or more adults aged 18-59 with a health problem or disability or any adult age 60 or older.

This survey will be analyzed to develop a snapshot view of the caregiver needs within the two-county area of San Luis Obispo and Santa Barbara Counties. With this survey we will be attempting to identify the needs of caregivers including, but not limited to:

- Information about available services.
- Assistance in gaining access to supportive services.
- Individual counseling, support groups, and/or caregiver training.
- Respite care to provide relief from caregiving responsibilities.

All individual responses are anonymous and will be kept strictly confidential.

Please return your completed questionnaire by September 15, 2004 to: Area Agency On Aging, 528 South Broadway, Santa Maria, CA 93454. If you have any questions, please feel free to contact us. Thank you for your time and cooperation.

Leon Mountain, President
Board of Directors

Colleen McLean, Chair
AAA Advisory Council

joyce ellen lippman
Area Agency on Aging Director
805.925.9554, seniors@KCBX.net

SECTION 1: ABOUT YOU

1. Your gender: _____ Male _____ Female
2. Your age: _____ Less than 30 _____ 30-39
 _____ 40 – 49 _____ 50-59
 _____ 60 – 69 _____ 70 or older
3. Your race/ethnicity: *(Please check all that apply.)*
 _____ White (not of Hispanic origin)
 _____ Hispanic/Latino
 _____ African American/Black
 _____ Asian/Pacific Islander
 _____ American Indian/Alaskan Native
 _____ Other (specify) _____
4. Your marital status: *(Please check one.)*
 _____ Married/living with partner
 _____ Divorced/separated
 _____ Widowed
 _____ Single (never married)
5. Your total annual household income: *(Please check one.)*
 _____ Under \$25,000
 _____ \$25,000 - \$50,000
 _____ \$50,001- \$100,000
 _____ Over \$100,000
6. What town or city do you live in? _____
7. What is your current zip code? _____
8. Do you currently, or have you in the past, cared for an adult family member or friend with a health problem or disability or any adult age 60 or over? *(Please check all that apply.)*
 _____ Adult(s) aged 18-59
 _____ Adult(s) age 60 or older
 _____ I have not cared for an adult with a health problem or disability or an older adult.
9. Do you anticipate needing to care for an adult family member or friend with a health problem or disability or any adult age 60 or older in the NEXT FIVE YEARS? _____ Yes
 _____ No
10. How many adults do you anticipate providing care for in the future? _____ # of adults

PLEASE READ

If you have cared for any adult age 18 or older with a health problem or disability or any adult age 60 or older, proceed to Question 11 and tell us about the adults you cared for. Otherwise, go to Question 28 on the last page of this survey.

SECTION II. ADULT AND OLDER ADULT CAREGIVER NEEDS

11. How many adult family members or friends with a health problem or disability or adults age 60 or over do you (or have you) provided care for? _____ # of adults
12. How are these persons related to you? *(Please check all that apply.)*
- _____ Spouse/partner
 _____ Mother or father
 _____ Mother-in-law or father-in-law
 _____ Grandparent
 _____ Son or daughter (over age 18)
 _____ Other relative
 _____ Friend or neighbor
 _____ Other (*specify*) _____
13. Do any of these persons live in San Luis Obispo County? _____ Yes _____ No
 Do any of these persons live in Santa Barbara County? _____ Yes _____ No
14. Do any of these persons live with you? _____ Yes _____ No
15. What kind of assistance do you provide? *(Please check all that apply.)*
- _____ Cooking, laundry or house cleaning
 _____ Home Maintenance or repair
 _____ Transportation
 _____ Interpreter
 _____ Feeding, bathing toileting, dressing or grooming
 _____ Assistance with transferring
 _____ Administering medications
 _____ Managing the person's financial affairs
 _____ Direct financial support
 _____ Providing emotional reassurance
 _____ Arranging and monitoring outside help or services
 _____ Other (*specify*) _____
-
16. Overall, approximately how many hours do you spend caregiving or supervising this person(s) in a typical week? *(Please check one.)*
- _____ None
 _____ 1-4 hours/week
 _____ 5-9 hours/week
 _____ 10-19 hours/week
 _____ 20-29 hours/week
 _____ 30-39 hours/week
 _____ 40 + hours/week
 _____ Full Time
17. Overall, how much money do you spend caregiving or supervising this person(s) in a typical month? *(Please check one.)*
- _____ None
 _____ Less than \$100/mo.
 _____ \$100-\$249/mo.
 _____ \$250-\$499/mo.
 _____ \$500-\$999/mo.
 _____ \$1000-\$1499/mo.
 _____ \$1500+ per mo.

