

# Appendix A: Full Questionnaires

## ONLINE VERSION

### SCREENER

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#### **SAMPLE**

- 1 = Base sample
- 2 = African-American oversample
- 3 = Hispanic oversample
- 4 = Asian oversample
- 5 = Age-based oversample (age 65-74)
- 6 = Age-based oversample (age 75+)

Thank you for taking the time to participate in this important national study. This is a one-time survey and should take about 20 minutes of your time.

SC1a. At any time in the last 12 months, has anyone in your household provided unpaid care to a relative or friend 18 years or older to help them take care of themselves?

This may include helping with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This adult need not live with you.

- Yes, I have provided care to an adult in the last year ..... 1
- Someone else in my household has provided care ..... 2
- No..... 3

**IF AGE TARGETED CAREGIVERS (SAMPLE>4) AND RESPONDENT NOT CAREGIVER (SC1a>1), TERMINATE AS NON-CAREGIVER.**

**IF BASE/ETHNIC (SAMPLE<5) AND RESPONDENT REFUSES (SC1a=missing), TERMINATE.**

SC1c. **[IF HH ADULT CG (SC1a=1 or 2)]:** Were any of the adults that **[IF ADULT CG (SC1a=1):** you/**IF HH ADULT CG (SC1a=2):** someone in your household] cared for age 50 or older?

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

SC1b. **[IF (SAMPLE<5)]:** In the last 12 months, has anyone in your household provided unpaid care to any child under the age of 18 because of a medical, behavioral, or other condition or disability?

This kind of unpaid care is more than the normal care required for a child of that age. This could include care for an ongoing medical condition, a serious short-term condition, emotional or behavioral problems, or developmental problems.

- Yes, I have provided care to a child in the last year ..... 1
- Someone else in my household has provided care ..... 2
- No..... 3

This is an important study and to be sure we talk to a variety of people, we need to ask you some basic questions about you and your household.

SC6. How many people, including children, live in your household?

*Please include yourself.*

\_\_\_\_\_ [ALLOW 1 - 30]

**IF LIVES ALONE (SC6 = 1), SKIP TO CHECKPOINT.**

SC7. Are you the person who owns or rents the residence where you live?

*Is your name on the lease or do you pay for the mortgage?*

Yes ..... 1

No ..... 2

**IF (SC7=REFUSED), SKIP TO CHECKPOINT BEFORE Q1.**

SC8. **[IF HOUSEHOLDER (SC7=1)]:** Are you related by marriage, blood, or adoption to anyone else who lives with you?

Yes ..... 1

No ..... 2

**IF HOUSEHOLDER (SC7=1), SKIP TO CHECKPOINT.**

**IF NOT HOUSEHOLDER (SC7=2), CONTINUE.**

SC9. **[IF NOT HOUSEHOLDER (SC7=2)]:** For the next few questions, please think about the person you live with who owns or rents the place where you live. Is that person related to anyone in your household by marriage, blood, or adoption?

Yes ..... 1

No ..... 2

**IF REFUSES (SC9=missing), TERMINATE AS NOT FULL HH DATA.**

SC10. **[IF NOT HOUSEHOLDER (SC7=2)]:** How old is that person who owns or rents the house?

*Your best estimate is fine.*

\_\_\_\_\_ [RECORD AGE; ALLOW 18-96]

97 or older ..... 97

**IF REFUSES (SC10=missing), TERMINATE AS NOT FULL HH DATA.**

SC11a. **[IF NOT HOUSEHOLDER (SC7=2)]:** This question is about Hispanic ethnicity. As far as you know, is that person of Spanish, Hispanic, or Latino descent?

- No, he/she is not..... 1
- Yes, Mexican, Mexican-American, Chicano ..... 2
- Yes, Puerto Rican..... 3
- Yes, Cuban, Cuban American..... 4
- Yes, Central or South American..... 5
- Yes, Other Spanish/Hispanic/Latino [specify].... 8
- Not sure ..... 9

**IF REFUSES (SC11a=missing), TERMINATE AS NOT FULL HH DATA.**

SC12a. **[IF NOT HOUSEHOLDER (SC7=2)]:** Would you say they are...? **[ALLOW MULTIPLE RESPONSE]**

- White ..... 1
- Black or African American ..... 2
- American Indian or Alaska Native..... 3
- Asian ..... 4
- Native Hawaiian/Pacific Islander ..... 5
- 2+ races..... 6

**IF REFUSES AND HH NOT HISPANIC (SC12a=missing AND SC11a=1), TERMINATE AS NOT FULL HH DATA.**

**IF PANELIST IS NOT HOUSEHOLDER (SC7=2), CONTINUE TO CHECKPOINT.**

**CHECKPOINT:**

**IF NO ONE IS ADULT CAREGIVER (SC1a=3 or REFUSED): TERMINATE AS “NO ADULT CAREGIVER”.**

**IF RESPONDENT IS NOT ADULT CAREGIVER (SC1a=2): TERMINATE AS “CG HOUSEHOLD BUT R NOT CG”.**

**C. CHARACTERISTICS OF THE RELATIONSHIP**

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This survey is part of an important national study conducted by the National Alliance for Caregiving and AARP. We really appreciate your participation.

1. Are you currently providing unpaid help to an adult relative or friend, or was this something you did in the past 12 months and are no longer doing?

- Currently..... 1
- Past 12 months but not currently ..... 2

**WORDING NOTE 1:**

**IF CURRENTLY (Q1=1 or 5): USE PRESENT TENSE, first verb in {BRACKETS}**

**IF PAST 12 MONTHS (Q1=2 or REFUSED): USE PAST TENSE, second verb in {BRACKETS}**

2. How many adults {are you currently caring for? / did you care for in the past 12 months?}  
\_\_\_\_\_ [ALLOW 0-97; TERMINATE IF 0 or REFUSED]

**FOR THE FEW RESPONDENTS WHO SAY THEY ARE CAREGIVERS TO 5+ PEOPLE, WE WILL DOUBLE CHECK THAT THEY ARE TRULY CAREGIVERS – THEY CAN'T BE IN AN INSTITUTIONAL SETTING AND THEY MUST BE CARING FOR RECIPIENTS WHO DO HAVE SPECIAL NEEDS.**

3. [IF Q2 >= 5] {Are/were} all of these people together in an institutional or group setting, like a nursing home, senior center, or school where you work or volunteer?  
Yes ..... 1 TERMINATE  
No.....2

**IF REFUSES (Q3=missing), TERMINATE.**

4. [IF Q2 >= 5] How many of the people you {help care for have/ helped care for had} some sort of special need that {is/was} the reason for their care?  
A special need could be an illness, injury, disability, or mental health problem.  
All ..... 1 SKIP TO TEXT AFTER Q2B  
Some..... 2  
None..... 3 TERMINATE

**IF REFUSES (Q4=missing), TERMINATE.**

2b. How many adults with some sort of special need {do you provide care for? / did you provide care for in the past 12 months?}  
\_\_\_\_\_ [ALLOW 0 thru Q2(answer); TERMINATE IF 0]

**IF REFUSES (Q2B=missing), TERMINATE.**

[IF ONE PERSON (Q2=1 OR Q2B=1): Now, we would like to get some information about the adult for whom you {provide/provided} care.]

[IF MORE THAN ONE (Q2=2 thru 4 OR Q2b=2 thru 97): For the next set of questions, please think about the adult for whom you {provide/provided} the most assistance.]

5. How old {is/was} that adult [IF Q1=2 or REFUSED: at the time you provided care]?  
*Your best estimate is fine.*  
\_\_\_\_ years old [RECORD AGE IN YEARS; ALLOW 18 - 130]

9. And {is/was} the person you {care/cared} for...  
Male .....1  
Female .....2

**PROGRAMMING NOTE: IF MALE (Q9=1), use masculine insert “he/his/him”. IF FEMALE (Q9=2), use feminine insert “she/hers/her”. IF REFUSED (Q9=refused), use neutral “he/she; his/hers; him/her”...etc. FOR REST OF SURVEY.**

7. Who {are you caring/did you care} for?

Please select one relationship.

