New York State Office for the Aging

2008 Caregiver Survey

We care, because you care.

David A. Paterson
Governor

Michael J. Burgess
Director

Welcome

The New York State Office for the Aging is conducting this survey to find out how we can provide better support and services to caregivers like yourself. Our records show that you have received services from your local Office for the Aging so that you could take better care of an older person. We would like to know if these services have been helpful to you and how they can be improved.

Over 2 million people are providing caregiver services across New York State. By participating in this survey, you will help yourself and many others obtain the support you need and deserve. Even if you are no longer a caregiver, your experience and opinions will help the many current and future caregivers.

We know that time is a precious commodity for you. We have designed this survey to be as concise and brief as possible so as not to use any more of your time than is necessary. We appreciate your taking the time to share your valuable experience and help your fellow caregivers.

Before you begin, we want you to know that:

- Your participation is voluntary.
- Your participation is very important to the success of the survey's purpose and to providing services for caregivers like yourself.
- Your answers will be kept confidential to the full extent of the law and will be used only for this study.
- Your eligibility for services **will not** be affected by
  (1) whether you decide to participate in this survey, or not,
  (2) any answers you give, or
  (3) anything related to this survey. This survey's sole purpose is to assist us in helping caregivers.

Please note that throughout this survey, *you* will be referred to as the ***CAREGIVER.*** That means that you are a family member, friend, or neighbor who helps care for an older individual or a person with a chronic illness or disability who is in need of assistance or supervision.

The older *person for whom you provide care* will be referred to in this survey as the ***CARE RECEIVER.***

Thank you in advance for participating in this survey and for choosing to help your fellow caregivers.

Michael J. Burger

Director
New York State Office for the Aging

D11. Does your care receiver live with you?

Yes ☐ 1
No ☐ 2

D12. Which best describes your total gross household annual income (including jobs, social security, retirement income, public assistance and the income of everyone who lives with you) for the past 12 months? Would you say…

$5,000 or less	☐ 1
$5,001 - $10,000	☐ 2
$10,001 - $20,000	☐ 3
$20,001 - $30,000	☐ 4
$30,001 - $40,000	☐ 5
$40,001 - $50,000	☐ 6
$50,001 - $75,000	☐ 7
Over $75,000	☐ 8
Don't know	☐ -8

Thank you very much for taking the time to fill out this survey so that we may better serve you and other care givers across New York State. If you would like us to send you information designed to assist caregivers, please fill out the form below and we will send it to you. If you wish to remain anonymous, you can also obtain the information by calling our Help Line at 1-800-342-9871.

Yes, I would like to obtain information on care giving:

First Name _____ Last Name _____

Mailing Address _____

City _____ State _____ Zip Code _____

D9. How many people live in your household, including yourself?

Number of household members |__|__|

Don't know ☐ -8

D10. What is your care receiver's relationship to you? Check only one - the one to whom you provide the most care.

She/he is your…

Husband	☐ 1
Wife	☐ 2
Domestic partner	☐ 3
Father (including step father)	☐ 4
Mother (including step mother)	☐ 5
Grandfather (including step grandfather)	☐ 6
Grandmother (including step grandmother)	☐ 7
Brother (including step brother)	☐ 8
Sister (including step sister)	☐ 9
Uncle (including step uncle)	☐ 10
Aunt (including step aunt)	☐ 11
Son (including step son)	☐ 12
Son-in-Law (including step son-in-law)	☐ 13
Daughter (including step daughter)	☐ 14
Daughter-in-Law (inc. stepdaughter-in-law)	☐ 15
Other relative (not mentioned above)	☐ 16
Friend, neighbor or another person	☐ 17
Don't know	☐ -8

2008 Caregiver Support Program Survey

You may be a Caregiver for more than one person. Please answer these questions based on your experience with the person for whom you provide the most care.

Note: Disregard the small numbers that appear next to the boxes that you check (for example, "No ☐ 2"). Those numbers only appear to help us tabulate your answers; they do not represent point values or have any other purpose.

