

Family Caregiver Survey

Have you been a family caregiver age 60 or over?

Are you currently caring for a family member or friend age 60 or over?

Do you plan to care for a family member or friend in the future
age 60 or over?

We want to hear from YOU!

We need to hear from YOU!

Please take a few moments to complete this questionnaire
and return it to us as soon as possible.



Co-sponsored by:

Active Seniors' Options

Illiana Alzheimer's Foundation

Health Professions Institute, DACC

Department of Family Medicine, UIUC

Dr. William Gingold

Survey Facilitator

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PURPOSE

We are interested in learning about past, 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 and services 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.

INSTRUCTIONS

Please provide the best answer to the questions presented in the survey.

Section I ABOUT YOU.....Page 3
Please tell us a little about yourself and your current or future caregiving responsibilities.

Section II CAREGIVER STATUS.....Page 3
Please share with us your current or future caregiver status.

Section III CAREGIVER RESPONSIBILITIES.....Page 4
Please share with us your current duties and responsibilities

Section IV CAREGIVER RESOURCES.....Page 7
Please share with us the resources you currently use, would use or would like to know more about.

This survey will be analyzed to develop a snapshot view of the needs of caregivers. With this survey we propose 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 caregiving information meetings
- Respite care to provide relief from caregiving responsibilities

All individual responses will be kept strictly confidential.

Please return your completed questionnaire to:

Active Seniors’ Options
2404 Windsor Place, Suite B
Champaign, IL 61820

If you have any questions, please feel free to contact:

Dr. William Gingold
Survey Facilitator
Telephone: (217) 265-0876
Email: wgingold@illinois.edu

Section I: 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 (check all that apply).
 White (non-hispanic origin)
 Hispanic/Latino
 African/American Black
 Asian/Pacific Islander
 American Indian/Alaskan Native
 Other (specify) _____

4. Your marital status:
 Married/living with partner
 Divorced/separated
 Widowed
 Single (never married)

5. Your total annual 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? _____

Section II: Caregiver Status

8. What is your current caregiver situation?
 Anticipate future caregiving
 Family caregiver
 Professional caregiver
 Both family and professional
 Distant family or friend caregiver
 Past caregiver

9. Do you currently care for a family member or friend with a health problem or disability for any adult age 60 or over? (Please check all that apply).
 Yes
 No

10. How many adults aged 60 or over are you currently providing care?
 One
 Two
 More than two

11. Do you anticipate caring for a family member or friend with a health problem or disability for any adult age 60 or over within the NEXT FIVE YEARS?
- Yes
 - No
12. How many adults aged 60 or over do you anticipate providing care for in the future?
- One
 - Two
 - More than two
13. How are the people you are caring or plan to care for in the future related to you? (Please check all that apply.)
- Spouse/partner
 - Mother or father
 - Mother-in-law or father-in-law
 - Grandparent
 - Son or daughter
 - Other relative
 - Friend or neighbor
 - Other (specify) _____
14. Do any of these persons live in Illinois?
- Yes
 - No
15. Which of the following statements best describes your care recipient's memory?
- No memory problem
 - Memory or cognitive issue suspected
 - Probable Alzheimer's Disease or other dementia, but is not medically diagnosed
 - Yes, Alzheimer's Disease or other dementia has been diagnosed
16. Do you anticipate moving your care recipient to a long-term care facility in the future?
- Yes
 - No
17. If yes to question 16, how soon do you anticipate moving care recipient to a long-term care facility?
- Six months
 - One year
 - Not sure

Section III: Caregiver Responsibilities

18. What kind of assistance do you provide to care recipient(s)? (Please check all that apply.)
- Cooking, laundry or house cleaning, shopping
 - Home maintenance or repair
 - Transportation
 - Interpreter
 - Feeding, bathing, toileting, dressing, grooming
 - Assistance with transferring
 - Administering medications
 - Managing personal financial affairs
 - Direct financial support
 - Providing emotional reassurance
 - Arranging and monitoring outside help or services
 - Other (specify) _____