<b>[SHOW IF Q9=1 or REFUSED]:</b>	<b>[SHOW IF Q9=2 or REFUSED]:</b>
<b>RELATIVE:</b>	<b>RELATIVE:</b>
Brother..... 2	Aunt..... 1
Brother-In-Law..... 3	Companion/Partner ..... 4
Companion/Partner ..... 4	Daughter..... 5
Father ..... 6	Granddaughter ..... 8
Father-In-Law ..... 7	Grandmother ..... 10
Grandfather ..... 9	Grandmother-In-Law ..... 11
Grandfather-In-Law ..... 11	Mother ..... 13
Grandson..... 12	Mother-In-Law ..... 14
Husband..... 20	Niece ..... 16
Nephew ..... 15	Same-sex partner..... 30
Same-sex partner..... 30	Sister ..... 17
Son ..... 19	Sister-In-Law ..... 18
Uncle ..... 21	Wife ..... 20
Other relative <b>[SPECIFY ___]</b> ..... 22	Other relative <b>[SPECIFY ___]</b> ..... 22
<b>NON-RELATIVE:</b>	<b>NON-RELATIVE:</b>
Foster child..... 23	Foster child..... 23
Friend ..... 24	Friend ..... 24
Neighbor..... 26	Neighbor..... 26
Other non-relative..... 27	Other non-relative..... 27

**INSERT RESPONSE FROM Q7 ANYWHERE IT SAYS [Q7 CODE], EXCEPT FOR:**  
**IF Q7=4 or 30 [Use "partner"]**  
**IF Q7=22 [Use "relative"]**  
**IF Q7=27 OR REFUSED [Use "care recipient"]**

11. Where {does/did} your **[Q7 CODE]** live **[IF Q1=2 or REFUSED: at the time you provided care]**?

- In your household..... 1 **[SKIP TO Q17]**
- Within twenty minutes of your home ..... 2
- Between twenty minutes and an hour from your home ..... 3
- One to two hours from your home, or ..... 4
- More than two hours away? ..... 5

12. **[IF NOT IN HOUSEHOLD (Q11=2 thru 5):** On average, how often {do/did} you visit your **[Q7 CODE]**?

- More than once a week..... 1
- Once a week ..... 2
- Few times a month ..... 3
- Once a month ..... 4
- Few times a year ..... 5
- Less often ..... 6

13. **[IF NOT IN HOUSEHOLD (Q11=2 thru 5)]:** Which of the following best describes where your **[Q7 CODE]** {lives/lived at the time you provided care}?

- His or her own home ..... 1
- Someone else’s home..... 2 **[SKIP TO Q15]**
- An independent living or retirement community ..... 3
- In an assisted living facility where some care may be provided..... 4 **[SKIP TO Q15]**
- A nursing care or long-term care facility..... 5 **[SKIP TO Q15]**
- Or somewhere else? **[SPECIFY \_\_\_\_\_]** ..... 8

14c. {Does/Did} your **[Q7 CODE]** live alone **[IF Q1=2 or REFUSED:** at the time you provided care]?

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

15. {Does/Did} your **[Q7 CODE]** live in a rural area **[IF Q1=2 or REFUSED:** at the time you provided care]?

- Yes .....3
- No.....6

**D. CHARACTERISTICS OF RECIPIENT**

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17. {Does/Did} your **[Q7 CODE]** need care because of a...? **[MAINTAIN ORDER A-G]**

		Yes	No
a.	Short-term physical condition	1	2
b.	Long-term physical condition	1	2
c.	Emotional or mental health problem	1	2
d.	Developmental or intellectual disorder or mental retardation	1	2
f.	Behavioral issue	1	2
g.	Memory problem	1	2

18. What {is/was} the main problem or illness your [Q7 CODE] {has/had}, for which he/she {needs/needed} your care?

Alzheimer’s, confusion, dementia, forgetfulness.....	3
Arthritis .....	5
Back problems .....	8
Blood pressure, hypertension .....	11
Brain damage or injury .....	12
Broken bones .....	13
Cancer.....	14
Developmental or intellectual disorder, mental retardation, Down syndrome .....	21
Diabetes .....	16
Feeble, unsteady, falling .....	18
Hearing loss, deafness.....	15
Heart disease, heart attack .....	19
Lung disease, emphysema, COPD.....	20
Mental illness, emotional illness, depression .....	22
Mobility problem, can’t get around .....	23
Old age, Aging .....	24
Parkinson’s.....	27
Stroke.....	30
Substance, drug, alcohol abuse.....	31
Surgery, wounds .....	32
Vision loss, blindness, can’t see well .....	10
Other [SPECIFY REQUIRED: _____] .....	33
Not sure.....	34

20. [IF ALZHEIMER’S NOT MENTIONED (Q18#3)] {Does/Did} your [Q7 CODE] suffer from Alzheimer’s or other mental confusion?

Yes—Alzheimer’s .....	1
Yes--Other .....	2
No .....	3
Not sure.....	4

20B. [IF PARKINSON’S NOT MENTIONED (Q18#27)] {Does/Did} your [Q7 CODE] suffer from Parkinson’s?

Yes .....	1
No .....	2
Not sure.....	3

21. How long {have you been providing/did you provide} care to your [Q7 CODE]?

*Your best estimate is fine.*

\_\_\_ \_\_\_ years [ALLOW 1 - 93]

Less than six months .....	96
Six months to one year .....	95
All their life.....	94

22. Which of these {do/did} you help your [Q7 CODE] with? [RANDOMIZE A-F ORDER]

	<i>ADL list</i>	Yes	No
a.	Getting in and out of beds and chairs	1	2
b.	Getting dressed	1	2
c.	Getting to and from the toilet	1	2
d.	Bathing or showering	1	2
e.	By dealing with incontinence or diapers	1	2
f.	By feeding him or her	1	2
g.	By giving medicines, like pills, eye drops, or injections for his/her condition	1	2

N1. [IF DOES ADLS (ANY Q22a thru Q22f = 1)]: How difficult {is/was} it for you to help your [Q7 CODE] with {these/those} kinds of tasks? [ROTATE 1-5/5-1]

Not at all difficult				Very difficult
1	2	3	4	5

23. {Do/Did} you provide help to your [Q7 CODE] with...[RANDOMIZE ITEMS A-F]

		Yes	No
a.	Managing finances, such as paying bills or filling out insurance claims	1	2
b.	Grocery or other shopping	1	2
c.	Housework, such as doing dishes, laundry, or straightening up	1	2
d.	Preparing meals	1	2
e.	Transportation, either by driving him/her, or helping him/her get transportation	1	2
f.	Arranging outside services, such as nurses, home care aides, or meals-on-wheels	1	2

N2. [IF MANAGES FINANCES (Q23A=1)]: {Have/Did} you {experienced/experience} any problems dealing with a bank or credit union when you were helping your [Q7 CODE] manage his/her finances?

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

23\_1. And {do/did} you provide help to your [Q7 CODE] by...[RANDOMIZE ITEMS G-J]

		Yes	No
g.	Advocating for him/her with health care providers, community services, or government agencies	1	2
i.	Monitoring the severity of his/her condition so that you {can/could} adjust care accordingly	1	2
j.	Communicating with health care professionals like doctors, nurses, or social workers about his/her care	1	2

25. Thinking now of all the kinds of help you {provide/provided} for your [Q7 CODE], about how many hours {do/did} you spend in an average week, helping [IF Q9=1: him / IF Q9=2: her / IF Q9=REFUSED: him/her]?

\_\_\_ \_\_\_ \_\_\_ hours [ALLOW 1-168]

Less than 1 hour per week ..... 169  
 Constant care ..... 170

**E. Medical/Nursing Tasks**

N3. {Do/Did} you help your [Q7 CODE] with any medical/nursing tasks?

This might include giving medicines like pills, eye drops, or injections, preparing food for special diets, tube feedings, or wound care. You could be monitoring things like blood pressure or blood sugar, helping with incontinence, or operating equipment like hospital beds, wheelchairs, oxygen tanks, nebulizers, or suctioning tubes.

Yes ..... 1  
 No ..... 2  
 Not sure..... 3

N3B. [IF DOES MEDICINE (Q22G=1) AND NOT M/N TASKS (N3>1)]: You said earlier in the survey that you {help/helped} your [Q7 CODE] by giving medicines, like eye drops, pills, or injections for his/her condition. Is that correct?

Yes, I {help/helped} give medicines ..... 1 [REPUNCH N3=1]  
 No, I {do/did} not help with that ..... 2 [REPUNCH Q22G=2]

**IF NO/DK/REF TO ADLS (ALL Q22a thru f > 1) AND IADLS (Q22G>1 and ALL Q23a thru f > 1) AND Medical/Nursing (N3>1), THEN TERMINATE AS NON CAREGIVER.**

**IF DOES M/N TASKS (N3=1), CONTINUE.  
 IF NO M/N (N3>1), SKIP TO N8.**

N4. [IF DOES M/N TASKS (N3=1)]: How difficult {is/was} it for you to do the medical/nursing tasks that {are/were} required to help your [Q7 CODE]? [ROTATE 1-5/5-1]

**HOVER DEFINITION FOR UNDERLINED TEXT ABOVE:** Medical/nursing tasks include: giving medicines like pills, eye drops, or injections, preparing food for special diets, tube feedings, wound care, monitoring things like blood pressure or blood sugar, helping with incontinence, or operating equipment like hospital beds, wheelchairs, oxygen tanks, nebulizers, or suctioning tubes.

<b>Not at all difficult</b>				<b>Very difficult</b>
1	2	3	4	5

N5. [IF DOES M/N TASKS (N3=1)]: Did anyone prepare you to do these tasks?