1A. Are you currently caring for someone 60 years of age or older?

Yes ☐ 1 (if you checked "Yes," please go straight to question #2 below)

No ☐ 2 (if you checked "No," continue with question #1B below)

1B. If you checked "No," what happened that changed your caregiving situation? Check all that apply.

a. My care receiver was placed in a nursing home	☐ 1
b. My care receiver was placed in an assisted living facility	☐ 1
c. My care receiver was placed in a family type group home (family care home)	☐ 1
d. My care receiver is getting help temporarily from a different caregiver, but I will resume caregiving later	☐ 1
e. My care receiver has a different caregiving arrangement permanently	☐ 1
f. My care receiver got better and no longer needs help	☐ 1
g. My care receiver's needs exceeded my capacity to help	☐ 1
h. My care receiver died	☐ 1
i. My health status has declined	☐ 1
j. My employment status has changed	☐ 1
k. My family situation has changed	☐ 1
l. Other reason. *Please specify:* _____	☐ 1

We want to ask you about your caregiving experience. Please continue answering these questions based on your current or past caregiving experience, even if your caregiving situation has changed.

2. How long have you been caring for your care receiver?

|__|__| Months |__|__| Years Don't know ☐ -8

3. In a typical week, how many hours of care, on average, do you usually provide to your care receiver?

|__|__|__| Hours per week Don't know ☐ -8

4. Has a medical doctor ever told your care receiver that s/he has any of the following conditions?

	Yes	No	Don't know
a) arthritis?	☐ 1	☐ 2	☐ -8
b) hypertension or high blood pressure?	☐ 1	☐ 2	☐ -8
c) heart disease?	☐ 1	☐ 2	☐ -8
d) high cholesterol?	☐ 1	☐ 2	☐ -8
e) diabetes?	☐ 1	☐ 2	☐ -8
f) breathing or lung problems including emphysema, allergies, or asthma?	☐ 1	☐ 2	☐ -8
g) cancer?	☐ 1	☐ 2	☐ -8
h) stroke?	☐ 1	☐ 2	☐ -8
i) anemia?	☐ 1	☐ 2	☐ -8
j) osteoporosis?	☐ 1	☐ 2	☐ -8
k) kidney disease?	☐ 1	☐ 2	☐ -8
l) eye or vision conditions (glaucoma, cataracts, macular degeneration or others?)	☐ 1	☐ 2	☐ -8
m) hearing problems?	☐ 1	☐ 2	☐ -8
n) depression or anxiety?	☐ 1	☐ 2	☐ -8
o) Alzheimer's or dementia?	☐ 1	☐ 2	☐ -8
p) nothing that you know of.	☐ 1	☐ 2	☐ -8
q) something else?	☐ 1	☐ 2	☐ -8

Please specify: _____

5. We would like to ask about whether your care receiver needs assistance in some common activities of everyday life. Please exclude the effects of temporary conditions.

Overall, how much assistance does your care receiver need for each of the following activities of daily living?

	Always	Very often	Some-times	Rarely	Never	Don't know
a) walking?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
b) getting around inside the home?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
c) getting in or out of a bed or chair?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
d) dressing?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
e) taking a bath or shower?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
f) using the toilet?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
g) eating?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8

6. When you include all of your family members, friends and neighbors who provide care or supervision for your care receiver (not including paid/professional caregivers), what proportion of that care do you usually provide during a typical week? (please check only one)

All ☐ 1
Nearly all ☐ 2
About half ☐ 3
A little ☐ 4
Don't know ☐ -8

D3. 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
Don't know ☐ -8

D4. Are you Spanish, Hispanic or Latino?

Yes ☐ 1
No ☐ 2
Don't know ☐ -8

D5. What is your race? Please check all that apply.

American Indian or Alaskan Native ☐ 1
Asian ☐ 2
Black or African-American ☐ 3
White/Caucasian ☐ 4
Native Hawaiian/Other Pacific Islander ☐ 5
Other race ☐ 6
Please Specify: _____
Don't know ☐ -8

D6. What is your marital status?