19. Overall, approximately how many hours do you spend caregiving in a typical week?
(This question also applies to distant caregivers.)
- None 21-30 hours per week
 1-10 hours per week 31-40 hours per week
 11-20 hours per week More than 40 hours per week
20. Overall, how much of your personal funds do you spend caregiving in a typical month? (Please check one.)
- None \$500-\$999
 Less than \$100 \$1,000-\$1,499
 \$100-\$249 More than \$1,500
 \$250-\$499
21. Which of these problems have you experienced as a result of your caregiving responsibilities? (Please rate each problem as either a major, minor, no problem or if the problem is not applicable to you.)

	Major Problem	Minor Problem	No Problem	Not Applicable
a. Finding trained and reliable home health or care providers	0	0	0	0
b. Finding affordable residential care	0	0	0	0
c. Finding services	0	0	0	0
d. Having enough money for care	0	0	0	0
e. Understanding government programs (Medicare, Medicaid, SSI etc.)	0	0	0	0
f. Finding out about legal options	0	0	0	0
g. Getting cooperation and assistance from family members	0	0	0	0
h. Dealing with the breakdown in care arrangements	0	0	0	0
i. Getting information about diagnosis of care recipient	0	0	0	0
j. Ensuring the care recipient's safety	0	0	0	0
k. Identifying available transportation resources	0	0	0	0
l. Finding culturally-sensitive resources	0	0	0	0
m. Communicating with professional resource providers	0	0	0	0
n. Doing end-of-life planning	0	0	0	0
o. Balancing family responsibilities (i.e., children)	0	0	0	0
p. Dealing with dangerous, unwanted or difficult behaviors	0	0	0	0
q. Involvement in decisions about care recipients medical treatment	0	0	0	0
r. Modifying my home to meet care requirements	0	0	0	0
s. Adjusting my work schedule, meeting work responsibilities	0	0	0	0
t. Meeting my personal needs such as personal time, exercise	0	0	0	0
u. Other (specify)	0	0	0	0

22. 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.**)

	Not At All	Some	Quite A Bit	A Great Deal
a. Physical strain/fatigue	0	0	0	0
b. Financial strain	0	0	0	0
c. Emotional upset, guilt	0	0	0	0
d. Interference with social life	0	0	0	0
e. Interference with family relationships	0	0	0	0
f. Interference with free time	0	0	0	0
g. Interference with work	0	0	0	0
h. Physical health changes	0	0	0	0
i. Reluctance to ask for help	0	0	0	0
j. Unappreciated	0	0	0	0
k. Conflict with care recipient	0	0	0	0
l. Feelings of hopelessness	0	0	0	0
m. Unreasonable requests from care recipient	0	0	0	0
o. Other (specify)	0	0	0	0

23. 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 Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree
a. I have more caregiving responsibilities than I can handle comfortably.	0	0	0	0
b. I don't have enough time for myself due to my caregiving responsibilities.	0	0	0	0
c. I cannot get a restful night's sleep.	0	0	0	0
d. I have a good balance between work, family and personal responsibilities.	0	0	0	0
e. I am doing a good job of meeting work, family and personal responsibilities.	0	0	0	0
f. I feel in control of the important things in my life.	0	0	0	0
g. I feel confident in my ability to handle my personal problems.	0	0	0	0
h. I feel that difficulties are piling up so high that I cannot overcome them	0	0	0	0
i. I feel that my caregiving responsibilities have given my life more meaning.	0	0	0	0
j. Other (specify)	0	0	0	0

24. Approximately how many workdays did you miss during the past 12 months due to your caregiving responsibilities? (Please check one.)

- None
 Over 9
 1-4
 Not applicable
 5-9
 Retired

25. During the past 12 months, have you considered a reduced work schedule because of your caregiving responsibilities?

- Yes
- No

26. During the past 12 months, have you considered taking early retirement as a result of your caregiving responsibilities?