Yes ..... 1  
 No ..... 2 [SKIP TO N8]  
 Not sure..... 3 [SKIP TO N8]

N6. [IF PREPARED (N5=1)]: Who prepared you to do the medical/nursing tasks needed to help

your [Q7 CODE]?

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N7. **[IF PREPARED (N5=1)]:** How well do you feel that person prepared you to take on these medical/nursing tasks? **[ROTATE 1-3/3-1]**

- Very well..... 1
- Somewhat well ..... 2
- Not well ..... 3
- Not sure..... 4

N8. If you had to learn how to do a **medical/nursing task**, how would you prefer to learn? **[RANDOMIZE ORDER OF 1-7; ALLOW MULTIPLE RESPONSE]**

*Select all answers that apply.*

**HOVER DEFINITION FOR UNDERLINED TEXT ABOVE:** Medical/nursing tasks include: giving medicines like pills, eye drops, or injections, preparing food for special diets, tube feedings, wound care, monitoring things like blood pressure or blood sugar, helping with incontinence, or operating equipment like hospital beds, wheelchairs, oxygen tanks, nebulizers, or suctioning tubes.

- Ask: have a 24-hour number to call if I have questions ..... 1
- Hands-on: I do it while a qualified person watches me ..... 2
- Listen: have someone tell me how to do it ..... 3
- On-demand: have unlimited access to a video of a qualified person doing the task ..... 4
- Read: have word-only written instructions ..... 5
- See: have instructions with pictures of what to do ..... 6
- Show: have a qualified person show me how to do it ..... 7
- Other **[SPECIFY: \_\_\_\_\_]** ..... 8

**F. Hospitalization**

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N9. In the last 12 months **[IF Q1=2 or refused: that you were caring for him/her]**, how many times was your **[Q7 CODE]** hospitalized overnight?

- None..... 1
- One time ..... 2
- 2 times..... 3
- 3 or more times ..... 4
- Not sure..... 5

N10. **[IF HOSPITAL (N9=2, 3, OR 4)]:** When your **[Q7 CODE]** was in the hospital, were you included by health care workers, like nurses, doctors, or social workers, in discussions about your **[Q7 CODE]**'s care?

- Yes, all the time ..... 3
- Only some of the time ..... 2
- No and I should have been ..... 1
- No, but I did not need to be ..... 5
- Not sure..... 4

N11. **[IF HOSPITAL (N9=2, 3, OR 4) AND DOES M/N (N3=1)]:** Before your **[Q7 CODE]** left the hospital or was discharged, did you receive clear instructions about any **medical/nursing**

**tasks** you would need to perform for your [Q7 CODE]?

- Yes ..... 1
- No..... 2
- Not sure..... 3
- Not applicable ..... 4

**G. OTHER CAREGIVER SUPPORT**

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28. Has anyone else provided unpaid help to your [Q7 CODE] during the last 12 months?

- Yes ..... 1
- No..... 2 [SKIP TO Q30]

29. Who would you consider to be the person who {provides/provided} most of the unpaid care for your [Q7 CODE]?

- You (yourself) ..... 1
- Someone else ..... 2
- We split it evenly ..... 3

30. During the last 12 months, did your [Q7 CODE] receive paid help from any aides, housekeepers, or other people who were paid to help him/her?

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

38. Please think about all of the health care professionals or service providers who {give/gave} care or treatment to your [Q7 CODE]. How easy or difficult {is/was} it for you to coordinate care between those providers? [ROTATE 1-4/4-1]

- Very easy ..... 1
- Somewhat easy..... 2
- Somewhat difficult ..... 3
- Very difficult..... 4
- [IF Q28=1: Not applicable: someone else {does/did} this] ..... 7

N12. Do you expect to have some responsibility for the care of {your [Q7 CODE] or another adult/another adult family member or friend} in the next five years?

- Yes ..... 1
- No ..... 2
- Not sure..... 3

**I. PHYSICAL, EMOTIONAL AND FINANCIAL STRESS OF CAREGIVING**

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35. How much of a physical strain would you say that caring for your [Q7 CODE] {is/was} for you? [ROTATE 1-5/5-1]

<b>Not a strain at all</b>				<b>Very much a strain</b>
1	2	3	4	5

36. How emotionally stressful would you say that caring for your [Q7 CODE] {is/was} for you? [ROTATE 1-5/5-1]

<b>Not at all stressful</b>				<b>Very stressful</b>
1	2	3	4	5

37B. How much of a financial strain would you say that caring for your [Q7 CODE] {is/was} for you? [ROTATE 1-5/5-1]

<b>Not a strain at all</b>				<b>Very much a strain</b>
1	2	3	4	5

39. Do you feel you had a choice in taking on this responsibility for caring for your [Q7 CODE]?

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

**H. WORKING CAREGIVERS**

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32A. Now we have some questions about you. Are you currently employed?

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

**IF CURRENT CG (Q1=1) AND CURRENTLY WORKING (Q32A=1), SKIP TO N13.**

33. {Have you been/Were you} employed at any time in the last year while you were also helping your [Q7 CODE]?

Yes ..... 1  
 No ..... 2 [SKIP TO N17]

**[IF Q33=1]:** For the next few questions, please think about the most recent time in the last year when you were working and providing care to your [Q7 CODE].

N13. **[IF CURRENTLY EMPLOYED AND CAREGIVING (Q1=1 and Q32A=1)]:** About how many hours a week, on average, do you work?

N13\_1. **[IF EMPLOYED CAREGIVER IN LAST YEAR (Q33=1)]:** When you were last working and helping your **[Q7 CODE]**, about how many hours a week, on average, did you work?

\_\_\_ \_\_\_ **[ALLOW 1-80]**

N13B. **[IF CURRENTLY EMPLOYED AND CAREGIVING (Q1=1 and Q32A=1)]:** Are you currently self-employed or do you own your own business?

N13B\_1. **[IF EMPLOYED CAREGIVER IN LAST YEAR (Q33=1)]:** When you were last working and helping your **[Q7 CODE]**, were you self-employed or did you own your own business?

Yes ..... 1

No.....2

**IF SELF-EMPLOYED (N13B=1 or REFUSED or N13B\_1=1 or REFUSED), SKIP TO Q34.**

N14. **[IF CURRENTLY EMPLOYED AND CAREGIVING (Q1=1 and Q32A=1) AND NOT SELF-EMPLOYED (N13B=2)]:** Does your supervisor know that you are caring for your **[Q7 CODE]**?

N14\_1. **[IF EMPLOYED CAREGIVER IN LAST YEAR (Q33=1) AND NOT SELF-EMPLOYED (N12B\_1=2)]:** At that time, did your supervisor know that you were caring for your **[Q7 CODE]**?

Yes ..... 1

No.....2

Not sure.....3

N16. **[IF CURRENTLY EMPLOYED AND CAREGIVING (Q1=1 and Q32A=1) AND NOT SELF-EMPLOYED (N13B=2)]:** For employees in your position, which of the following does your employer offer?

N16\_1. **[IF EMPLOYED CAREGIVER IN LAST YEAR (Q33=1) AND NOT SELF-EMPLOYED (N13B\_1=2)]:** At the time when you were last working and providing care to your **[Q7 CODE]**, for employees in your position, which of the following did your employer offer?

**[RANDOMIZE ITEMS A-E]**

		Yes	No
a.	Flexible work hours	1	2
b.	Telecommuting or working from home	1	2
c.	Programs like information, referrals, counseling, or an employee assistance program, to help caregivers like yourself	1	2
d.	Paid leave, where you could take paid time off from work for several weeks to care for a family member	1	2
e.	Paid sick days	1	2

34. As a result of caregiving, did you ever experience any of these things at work?  
**[RANDOMIZE ITEMS A-H]**

		Yes	No
a.	Went in late, left early, or took time off during the day to provide care	1	2
b.	Took a leave of absence	1	2
c.	Went from working full-time to part-time, or cut back your hours	1	2
d.	Turned down a promotion	1	2
e.	Lost any of your job benefits	1	2
f.	Gave up working entirely	1	2
g.	Retired early	1	2
h.	Received a warning about your performance or attendance at work	1	2

N15. **[IF LEFT (Q34b=1 OR Q34f=1 OR Q34g=1)]:** Why did you leave your job? **[RANDOMIZE ITEMS 1-4; ALLOW MULTIPLE RESPONSE]**

*Select all answers that apply.*

- Needed more time to care for your **[Q7 CODE]** ..... 1
- Could not afford paid help for your **[Q7 CODE]** ..... 2
- Job did not allow flexible work hours..... 3
- Job did not allow time off with pay ..... 4
- Other reason **[SPECIFY: \_\_\_\_\_]** ..... 5

N17. Have you ever been fired from any job as a result of being a caregiver for your **[Q7 CODE]** or any other loved one?