Now married ☐ 1
Widowed ☐ 2
Divorced ☐ 3
Separated ☐ 4
Never Married ☐ 5
Don't know ☐ -8

D7. Is your home located

In a city ☐ 1
In a suburban area ☐ 2
In a rural area ☐ 3
Don't know ☐ 4

D8. We would like to ask about who lives in your household. Do you…

	Yes	No
Live alone?	☐ 1	☐ 2
Live with your spouse?	☐ 1	☐ 2
Live with your children?	☐ 1	☐ 2
Live with other relatives?	☐ 1	☐ 2
Live with a domestic partner?	☐ 1	☐ 2
Live with non-relatives other than a domestic partner	☐ 1	☐ 2

30. What additional or new kinds of information would be valuable to you as a caregiver? Please check yes or no for each one.

	Yes	No
a) A help line/central place to call to find out what kind of help is available and where to get it	☐ 1	☐ 2
b) Someone to talk to/counseling services or support groups	☐ 1	☐ 2
c) Information about how to care for your care receiver's condition or disability	☐ 1	☐ 2
d) Information about changes in laws that might affect your situation	☐ 1	☐ 2
e) Information on how to select a nursing home, group home, assisted living facility or other care facility	☐ 1	☐ 2
f) Information on how to pay for nursing homes, assisted living facilities, adult day care and other services	☐ 1	☐ 2
g) Information on how to deal with agencies (e.g., government) to get services	☐ 1	☐ 2
h) Information on health insurance and/or long term care insurance	☐ 1	☐ 2
i) Information on housing options	☐ 1	☐ 2
j) Other information not listed above	☐ 1	☐ 2

Please specify: _____

k) No additional information needed	☐ 1	☐ 2
l) Don't know	☐ -8	

We are interested in knowing about your individual characteristics. All of this information will be kept confidential.

D1. What is your gender?

Male ☐ 1
Female ☐ 2

D2. In what year were you born? Please fill in year: |__|__|__|__|

7A. Can your care receiver be left alone (meaning s/he does not require 24 hour help/supervision)?

Yes, my care receiver can be left alone for extended periods with no concerns ☐ 1
Yes, my care receiver can be left alone, but needs to be checked on in person several times a day ☐ 2
Yes, my care receiver can be left alone, but only for short periods of time (an hour or less) ☐ 3
No, my care receiver cannot be left alone and needs 24-hour supervision (proceed to question #7B) ☐ 4
Don't know ☐ -8
(If you answered "Yes" or "Don't know," proceed to question #8.)

7B. Are you responsible for providing care or supervision to your care receiver on a 24-hour basis?

Yes ☐ 1
No ☐ 2
Don't know ☐ -8

8. How often do you help your care receiver with the following activities because of his/her impairments?

	Always	Very often	Some-times	Rarely	Never	Don't know
a) Activities such as dressing, eating, bathing, or getting to the bathroom?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
b) Medical needs such as taking medicine or changing bandages?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
c) Keeping track of bills, checks, or other financial matters?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
d) Preparing meals, doing laundry, or cleaning the house?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
e) Going shopping or to the doctor's office?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
f) Arranging for care or services provided by others?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
g) Arranging for home repair, home maintenance, or home modifications?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
h) Performing home repair, home maintenance, or home modifications	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
i) Paying for care or services provided by others?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
j) Other.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8

Please specify: _____

9. Does your care receiver live alone?

Yes ☐ 1
No ☐ 2
Don't know ☐ -8

10. What is the gender of your care receiver?

Male ☐ 1
Female ☐ 2

11. How old is your care receiver?

Number of years |__|__|__|
Don't know ☐ -8

***12.* Now we would like to know about potential difficulties you may face in caring for your care receiver.**
In your experience as a caregiver, how often do you feel that:

	Always	Very often	Some-times	Rarely	Never	Don't know
a) Caregiving creates a financial burden for you?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
b) Caregiving does not leave you enough time for yourself?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
c) Caregiving does not leave enough time for your family?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
d) Caregiving interferes with your work?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
e) Caregiving negatively affects your health?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
f) Caregiving conflicts with your social life?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
g) Caregiving causes you emotional strain?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
h) Caregiving causes you physical stress?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
i) Other.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8