18. Which of these problems have you experienced as a result of your caregiving responsibilities? (*Please rate each problem as a major problem, a minor problem, or no problem.*)

	<u>Major Problem</u>	<u>Minor Problem</u>	<u>No Problem Not Applicable</u>
a. Finding trained & reliable home care providers	_____	_____	_____
b. Finding affordable residential care	_____	_____	_____
c. Finding services	_____	_____	_____
d. Having enough money to pay for care	_____	_____	_____
e. Understanding government programs such as Medicare, SSI or In-Home Supportive Services (IHSS)	_____	_____	_____
f. Finding out about legal options	_____	_____	_____
g. Getting cooperation & assistance from other family members	_____	_____	_____
h. Dealing with a break down in care arrangements	_____	_____	_____
i. Getting information about the illness/ disability of the person(s) I care for	_____	_____	_____
j. Ensuring the care recipient's safety	_____	_____	_____
k. Identifying available transportation resources	_____	_____	_____
l. Finding culturally-sensitive resources	_____	_____	_____
m. Communicating with professional resource providers	_____	_____	_____
n. Doing end-of-life planning	_____	_____	_____
o. Balancing other family responsibilities, i.e., children	_____	_____	_____
p. Dealing with dangerous, unwanted, or difficult behaviors of the care recipient	_____	_____	_____
q. Involvement in decisions about the care recipient's medical treatment	_____	_____	_____
r. Modifying my home to meet care requirements	_____	_____	_____
s. Adjusting my work schedule, meeting my work responsibilities.	_____	_____	_____
t. Meeting my personal needs such as personal time, exercise.	_____	_____	_____

19. To what extent do you experience the following problems as a result of your caregiving responsibilities? (*Please rate the extent of each problem as not at all, some, quite a bit, or a great deal.*)

	<u>Not at all</u>	<u>Some</u>	<u>Quite a bit</u>	<u>A great deal</u>
a. Physical strain/fatigue	_____	_____	_____	_____
b. Financial strain	_____	_____	_____	_____
c. Emotional upset, guilt	_____	_____	_____	_____
d. Interference w/social life	_____	_____	_____	_____
e. Interference w/family relationships	_____	_____	_____	_____
f. Interference w/free time	_____	_____	_____	_____
g. Interference w/work	_____	_____	_____	_____
h. Physical health changes	_____	_____	_____	_____
i. Reluctance to ask for help	_____	_____	_____	_____
j. Unappreciated	_____	_____	_____	_____

k. Other(*specify*) _____

20. To what extent do you agree/disagree with the following statements? (*Please rate whether you strongly agree, somewhat agree, somewhat disagree, or strongly disagree with each statement.*)

	Strongly <u>Agree</u>	Somewhat <u>Agree</u>	Somewhat <u>Disagree</u>	Strongly <u>Disagree</u>
a. I have more caregiving responsibilities than I can handle comfortably.	_____	_____	_____	_____
b. I don't have enough time for myself due to my caregiving responsibilities.	_____	_____	_____	_____
c. I cannot get a restful nights sleep.	_____	_____	_____	_____
d. I have a good balance between work, family & personal responsibilities.	_____	_____	_____	_____
e. I am doing a good job of meeting work, family & personal responsibilities.	_____	_____	_____	_____
f. I feel in control of the important things in my life.	_____	_____	_____	_____
g. I feel confident in my ability to handle my personal problems.	_____	_____	_____	_____
h. I feel that difficulties are piling up so high that I cannot overcome them.	_____	_____	_____	_____
i. Other (<i>specify</i>)	_____	_____	_____	_____

21. Approximately how many full or partial scheduled workdays did you miss during the past 12 months due to your caregiving responsibilities? (*Please check one.*)
- Zero
 1-4
 5-9
 Over 9
 Not Applicable
 Retired
- If not applicable, please proceed to Question 24.