- Yes ..... 1
- No ..... 2
- Not sure..... 3

N18. Would you support banning workplace discrimination against workers who have caregiving responsibilities?

- Yes ..... 1
- No ..... 2
- Not sure..... 3

**J. INFORMATION/SERVICES/POLICY**

45. In your experience as a caregiver, have you ever.... **[RANDOMIZE ORDER A-F]**

		Yes	No
a.	Requested information about how to get financial help for your <b>[Q7 CODE]</b> ?	1	2
b.	Used respite services where someone would take care of your <b>[Q7 CODE]</b> to give you a break?	1	2
c.	Had an outside service provide transportation for your <b>[Q7 CODE]</b> instead of you providing the transportation?	1	2
d.	Had modifications made in the house or apartment where your <b>[Q7 CODE]</b> {lives/lived} to make things easier for him/her?	1	2
e.	Had a doctor, nurse, or social worker ask you about what you {need/needed} to help care for your <b>[Q7 CODE]</b> ?	1	2
f.	Had a doctor, nurse, or social worker ask you what you {need/needed} to take care of <u>yourself</u> ?	1	2

N19. How difficult {is/was} it to get affordable services in your **[Q7 CODE]**'s local area or community that {could help/would have helped} you care for your **[Q7 CODE]**, like delivered meals, transportation, or in-home health services? **[ROTATE 1-5/5-1]**

Not at all difficult				Very difficult
1	2	3	4	5

N20. Various organizations are thinking about ways to help caregivers like you. Which of the following do you think would {be/have been} helpful to you? **[RANDOMIZE ITEMS 1-6; ALLOW MULTIPLE RESPONSE]**

*Select all answers that apply.*

- Requiring health care providers to include your name on your **[Q7 CODE]**'s medical chart, so you {are/were} part of conversations or decisions about his/her care..... 1
- Requiring hospitals to {keep/have kept} you informed about major decisions, like transferring or discharging your **[Q7 CODE]**..... 2
- Requiring hospitals or facilities to instruct or demonstrate any medical/nursing tasks you might {need/have needed} to do ..... 3
- Having respite services available, where someone would {take/have taken} care of your **[Q7 CODE]** to give you a break ..... 4
- Requiring a doctor, nurse, or social worker ask you about what you {need/needed} to help care for your **[Q7 CODE]** ..... 5
- Requiring a doctor, nurse, or social worker ask you what you {need/needed} to take care of yourself ..... 6
- None of the above ..... 7

47a. Below are some ways that people are proposing to help caregivers financially. Which one would you {find/have found} most helpful? **[RANDOMIZE ORDER OF ITEMS 2-3-4]**

	<b>Q47a: MOST</b>
An income tax credit to caregivers, to help offset the cost of care	2
A partially paid leave of absence from work, for caregivers who are employed	3
A program where caregivers could be paid for at least some of the hours they provide care	4
Not sure	7

48. Which of the following topics do you feel you {need/needed} more help or information? **[RANDOMIZE ITEMS A-N]**

*Select all answers that apply.*

	<b>Yes</b>
a. Keeping your <b>[Q7 CODE]</b> safe at home	<input type="checkbox"/> 1
b. Managing his/her challenging behaviors, such as wandering	<input type="checkbox"/> 1
d. Managing his/her incontinence or toileting problems	<input type="checkbox"/> 1
l. Managing your emotional or physical stress	<input type="checkbox"/> 1
m. Making end-of-life decisions	<input type="checkbox"/> 1
n. Finding non-English language educational materials	<input type="checkbox"/> 1

N21. {Does/Did} your **[Q7 CODE]** have plans in place for his/her future care, such as instructions for handling financial matters, healthcare decisions, or living arrangements?

Yes ..... 1  
 No ..... 2  
 Not sure..... 3

N22. Do you have your own plans for your own future care, such as handling financial matters, healthcare decisions, or living arrangements?

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

**K. DEMOGRAPHICS**

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And finally, we have just a few questions for classification purposes only.

D1. {How would you describe your own health?/When you were last caregiving, was your health...}?

Excellent ..... 5  
 Very good ..... 4  
 Good ..... 3  
 Fair ..... 2  
 Poor ..... 1

D2. How would you say taking care of your [Q7 CODE] [IF Q1=1, INSERT: has] affected your health?

- Made it better ..... 1
- Not affected it ..... 2
- Made it worse ..... 3

D3. {Are you currently/When you were last caregiving, were you}...

- Married ..... 1
- Living with a partner ..... 2
- Widowed ..... 3
- Separated..... 4
- Divorced ..... 5
- Single, never married ..... 6
- Decline to respond ..... 8

D5. Did your [Q7 CODE] serve in the US Armed Forces?

*This includes Army, Navy, Air Force, Marines, Coast Guard or Women’s Armed Forces.*

- Yes ..... 1
- No..... 2
- Not sure..... 3

D5B. [IF CR IS VET (D5=1), ASK]: Did your [Q7 CODE] serve before September 11<sup>th</sup>, 2001?

- Yes ..... 1
- No..... 2
- Not sure..... 3

D6. {Are/When you were last caregiving, were} there any children or grandchildren living in your household under 18 years of age?

- Yes ..... 1
- No..... 2
- Decline to respond ..... 4

D10. If the situation arose, would you be interested in participating in future research on caregivers?

By agreeing to be contacted, GfK will provide your phone number to AARP and the National Alliance for Caregiving’s third-party research firm, who may contact you for follow-up research about caregiving. It is completely optional.

- Yes ..... 1
- No/Decline..... 2

D11. The results of this survey are totally confidential. However if a reporter writing a story about the results of the survey wanted to interview you for a news story, would you be willing or not?

By agreeing to be contacted, GfK will provide your phone number to AARP and the National Alliance for Caregiving, who may share your phone number with reporters looking to speak with a caregiver. It is completely optional.

Yes ..... 1  
No/Decline..... 2

**[THANK YOU]:** Thank you very much for your time. Your responses have been very helpful to this research.

## PHONE VERSION

### A. INTRO

---

**SAMPLE:**

7 = Asian oversample (phone)

**TYPE:**

1 = Landline

2 = Cell

Hello. My name is \_\_\_\_\_ and I am an interviewer with National Research. We are conducting an important national study on behalf of the National Alliance for Caregiving and A-A-R-P. We are not selling anything or raising money. The survey is completely confidential.

**[IF LANDLINE (type=1)]:**

If you qualify and complete this important research survey, we'll provide you with a \$15 honorarium. May I please speak to an adult 18 years old or older? **[IF NECESSARY ARRANGE FOR A CALL BACK AND RECORD DATE AND TIME. REPEAT INTRO. AS NECESSARY]**

**[IF CELL SAMPLE (type=2):**

If you qualify and complete this important research survey, we'll provide you with a \$15 check to compensate you for your cell phone minutes. Is now a safe time to talk? **[IF NOT ARRANGE FOR CALLBACK.]**

**[IF NEEDED]:**

This research company will never try to sell you anything.

The survey takes about 20 minutes.

This study is sponsored by the National Alliance for Caregiving and A-A-R-P.

### B. SCREEN

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SC1a. At any time in the last 12 months, has anyone in your household provided unpaid care to a relative or friend 18 years or older to help them take care of themselves?

This may include helping with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This adult need not live with you.

**[IF YES: Is that you or someone else?]**

**[IF R. IS UNSURE, RE-READ QUESTION]**

**[IF R. ASKS "DOES GIVING MONEY COUNT?," ASK: Aside from giving money, do you provide any other type of unpaid care to help them take care of themselves, such as help with personal needs, household chores, arranging for outside services, or other things?]**

**[IF NOTHING OTHER THAN MONEY, CODE "NO"]**

Yes -- Person On Phone Is Caregiver ..... 1  
Yes -- Another Person In Household ..... 2  
No..... 3 **TERMINATE**  
(VOL) Don't know..... 4 **TERMINATE**  
(VOL) Refused..... 5 **TERMINATE**

**IF INITIAL RESPONDENT IS CAREGIVER (SC1a=1), SKIP TO INTRO STATEMENT BEFORE SC2.  
IF ANOTHER IN HOUSEHOLD IS CG (SC1a=2) AND CELL SAMPLE, TERMINATE.  
IF ANOTHER IN HOUSEHOLD IS CG (SC1a=2) AND LANDLINE SAMPLE, CONTINUE.**

SC13. May I please speak to the person in your household who is providing unpaid care to a relative or friend 18 years or older?