Please specify: _____

28. From your perspective, how could services be improved? You can check more than one.

Services would be improved if they were:	Yes	No
a) less complicated (less bureaucracy/paper work)	☐ 1	☐ 2
b) more timely (start sooner/provided when needed; shorter wait)	☐ 1	☐ 2
c) more competent (better skills, professional demeanor)	☐ 1	☐ 2
d) more reliable (come as scheduled)	☐ 1	☐ 2
e) more consistent (same worker each time)	☐ 1	☐ 2
f) more personable (friendly, respectful)	☐ 1	☐ 2
g) increased in amount (need more of current services)	☐ 1	☐ 2
h) easier to access	☐ 1	☐ 2
i) more culturally diverse (e.g., need more bilingual staff, ethnic-sensitive services)	☐ 1	☐ 2
j) no suggestion	☐ 1	☐ 2
k) other:	☐ 1	☐ 2

Please specify: _____

29. In addition to the services you and your care receiver are receiving, what additional or new kinds of assistance would be valuable to you as a caregiver? Please check yes or no for each one.

	Yes	No
a) Housekeeping assistance for care receiver	☐ 1	☐ 2
b) Shopping assistance for care receiver	☐ 1	☐ 2
c) Transportation assistance for care receiver	☐ 1	☐ 2
d) Assistance in making meals for care receiver	☐ 1	☐ 2
e) Assistance in bathing, dressing, grooming, toileting, feeding, and other personal care for care receiver	☐ 1	☐ 2
f) Adult daycare for care receiver	☐ 1	☐ 2
g) Assistance in getting other family members involved in caring for care receiver	☐ 1	☐ 2
h) Assistance in administering medications and monitoring their side effects	☐ 1	☐ 2
i) In-home respite care	☐ 1	☐ 2
j) Help with money management and financial advice	☐ 1	☐ 2
k) Financial assistance – money to pay for services	☐ 1	☐ 2
l) Tax credits or tax break	☐ 1	☐ 2
m) No additional help needed	☐ 1	☐ 2
n) Don't know	☐ -8	
o) Other services or assistance not listed above	☐ 1	☐ 2

Please specify: _____

_____

_____

QUESTIONS ABOUT CARE RECEIVER SERVICES:

23. Thinking about the services that your care receiver has received, how would you rate those services overall? (Please check only one.)

- Excellent ☐ 1
- Very good ☐ 2
- Good ☐ 3
- Fair ☐ 4
- Poor ☐ 5
- Don't know ☐ -8

24. Would you recommend those services to a friend?

- Yes ☐ 1
- Not Sure ☐ 2
- No ☐ 3
- Don't know ☐ -8

QUESTIONS ABOUT CAREGIVER SERVICES:

25. Thinking about the services that you have received as a caregiver, how would you rate those services overall? (Please check only one.)

- Excellent ☐ 1
- Very good ☐ 2
- Good ☐ 3
- Fair ☐ 4
- Poor ☐ 5
- Don't know ☐ -8

26. Would you recommend those caregiver services to a friend?

- Yes ☐ 1
- Not Sure ☐ 2
- No ☐ 3
- Don't know ☐ -8

27. How have these caregiver services affected you and your caregiving tasks?

_____

_____

_____

_____

13. We would also like to know about positive aspects of caregiving.

Please choose the answer that best tells how you feel:

	Always	Very often	Some-times	Rarely	Never	Don't know
a) As a caregiver, how often do you feel that you are helping your care receiver?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
b) As a caregiver, how often do you feel that you are helping your family by caring for your care receiver?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
c) How often does being a caregiver provide you with a sense of accomplishment?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
d) How often does providing care give you the satisfaction of caring for someone who cared for you?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
e) How often do you feel that your care receiver appreciates the care that you are providing for him/her?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
f) How often does being a caregiver provide companionship for you?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8
g) Other.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ -8

Please specify: _____

In the following section, we would like to obtain information about your experience with the Family Caregiver Support Program.