22. During the past 12 months, have you considered a reduced work schedule because of your caregiving responsibilities? Yes No

23. During the past 12 months, have you considered taking early retirement as a result of your caregiving responsibilities: Yes No

24. Do you have the help you need:
- | | | | | |
|---------------------------|-------|-----|-------|----|
| a. In the morning? | _____ | Yes | _____ | No |
| b. In the afternoon? | _____ | Yes | _____ | No |
| c. In the evening? | _____ | Yes | _____ | No |
| d. At night? | _____ | Yes | _____ | No |
| e. On weekends/holidays? | _____ | Yes | _____ | No |
| f. In a crisis situation? | _____ | Yes | _____ | No |

25. Which of the following resources do you currently use, or would you find useful if they were available? (Please check all that apply.)

	Currently <u>Use</u>	Would <u>Use</u>
a. Workshops/seminars on adult care issues	_____	_____
b. Brochures, pamphlets, or other written information	_____	_____
c. Internet references on caregiving	_____	_____
d. Caregiver support group/counseling	_____	_____
e. Help locating services	_____	_____
f. Legal consultation	_____	_____
g. Mediation services to aid in caregiver family disputes	_____	_____
h. Equipment/home adaptation	_____	_____
i. Help in determining long term care options	_____	_____
j. Help with admitting care recipient to long term care facility	_____	_____
k. Social support following the death of the care recipient	_____	_____
l. Other (<i>List below.</i>)	_____	_____

26. Which of the following work-related benefits do you currently use, or would you find useful if they were available (Please check all that apply.)

	Currently <u>Use</u>	Would <u>Use</u>
a. Ability to adjust work schedule to fit care responsibilities	_____	_____
b. Ability to work at home	_____	_____
c. Part-time work or job sharing	_____	_____
d. Ability to use accrued sick leave to help an ill family member	_____	_____
e. Ability to take up to 12 weeks unpaid leave w/out loss of benefits, to care for an ill family member	_____	_____
f. Ability to use sick/vacation time donated by other employees	_____	_____
g. Dependent care assistance account (tax deductions for adult care expenses)	_____	_____
h. Long term care insurance to cover family members	_____	_____
i. Health coverage for domestic partners	_____	_____
j. Flexible "cafeteria style" benefit plan that allows use of benefit dollars for adult care expenses.	_____	_____
k. Employee Assistance Program (EAP)	_____	_____
l. Adult day care center at work	_____	_____
m. Subsidized respite care	_____	_____
n. Health promotion activities such as exercise	_____	_____
o. Other (<i>specify</i>)	_____	_____

27. What community and/or in home services do you currently use, have used or would you find helpful if they were available. (Please check all that apply)

	<u>Have used</u>	Currently <u>Use</u>	Would <u>Use</u> *
a. Adult Day Care	_____	_____	_____
b. Adult Protective Services	_____	_____	_____
c. Care Management	_____	_____	_____
d. Chores or heavy housekeeping	_____	_____	_____
e. Counseling	_____	_____	_____

- f. Education/ training _____
- g. Employee Assistance Program (EAP) _____
- h. Financial Assistance (rental help, tax relief) _____
- i. Form completion / letter writing _____
- j. Home Health Care _____
- k. Home Delivered Meals _____
- l. Home Repair services _____
- m. Hospice _____
- n. Health promotion, e.g. exercise _____
- o. Home security, e.g. emergency alert _____
- p. Housekeeping _____
- q. Information Service _____
- r. In Home visiting _____
- s. In Home Services/ Respite Registry _____
- t. Legal services _____
- u. Money Management _____
- v. Nutrition education/ counseling _____
- w. Placement Assistance _____
- x. Personal Care, e.g. bathing _____
- y. Respite Care _____
- z. Shopping assistance _____
- aa. Support groups _____
- bb. Translation services (bilingual services) _____
- cc. Transportation/ escort _____
- o. Other (*specify*) _____

*Assume the service was available at either an 'affordable' cost or by donation.

If you need information about available senior services, call the Area Agency on Aging at 965-3288, 925-9554, 541-0384 or 1-800-510-2020.

28. Please provide any additional comments you might have about your past, present, and anticipated caregiver needs.

<p>Thank you very much for completing this survey! Please return the completed form by September 15, 2004, to 528 So. Broadway, Santa Maria, CA 93454 For information call joyce ellen lippman at 925.9554</p>
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