**[IF MORE THAN ONE CAREGIVER, ASK TO SPEAK TO THE ONE WITH THE LAST BIRTHDAY]**

Yes ..... 01  
Not available **[DO NOT GO TO SC2; THANK & ARRANGE CALLBACK]**..... 09  
No/Don't know/Refused  
**[DO NOT GO TO SC2; THANK & CALL BACK TO CONVERT]**..... 16

**CALLBACK SCREENS:**

**CB:** When would be a good time to call back? **[RECORD DATE AND TIME]**

**CONF:** Your appointment is set for **[DATE]** at **[TIME]**. Is that correct? **[CONFIRM OR CHANGE DATE AND TIME IF NEEDED]**

**INTRO FOR CALLBACK - (WHEN CALL BACK SCHEDULED AT SC13)**

Hello. My name is \_\_\_\_\_ and I am an interviewer with National Research. We called you recently and we were told that someone in your household is providing unpaid care to a relative or friend.

**[GO TO SC13 AND ASK FOR THE CAREGIVER. USE THE CAREGIVER'S NAME IF KNOWN.]**

**[IF NEEDED]:**

We are conducting a survey about caregiving. We are not selling anything or raising money. The survey is completely confidential.

This research company will never try to sell you anything.

The survey takes about 20 minutes.

This research is sponsored by the National Alliance for Caregiving and A-A-R-P.

SC14a. **[IF NEW CAREGIVER COMES TO PHONE (SC13=1)]** Hello. We are conducting a survey about caregiving. Just to confirm...

At any time in the last 12 months, including now, have you provided unpaid care to a relative or friend 18 years or older to help them take care of themselves?

**[IF NEEDED:** Unpaid care may include help with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing.]

Yes ..... 1 **SKIP TO INTRO BEFORE SC2**  
No ..... 2  
**(VOL)** Don't know..... 3  
**(VOL)** Refused..... 4

SC14c. Is there someone else in your household who is a caregiver?

- Yes ..... 1 **[SKIP BACK TO SC13]**
- No ..... 2 **[TERMINATE]**
- (VOL) Don't know..... 3 **[TERMINATE]**
- (VOL) Refused..... 4 **[TERMINATE]**

**CAREGIVER ON PHONE** (initial respondent or handed the phone by initial respondent):

**INTRO STATEMENT:** This is an important study and to be sure we talk to a variety of people, I need to ask you some basic questions.

SC2. How old were you on your last birthday? **[RECORD AGE]**

\_\_\_\_\_ **[SKIP TO SC3. TERMINATE IF <18.]**

- (VOL) Don't know..... 998
- (VOL) Refused..... 999

SC2b. **[IF DON'T KNOW/REFUSED (SC2=98 or 99)]** Well are you... **[READ LIST]**

- 18 to 24 ..... 1
- 25 to 34 ..... 2
- 35 to 44 ..... 3
- 45 to 54 ..... 4
- 55 to 64 ..... 5
- 65 to 74, or ..... 6
- 75 or older? ..... 7
- (VOL) Don't know..... 8 **[TERMINATE]**
- (VOL) Refused..... 9 **[TERMINATE]**

SC4. Would you say you are White, Black or African American, Asian or Pacific Islander, or something else? **[ALLOW MULTIPLE RESPONSE]**

- White ..... 1
- Black ..... 2
- Asian/Pacific Islander..... 3 **[SKIP TO SC5]**
- Other **[SPECIFY\_\_\_\_\_]**..... 4
- (VOL) Don't know..... 5
- (VOL) Refused..... 6

SC4b. Are you of Asian origin, background, or descent, including the regions of the Indian subcontinent, Far East, Southeast Asia, or Pacific Islands?

- Yes ..... 1
- No..... 2 **[TERMINATE]**
- (VOL) Don't know..... 3 **[TERMINATE]**
- (VOL) Refused..... 4 **[TERMINATE]**

SC5. **RECORD GENDER, DO NOT ASK**

- Male ..... 1
- Female ..... 2

SC6. How many people, including children, live in your household?

[INTERVIEWER NOTE: Count should include the respondent.]

\_\_\_\_\_ [RECORD NUMBER; ALLOW 1 - 30]

Lives alone ..... 1 [SKIP TO TEXT BEFORE Q1]  
(VOL) Don't know ..... 98 [TERMINATE]  
(VOL) Refused ..... 99 [TERMINATE]

SC7. Are you the person in the household who owns or rents the residence?

[WE WANT THE PERSON WHO PAYS THE MORTGAGE OR WHOSE NAME IS ON THE LEASE. IF THERE ARE MULTIPLE PEOPLE, THAT IS OK AS LONG AS THEY ARE ONE OF THEM.]

Yes ..... 1  
No ..... 2 [SKIP TO SC9]  
(VOL) Don't know ..... 3 [TERMINATE]  
(VOL) Refused ..... 4 [TERMINATE]

SC8. [IF HOUSEHOLDER (SC7=1)] Are you related by marriage, blood, or adoption to anyone in the household?

Yes ..... 1 [SKIP TO TEXT BEFORE Q1]  
No ..... 2 [SKIP TO TEXT BEFORE Q1]  
(VOL) Don't know ..... 3 [TERMINATE]  
(VOL) Refused ..... 4 [TERMINATE]

SC9. Thinking about the person who owns or rents the house, please tell me, is that person related to anyone in the household by marriage, blood, or adoption?

[IF MORE THAN ONE PERSON OWNS/RENDS, WE WANT THE PERSON WHO PAYS THE MORTGAGE OR WHOSE NAME IS ON THE LEASE]

Yes ..... 1  
No ..... 2  
(VOL) Don't know ..... 3 [TERMINATE]  
(VOL) Refused ..... 4 [TERMINATE]

SC10. Thinking about the person who owns or rents the house, how old is that person?

[PROMPT: Your best estimate is fine]

\_\_\_\_\_ [RECORD AGE; ALLOW 18 - 96]

97 or older ..... 97  
(VOL) Don't know ..... 98 [TERMINATE]  
(VOL) Refused ..... 99 [TERMINATE]

SC11. As far as you know, is the person of Hispanic origin or background?

Yes ..... 1  
No ..... 2  
(VOL) Don't know ..... 3  
(VOL) Refused ..... 4

SC12. Would you say they are White, Black or African American, Asian or Pacific Islander, or something else? **[ALLOW MULTIPLE RESPONSE]**

**[IF HISPANIC, PROMPT:]** I've recorded their Hispanic ethnicity. This question asks their race. **[REPEAT QUESTION]**

- White ..... 1
- Black ..... 2
- Asian/Pacific Islander..... 3
- Other **[SPECIFY \_\_\_\_\_]** ..... 4
- (VOL)** Don't know..... 5 **[TERMINATE]**
- (VOL)** Refused..... 6 **[TERMINATE]**

**ALL CAREGIVERS:**

**C. CHARACTERISTICS OF THE RELATIONSHIP**

This survey is part of an important national study conducted by the National Alliance for Caregiving and A-A-R-P. We really appreciate your participation.

**[IF HELPFUL, INTERVIEWER MAY TELL RESPONDENT]** This is a national survey, and although individual answers are confidential, the results from the overall survey will be published.

1. Are you currently providing unpaid help to an adult relative or friend or, was this something you did in the past 12 months and are no longer doing?

**[IF BOTH CURRENT AND PAST, CODE "CURRENTLY" AND SAY:]** Let's talk about whomever you are currently providing care for.

- Currently..... 1
- Past 12 months but not currently ..... 2
- (VOL)** Don't know..... 3
- (VOL)** Refused..... 4

**WORDING NOTE 1:**

**IF CURRENTLY (Q1=1): USE PRESENT TENSE, first verb in {BRACKETS}**

**IF PAST 12 MONTHS (Q2=2, 3, or 4): USE PAST TENSE, second verb in {BRACKETS}**

2. How many adults {do you provide care for? / did you provide care for in the past 12 months?} **[RECORD NUMBER]**

\_\_\_\_\_ **[ALLOW 0-97; TERMINATE IF 0]**

- (VOL)** Don't know..... 98 **[TERMINATE]**
- (VOL)** Refused..... 99 **[TERMINATE]**

**FOR THE FEW RESPONDENTS WHO SAY THEY ARE CAREGIVERS TO 5+ PEOPLE, WE WILL DOUBLE CHECK THAT THEY ARE TRULY CAREGIVERS – THEY CAN'T BE IN AN INSTITUTIONAL SETTING AND THEY MUST BE CARING FOR RECIPIENTS WHO DO HAVE SPECIAL NEEDS.**

3. **[IF Q2 >= 5]** {Are/were} all of these people together in an institutional or group setting, like a nursing home, senior center, or school where you work or volunteer?

- Yes **[TERMINATE]**..... 1
- No..... 2
- (VOL)** Don't know **[TERMINATE]** ..... 3

4. **[IF Q2 >= 5]** How many of the people you help care for {have/had} some sort of special need that {is/was} the reason for their care? All of them, some of them, or none of them?