- Yes
- No

27. Do you have adequate help with your caregiving?

	Yes	No
a. In the morning?	<input type="radio"/>	<input type="radio"/>
b. In the afternoon?	<input type="radio"/>	<input type="radio"/>
c. In the evening?	<input type="radio"/>	<input type="radio"/>
d. Overnight?	<input type="radio"/>	<input type="radio"/>
e. Weekends/holidays?	<input type="radio"/>	<input type="radio"/>
f. Crisis situations?	<input type="radio"/>	<input type="radio"/>

Section IV: Caregiver Resources

29. Are you aware of the services available in your area to assist you in your caregiving duties?

- Yes
- No

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

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

30. 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 Use	Would Use
a. Ability to adjust work schedules to fit care responsibilities	0	0
b. Ability to work at home	0	0
c. Part-time work or job sharing	0	0
d. Ability to use accrued sick leave to help an ill family member	0	0
e. Ability to take up to 12 weeks unpaid leave without loss of benefits, to care for an family member	0	0
f. Ability to use sick/vacation time donated by other employees	0	0
g. Dependent care assistance account (tax deductions for adult care expenses)	0	0
h. Long-term care insurance to cover family members	0	0
i. Health coverage for domestic partners	0	0
j. Flexible "cafeteria style" benefit plan that allows use of benefit dollars for adult care expenses	0	0
k. Employee Assistance Program (EAP)	0	0
l. Adult day care center at work	0	0
m. Subsidized respite care	0	0
n. Health promotion activities such as exercise	0	0
o. Other (specify)	0	0

31. Would you be interested in receiving the opportunity to attend informational meetings relative to caregiver issues? If so, please list the **top three (3) issues of priority** in your life that you would like to learn more about.

	Priority
a. Finding trained and reliable home health providers	
b. Finding affordable residential care	
c. Finding services	
d. Having enough money for care	
e. Understanding government programs (Medicare, Medicaid, SSI etc.)	
f. Finding out about legal options	
g. Getting cooperation and assistance from family members	
h. Dealing with the breakdown in care arrangements	
i. Getting information about diagnosis of care recipient	
j. Ensuring the care recipients 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 family responsibilities (i.e., children)	
p. Dealing with dangerous, unwanted or difficult behaviors	
q. Involvement in decisions about care recipients medical treatment	
r. Modifying my home to meet care requirements	
s. Adjusting my work schedule, meeting work responsibilities	
t. Meeting my personal needs such as personal time, exercise	
u. Other	

32. What community and/or in-home services do you currently use, have used or would use if the services were available? (Please check all that apply.) (If you specify “would use”, assume that the service is available at either “affordable” cost or by donation.)

	Have Used	Currently Use	Would Use
a. Adult day care	0	0	0
b. Adult protective services	0	0	0
c. Care management	0	0	0
d. Chores or heavy housekeeping	0	0	0
e. Counseling	0	0	0
f. Education/training	0	0	0
g. Employee Assistance Program (EAP)	0	0	0
h. Financial assistance (rental help, tax relief)	0	0	0
i. Form completion/letter writing	0	0	0
j. Home health care	0	0	0
k. Home delivered meals	0	0	0
l. Home repair services	0	0	0
m. Hospice	0	0	0
n. Health promotion (e.g., exercise, nutrition)	0	0	0
o. Home security (e.g., emergency alert)	0	0	0
p. Housekeeping	0	0	0
q. Information service	0	0	0
r. In-home visiting	0	0	0
s. In-home services/respite registry	0	0	0
t. Legal services	0	0	0
u. Money management	0	0	0
v. Nutrition education/counseling	0	0	0
w. Placement assistance	0	0	0
x. Personal care (e.g., bathing)	0	0	0
y. Respite care	0	0	0
z. Shopping assistance	0	0	0
aa. Support groups	0	0	0
bb. Translation services (bilingual services)	0	0	0
cc. Transportation escort	0	0	0
dd. Other (specify)	0	0	0

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

Thank you very much for completing this survey!