14. Where did you first hear about the Family Caregiver Support Program (check one answer)? Did you hear from:

- a) Family ☐ 1
- b) Friends ☐ 2
- c) A physician ☐ 3
- d) Community organization ☐ 4
- e) TV/radio/newspaper/other media ☐ 5
- f) Social worker/case manager ☐ 6
- g) Hospital ☐ 7
- h) State/Local Office for the Aging ☐ 8
- i) Someplace else? ☐ 9 *(please specify)*_____
- j) Don't know ☐ -8

15. Has someone at your Local Office for the Aging helped you, or given you information, to connect you to the services and resources that you need as a caregiver?

- Yes ☐ 1
- No ☐ 2
- Don't know ☐ -8

16. Have you received respite care (short-term care provided to a care receiver, either in your home or someplace else) to allow you to take a brief break from the daily routine of caregiving?

Yes ☐ 1
No ☐ 2
Don't know ☐ -8

17. 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
Don't know ☐ -8

18. Has your Local Office for the Aging provided you with supplemental services (such as home delivered meals, transportation, personal emergency response system, etc.) to help you provide care?

Yes ☐ 1
No ☐ 2
Don't know ☐ -8

19. Of the caregiver services you received, which service was the most helpful? (check only one answer)

Help or information connecting to services and resources ☐ 1
Respite care services ☐ 2
Caregiver training or education, including counseling or a support group ☐ 3
Other supplemental support services? ☐ 4

Please specify: _____

Don't know ☐ -8

20. Does your care receiver receive any of the following eldercare services?

	Yes	No	Don't know
a) Adult day care (center-provided care)?	☐ 1	☐ 2	☐ -8
b) Case management, care monitoring, arranging for services, service linkages, or needs assessment?	☐ 1	☐ 2	☐ -8
c) Home care services (includes personal care, homemaker and chore services)?	☐ 1	☐ 2	☐ -8
d) Home delivered meals?	☐ 1	☐ 2	☐ -8
e) Transportation service (includes assisted transportation)?	☐ 1	☐ 2	☐ -8
f) Information about services?	☐ 1	☐ 2	☐ -8
g) Other services or assistance not listed above?	☐ 1	☐ 2	☐ -8

Please specify: _____

21. As a result of the caregiver and care receiver services that you received, do you:

	Yes	No	Some-times	Don't know
a) Have more time for personal activities?	☐ 1	☐ 2	☐ 3	☐ -8
b) Feel less stress?	☐ 1	☐ 2	☐ 3	☐ -8
c) Have a clearer understanding of how to get the services you and your care receiver need?	☐ 1	☐ 2	☐ 3	☐ -8
d) Know more about your care receiver's condition or illness?	☐ 1	☐ 2	☐ 3	☐ -8
e) Feel more confident in providing care to your care receiver?	☐ 1	☐ 2	☐ 3	☐ -8
f) Believe that the services enable you to provide care longer?	☐ 1	☐ 2	☐ 3	☐ -8
g) Think that the caregiver services you receive benefit the care receiver too?	☐ 1	☐ 2	☐ 3	☐ -8
h) Receive other benefits (e.g. State health insurance program, home energy assistance program)?	☐ 1	☐ 2	☐ 3	☐ -8

Please specify: _____

22A. Would your care receiver continue to live in the same home if caregiver and/or care receiver services had not been provided?

Yes ☐ 1 (if you checked "Yes," please go straight to question #23)
No ☐ 2 (if you checked "No," continue with question #22B below)
Don't know ☐ -8 (if you checked "Don't know," please go straight to question #23)

22B. Where would your care receiver be living? Please check only one answer.

At your home ☐ 1
In the home of another family member or friend ☐ 2
In an assisted living facility ☐ 3
In a nursing home ☐ 4
Care receiver may have died without services ☐ 5
Other. ☐ 6

Please specify: _____