**[IF NEEDED:]** A special need could be an illness, injury, disability, or mental health problem.

All **[SKIP TO TEXT AFTER Q2B]** ..... 1  
 Some **[GO TO Q2B]** ..... 2  
 None **[TERMINATE]** ..... 3  
**(VOL)** Don't know **[TERMINATE]** ..... 4

- 2b. How many adults with some sort of special need {do you provide care for? / did you provide care for in the past 12 months?} **[RECORD NUMBER]**

\_\_\_\_\_ **[ALLOW 0-97; TERMINATE IF 0]**

**(VOL)** Don't know.....98 **[TERMINATE]**  
**(VOL)** Refused.....99 **[TERMINATE]**

**[IF ONE PERSON (Q2=1 OR Q2B=1):** Now, I'd like to ask you some questions about the adult for whom you {provide/provided} care.]

**[IF MORE THAN ONE (Q2=2 thru 97 OR Q2b=2 thru 97):** Let's focus on the adult for whom you {provide/provided} the most assistance.]

5. How old {is/was} that adult? **[PROMPT: Your best estimate is fine]**

\_\_\_\_\_ **[RECORD AGE IN YEARS]**

**(VOL)** Less than 18 years old .....997 **[TERMINATE]**  
**(VOL)** Don't know .....998  
**(VOL)** Refused .....999

9. And {is/was} the person you {care/cared} for male or female?

Male ..... 1  
 Female ..... 2  
**(VOL)** Refused ..... 3

**INTERVIEWER TRAINING NOTE: FOR REST OF SURVEY, USE THE APPROPRIATE WORDING.**  
 IF MALE (Q9=1): USE MASCULINE TERM (he/his/him)  
 IF FEMALE (Q9=2): USE FEMININE TERM (she/hers/her)  
 IF REFUSED (Q9=3): USE BOTH TERMS (he/she; his/hers; him/her)

7. Who {are you caring/did you care} for? **[PRE-CODED OPEN END. DO NOT READ LIST]**

**[AS NEEDED: What {is/was} this person's relationship to you? She/He is your \_\_\_\_?]**

<b>RELATIVE:</b>	<b>[IF Q9&gt;1]:</b> Aunt .....	1
	<b>[IF Q9=1 or 3]:</b> Brother .....	2
	<b>[IF Q9=1 or 3]:</b> Brother-In-Law .....	3
	Companion/Partner.....	4 <b>[Use "Partner"]</b>
	<b>[IF Q9&gt;1]:</b> Daughter .....	5
	<b>[IF Q9=1 or 3]:</b> Father.....	6
	<b>[IF Q9=1 or 3]:</b> Father-In-Law.....	7
	<b>[IF Q9&gt;1]:</b> Granddaughter.....	8
	<b>[IF Q9=1 or 3]:</b> Grandfather.....	9
	<b>[IF Q9&gt;1]:</b> Grandmother.....	10
	Grandparent-In-Law.....	11
	<b>[IF Q9=1 or 3]:</b> Grandson .....	12
	<b>[IF Q9&gt;1]:</b> Mother.....	13
	<b>[IF Q9&gt;1]:</b> Mother-In-Law.....	14
	<b>[IF Q9=1 or 3]:</b> Nephew.....	15
	<b>[IF Q9&gt;1]:</b> Niece.....	16
	Same-sex partner .....	30 <b>[Use "Partner"]</b>
	<b>[IF Q9&gt;1]:</b> Sister.....	17
	<b>[IF Q9&gt;1]:</b> Sister-In-Law.....	18
	<b>[IF Q9=1 or 3]:</b> Son.....	19
Spouse (Husband or wife) .....	20	
	<b>[Use "Husband" if q9=1; Use "Wife" if q9=2; Use "Spouse" if q9&gt;2]</b>	
<b>[IF Q9=1 or 3]:</b> Uncle.....	21	
Other Relative <b>[SPECIFY _____]</b> .....	22 <b>[Use "Relative"]</b>	
<b>NON-RELATIVE:</b> Foster child .....	23	
Friend.....	24	
Neighbor .....	26	
Other non-relative .....	27 <b>[Use "care recipient"]</b>	
<b>(VOL)</b> Don't know .....	28 <b>[Use "care recipient"]</b>	
<b>(VOL)</b> Refused.....	29 <b>[Use "care recipient"]</b>	

11. {Does/At the time you provided care, did} your **[Q7 CODE]** live.... **[READ LIST]**

In your household.....	1 <b>[SKIP TO Q16]</b>
Within twenty minutes of your home .....	2
Between twenty minutes and an hour from your home.....	3
One to two hours from your home, or .....	4
More than two hours away? .....	5
<b>(VOL)</b> Don't know.....	6
<b>(VOL)</b> Refused.....	7

12. **[IF NOT IN HOUSEHOLD (Q11=2 thru 7)]** On average, how often {do/did} you visit your **[Q7 CODE]**.....more than once a week, once a week, few times a month, once a month, few times a year, or less often?
- More than once a week ..... 1  
 Once a week ..... 2  
 Few times a month ..... 3  
 Once a month ..... 4  
 Few times a year ..... 5  
 Less often ..... 6  
**(VOL)** Don't know ..... 7  
**(VOL)** Refused ..... 8
13. **[IF NOT IN HOUSEHOLD (Q11=2 thru 7)]** {Does/At the time you provided care, did} your **[Q7 CODE]** live in...**[READ ENTIRE LIST]**
- His or her own home ..... 1  
 Someone else's home..... 2 **[SKIP TO Q15]**  
 An independent living or retirement community ..... 3  
 In an assisted living facility where some care may be provided..... 4 **[SKIP TO Q15]**  
 A nursing care or long-term care facility..... 5 **[SKIP TO Q15]**  
 Or somewhere else? **[SPECIFY \_\_\_\_\_]** ..... 8  
**(VOL)** Don't know..... 9  
**(VOL)** Refused..... 10
- 14c. {Does/At the time you provided care, did} your **[Q7 CODE]** live alone?
- Yes ..... 1  
 No..... 2  
**(VOL)** Don't know..... 3  
**(VOL)** Refused..... 4
15. {Does/At the time you provided care, did} your **[Q7 CODE]** live in a rural area?
- Yes ..... 3  
 No..... 6  
**(VOL)** Don't know..... 4  
**(VOL)** Refused..... 5
16. And do you live in a rural area?
- Yes ..... 1  
 No..... 2  
**(VOL)** Don't know ..... 3  
**(VOL)** Refused ..... 4

**D. CHARACTERISTICS OF RECIPIENT**

17. {Does/Did} your [Q7 CODE] need care because of a...[READ ITEMS A-G IN ORDER]

		Yes	No	(VOL) DK	(VOL) RF
a.	Short-term physical condition?	1	2	3	4
b.	Long-term physical condition?	1	2	3	4
c.	Emotional or mental health problem?	1	2	3	4
d.	Developmental or intellectual disorder or mental retardation?	1	2	3	4
f.	Behavioral issue?	1	2	3	4
g.	A memory problem?	1	2	3	4

18. What {is/was} the main problem or illness your [Q7 CODE] {has/had}, for which he/she {needs/needed} your care?

**[DO NOT READ RESPONSE LIST. CODE BASED ON RESPONDENT ANSWER. ACCEPT ONLY ONE.]**

**[IF “DISABLED”, PROBE: “What kind of disability would that be?”]**

- Alzheimer’s, confusion, dementia, forgetfulness .....3
- Arthritis .....5
- Back problems .....8
- Blindness, vision loss, can’t see well .....10
- Blood pressure, hypertension .....11
- Brain damage or injury .....12
- Broken bones .....13
- Cancer .....14
- Deafness, hearing loss .....15
- Diabetes .....16
- Feeble, unsteady, falling .....18
- Heart disease .....19
- Lung disease, emphysema, COPD .....20
- Mental retardation, developmental or intellectual disorder,  
Down syndrome .....21
- Mental illness, emotional illness, depression .....22
- Mobility problem, can’t get around .....23
- Old age, just old, Aging .....24
- Parkinson’s .....27
- Stroke .....30
- Substance/drug/alcohol abuse .....31
- Surgery, wounds .....32
- Other [SPECIFY \_\_\_\_\_] .....33
- (VOL) Don't know.....34
- (VOL) Refused.....35

20. **[IF ALZHEIMER’S NOT MENTIONED (Q18#3)]** {Does/Did} your **[Q7 CODE]** suffer from Alzheimer’s or other mental confusion?

**[IF NEEDED: Is that Alzheimer’s or some other confusion?]**

- Yes—Alzheimer’s .....1
- Yes--Other .....2
- No .....3
- (VOL)** Don't know .....4
- (VOL)** Refused .....5

20B. **[IF PARKINSON’S NOT MENTIONED (Q18#27)]** {Does/Did} your **[Q7 CODE]** suffer from Parkinson’s?

- Yes .....1
- No .....2
- (VOL)** Don't know .....3
- (VOL)** Refused .....4

21. For how long {have you been providing/did you provide} care to your **[Q7 CODE]**?

**[DO NOT READ RESPONSES, CODE YEARS BEEN CARING, USE CODES FOR LESS THAN 1 YEAR]**

**[PROMPT: Your best estimate is fine]**

\_\_\_\_\_ **[ALLOW 1-93]**

**ALLOW PRE-CODED OPEN END:**

- Less than six months .....96
- Six months to one year .....95
- (VOL)** All their life.....94
- (VOL)** Don't know .....98
- (VOL)** Refused .....99

22. {Do/Did} you help your **[Q7 CODE]**...**[RANDOMIZE & READ LIST]**

**[READ STEM OR RESPONSES AS NEEDED.]**

		Yes	No	(VOL) DK	(VOL) RF
a.	Get in and out of beds and chairs?	1	2	3	4
b.	Get dressed?	1	2	3	4
c.	Get to and from the toilet?	1	2	3	4
d.	Bathe or shower?	1	2	3	4
e.	By dealing with incontinence or diapers?	1	2	3	4
f.	By feeding him or her?	1	2	3	4
g.	By giving medicines, like pills, eye drops, or injections for his/her condition?	1	2	3	4

N1. **[IF DOES ADLS (ANY Q22a thru Q22f = 1)]:** On a scale of 1 to 5, where 1 is not at all difficult and 5 is very difficult, how difficult {is/was} it for you to help your **[Q7 CODE]** with {these/those} kinds of tasks?

- Not at all difficult ..... 1
- 2 ..... 2
- 3 ..... 3
- 4 ..... 4
- Very difficult..... 5
- (VOL)** Don't know ..... 6
- (VOL)** Refused ..... 7

23. {Do/Did} you provide help to your **[Q7 CODE]** ...**[RANDOMIZE ITEMS A-F, KEEP G-H LAST]**

		Yes	No	(VOL) DK	(VOL) RF
a.	With managing finances, such as paying bills, or filling out insurance claims	1	2	3	4
b.	With grocery or other shopping	1	2	3	4
c.	With housework, such as doing dishes, laundry, or straightening up	1	2	3	4
d.	With preparing meals	1	2	3	4
e.	With transportation, either by driving him/her, or helping your <b>[Q7 CODE]</b> get transportation	1	2	3	4
f.	With arranging outside services, such as nurses, home care aides, or meals on wheels	1	2	3	4

N2. **[IF MANAGES FINANCES (Q23A=1)]:** {Have/Did} you {experienced/experience} any problems dealing with a bank or credit union when you were helping your **[Q7 CODE]** manage his/her finances? **[PROMPT YES OR NO IF NEEDED]**

- Yes ..... 1
- No ..... 2
- (VOL)** Don't know ..... 3
- (VOL)** Refused ..... 4

23\_1. And {do/did} you provide help to your **[Q7 CODE]** by...**[RANDOMIZE ITEMS G-J]**

		Yes	No	(VOL) DK	(VOL) RF
g.	Advocating for him/her with health care providers, community services, or government agencies	1	2	3	4
i.	Monitoring the severity of his/her condition so that you {can/could} adjust care accordingly	1	2	3	4
j.	Communicating with health care professionals like doctors, nurses, or social workers about his/her care	1	2	3	4

25. Thinking now of all the kinds of help you {provide/provided} for your [Q7 CODE], about how many hours {do/did} you spend in an average week, helping him/her? [RECORD HOURS PER WEEK]

\_\_\_\_\_ [ALLOW 1-168]

Less than 1 hour per week .....	169
(VOL) Constant care .....	170
(VOL) Don't know .....	171
(VOL) Refused .....	172

**E. MEDICAL-NURSING TASKS**

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N3. {Do/Did} you help your [Q7 CODE] with any medical-nursing tasks?

This might include giving medicines like pills, eye drops, or injections, preparing food for special diets, tube feedings, or wound care. You could be monitoring things like blood pressure or blood sugar, helping with incontinence, or operating equipment like hospital beds, wheelchairs, oxygen tanks, nebulizers, or suctioning tubes.

[PROMPT YES OR NO IF NEEDED]

Yes .....	1
No .....	2
(VOL) Don't know .....	3
(VOL) Refused .....	4

N3B. [IF DOES MEDICINE (Q22G=1) AND NOT M/N TASKS (N3>1)]: You said earlier in the survey that you {help/helped} your [Q7 CODE] by giving medicines, like eye drops, pills, or injections for his/her condition. Is that correct? [PROMPT YES OR NO IF NEEDED]

Yes, I {help/helped} give medicines .....	1 [REPUNCH N3=1]
No, I {do/did} not help with that .....	2 [REPUNCH Q22G=2]

**IF NO/DK/REF TO ADLS (ALL Q22a thru f > 1) AND IADLS (Q22G>1 and ALL Q23a thru f > 1) AND Medical-nursing (N3>1), THEN TERMINATE AS NON CAREGIVER.**

**IF NO M/N (N3>1), SKIP TO N8.**

N4. [IF DOES M/N TASKS (N3=1)]: On a scale of 1 to 5, where 1 is “not at all difficult” and 5 is “very difficult”, How difficult {is/was} it for you to do the medical-nursing tasks that {are/were} required to help your [Q7 CODE]?

[INTERVIEWER READ ONLY IF NEEDED]: These tasks include: giving medicines like pills, eye drops, or injections, preparing food for special diets, tube feedings, wound care, monitoring things like blood pressure or blood sugar, helping with incontinence, or operating equipment like hospital beds, wheelchairs, oxygen tanks, nebulizers, or suctioning tubes.

Not at all difficult .....	1
2 .....	2
3 .....	3
4 .....	4
Very difficult.....	5
(VOL) Don't know .....	6
(VOL) Refused .....	7

N5. **[IF DOES M/N TASKS (N3=1)]:** Did anyone prepare you to do these tasks? **[PROMPT YES OR NO IF NEEDED]**

**[INTERVIEWER READ ONLY IF NEEDED]:** These tasks include: giving medicines like pills, eye drops, or injections, preparing food for special diets, tube feedings, wound care, monitoring things like blood pressure or blood sugar, helping with incontinence, or operating equipment like hospital beds, wheelchairs, oxygen tanks, nebulizers, or suctioning tubes.

- Yes ..... 1
- No ..... 2 **[SKIP TO N8]**
- (VOL)** Don't know ..... 3 **[SKIP TO N8]**
- (VOL)** Refused ..... 4 **[SKIP TO N8]**

N6. **[IF PREPARED (N5=1)]:** Who prepared you to do the medical-nursing tasks needed to help your **[Q7 CODE]**? **[OPEN END RESPONSE; INTERVIEWER PROBE ABOUT THE TYPE OF PERSON WHO TRAINED THEM]**

\_\_\_\_\_

N7. **[IF PREPARED (N5=1)]:** How well do you feel that person prepared you to take on these medical-nursing tasks? Would you say... **[READ SCALE; ROTATE 1-3/3-1]**

- Very well..... 1
- Somewhat well, or..... 2
- Not well ..... 3
- (VOL)** Don't know ..... 4
- (VOL)** Refused ..... 5

N8. If you had to learn how to do a medical-nursing task, how would you prefer to learn? Would you prefer...**[RANDOMIZE ITEMS A-G, KEEP H LAST, PROMPT YES OR NO IF NEEDED]**

**[INTERVIEWER READ IF NEEDED]:** These tasks include: giving medicines like pills, eye drops, or injections, preparing food for special diets, tube feedings, wound care, monitoring things like blood pressure or blood sugar, helping with incontinence, or operating equipment like hospital beds, wheelchairs, oxygen tanks, nebulizers, or suctioning tubes.

		Yes	No	(VOL) DK	(VOL) RF
a.	Having a 24-hour number to call if you have questions	1	2	3	4
b.	You do the task while a qualified person watches you	1	2	3	4
c.	You listen to someone tell you how to do it	1	2	3	4
d.	Having unlimited access to a video of a qualified person doing the task	1	2	3	4
e.	Reading word-only written instructions	1	2	3	4
f.	Having instructions with pictures of what to do	1	2	3	4
g.	A qualified person show you how to do the task	1	2	3	4
h.	Some other way of learning? <b>[SPECIFY: _____]</b>	1	2	3	4

**F. HOSPITALIZATION**

---

N9. In the last 12 months **[IF PAST (Q1>1), INSERT: that you were caring for him/her]**, how many times was your **[Q7 CODE]** hospitalized overnight? **[CODE RESPONSE TO LIST; READ RESPONSE LIST ONLY IF NEEDED]**

- None.....1
- One time .....2
- 2 times.....3
- 3 or more times .....4
- (VOL) Don't know** .....5
- (VOL) Refused** .....6

N10. **[IF HOSPITAL (N9=2, 3, 4)]**: When your **[Q7 CODE]** was in the hospital, were you included by health care workers, like nurses, doctors, or social workers, in discussions about your **[Q7 CODE]**'s care?

Would you say...**[READ RESPONSE LIST]**

- Yes, all the time .....3
- Only some of the time .....2
- No and you should have been, or .....1
- No, but you did not need to be included?.....5
- (VOL) Don't know** .....4
- (VOL) Refused** .....6

N11. **[IF HOSPITAL (N9=2, 3, 4) AND DOES M/N (N3=1)]**: Before your **[Q7 CODE]** left the hospital or was discharged, did you receive clear instructions about any medical-nursing tasks you would need to perform for your **[Q7 CODE]**? Yes, no, or does this not apply to your situation?

- Yes .....1
- No.....2
- Not applicable (never left/no tasks to do).....4
- (VOL) Don't know** .....3
- (VOL) Refused** .....5

**G. OTHER CAREGIVER SUPPORT**

---

28. Has anyone else provided unpaid help to your **[Q7 CODE]** during the last 12 months?

- Yes .....1
- No.....2 **[SKIP TO Q30]**
- (VOL) Don't know**.....3 **[SKIP TO Q30]**
- (VOL) Refused**.....4 **[SKIP TO Q30]**

29. Who would you consider to be the person who {provides/provided} most of the unpaid care for your **[Q7 CODE]** – you yourself, or someone else?

- Self .....1
- Someone else .....2
- (VOL) We split it evenly** .....3
- (VOL) Don't know**.....4
- (VOL) Refused**.....5

30. During the last 12 months, did your [Q7 CODE] receive paid help from any aides, housekeepers, or other people who were paid to help him/her?

- Yes ..... 1
- No..... 2
- (VOL) Don't know..... 3
- (VOL) Refused..... 4

38. Please think about all of the health care professionals or service providers who {give/gave} care or treatment to your [Q7 CODE]. How easy or difficult {is/was} it for you to coordinate care between these providers? Would you say...[READ LIST]? [ROTATE 1-4/4-1]

- Very easy ..... 1
- Somewhat easy..... 2
- Somewhat difficult ..... 3
- Very difficult..... 4
- (VOL) Not applicable: some else {does/did} that ..... 7
- (VOL) Don't know..... 5
- (VOL) Refused..... 6

N12. Do you expect to have some responsibility for the care of {your [Q7 CODE] or another adult/another adult family member or friend} in the next five years? [PROMPT YES OR NO IF NEEDED]

- Yes ..... 1
- No..... 2
- (VOL) Don't know..... 3
- (VOL) Refused..... 4

**I. PHYSICAL, EMOTIONAL AND FINANCIAL STRESS OF CAREGIVING**

35. Think of a scale from 1 to 5, where 1 is “not a strain at all” and 5 is “very much a strain.” How much of a physical strain would you say that caring for your [Q7 CODE] {is/was} for you?

- 1 – Not a strain at all ..... 1
- 2 ..... 2
- 3 ..... 3
- 4 ..... 4
- 5 – Very much a strain ..... 5
- (VOL) Don't know..... 6
- (VOL) Refused..... 7

36. Using a scale from 1 to 5, where 1 is “not at all stressful” and 5 is “very stressful,” how emotionally stressful would you say that caring for your [Q7 CODE] {is/was} for you?

- 1 – Not at all stressful..... 1
- 2 ..... 2
- 3 ..... 3
- 4 ..... 4
- 5 – Very stressful ..... 5
- (VOL) Don't know..... 6
- (VOL) Refused..... 7

37B. And using a scale from 1 to 5, where 1 is “not a strain at all” and 5 is “very much a strain,” how much of a financial strain would you say that caring for your [Q7 CODE] {is/was} for you?

- 1 – Not a strain at all ..... 1
- 2 ..... 2
- 3 ..... 3
- 4 ..... 4
- 5 – Very much a strain ..... 5
- (VOL) Don't know ..... 6
- (VOL) Refused ..... 7

39. We have been talking about the help you {provide/provided} for your [Q7 CODE]. Do you feel you had a choice in taking on this responsibility for caring for your [Q7 CODE]?

- Yes ..... 1
- No ..... 2
- (VOL) Don't know ..... 3
- (VOL) Refused ..... 4

**H. WORKING CAREGIVERS**

---

32A. Now we have some questions about you. Are you currently employed?

- Yes ..... 1
- No ..... 2
- (VOL) Don't know ..... 3
- (VOL) Refused ..... 4

**IF CURRENT CG (Q1=1) AND CURRENTLY WORKING (Q32A=1), SKIP TO N13.**

33. {Have you been/Were you} employed at any time in the last year while you were also helping your [Q7 CODE]?

- Yes ..... 1
- No ..... 2 [SKIP TO N17]
- (VOL) Don't know ..... 3 [SKIP TO N17]
- (VOL) Refused ..... 4 [SKIP TO N17]

**[IF Q33=1]:** For the next few questions, please think about the most recent time in the last year when you were working and providing care to your [Q7 CODE].

N13. **[IF CURRENTLY EMPLOYED AND CAREGIVING (Q1=1 and Q32A=1)]:** About how many hours a week, on average, do you work?

N13\_1. **[IF EMPLOYED CAREGIVER IN LAST YEAR (Q33=1)]:** When you were last working and helping your [Q7 CODE], about how many hours a week, on average did you work?

- \_\_\_\_ [ENTER NUMBER OF HOURS]
- (VOL) Don't know ..... 98
- (VOL) Refused ..... 99

N13B. **[IF CURRENTLY EMPLOYED AND CAREGIVING (Q1=1 and Q32A=1)]:** Are you currently self-employed or do you own your own business?

N13B\_1. **[IF EMPLOYED CAREGIVER IN LAST YEAR (Q33=1)]:** When you were last working and helping your [Q7 CODE], were you self-employed or did you own your own business?

- Yes ..... 1 **SKIP TO Q34**
- No.....2
- (VOL) Don't know.....3 **SKIP TO Q34**
- (VOL) Refused.....4 **SKIP TO Q34**

N14. **[IF CURRENTLY EMPLOYED AND CAREGIVING (Q1=1 and Q32A=1) AND NOT SELF-EMPLOYED (N13B#1)]:** Does your supervisor know that you are caring for your [Q7 CODE]?

N14\_1. **[IF EMPLOYED CAREGIVER IN LAST YEAR (Q33=1) AND NOT SELF-EMPLOYED (N13B\_1#1)]:** At that time, did your supervisor know that you were caring for your [Q7 CODE]?

- Yes ..... 1
- No.....2
- (VOL) Don't know.....3
- (VOL) Refused.....4

N16. **[IF CURRENTLY EMPLOYED AND CAREGIVING (Q1=1 and Q32A=1) AND NOT SELF-EMPLOYED (N13B#1)]:** For employees in your position, which of the following does your employer offer?

N16\_1. **[IF EMPLOYED CAREGIVER IN LAST YEAR (Q33=1) AND NOT SELF-EMPLOYED (N13B\_1#1)]:** At the time when you were last working and providing care to your [Q7 CODE], for employees in your position, which of the following did your employer offer?

**[RANDOMIZE ITEMS A-E; PROMPT YES OR NO IF NEEDED]**

		Yes	No	VOL DK	VOL RF
a.	Flexible work hours?	1	2	3	4
b.	Telecommuting or working from home?	1	2	3	4
c.	Programs like information, referrals, counseling, or an employee assistance program, to help caregivers like yourself?	1	2	3	4
d.	Paid leave, where you could take paid time off from work for several weeks to care for a family member?	1	2	3	4
e.	Paid sick days?	1	2	3	4

34. As a result of caregiving, did you ever experience any of these things at work? You...  
**[RANDOMIZE ITEMS A-H AND READ LIST; PROMPT YES OR NO IF NEEDED]**

		Yes	No	VOL DK	VOL RF
a.	Went in late, left early, or took time off during the day to provide care?	1	2	3	4
b.	Took a leave of absence?	1	2	3	4
c.	Went from working full-time to part-time, or cut back your hours?	1	2	3	4
d.	Turned down a promotion?	1	2	3	4
e.	Lost any of your job benefits?	1	2	3	4
f.	Gave up working entirely?	1	2	3	4
g.	Retired early?	1	2	3	4
h.	Received a warning about your performance or attendance at work?	1	2	3	4

N15. **[IF LEFT (Q34b=1 OR Q34f=1 OR Q34g=1)]:** Why did you leave your job?  
**[OPEN-END RESPONSE, PROBE FOR PULL BETWEEN WORK AND CAREGIVING.]**

N17. Have you ever been fired from any job as a result of being a caregiver for your **[Q7 CODE]** or any other loved one?

- Yes ..... 1
- No..... 2
- (VOL)** Don't know..... 3
- (VOL)** Refused..... 4

N18. Would you support banning workplace discrimination against workers who have caregiving responsibilities? **[PROMPT YES OR NO]**

- Yes ..... 1
- No..... 2
- Don't know..... 3
- (VOL)** Refused..... 4

**J. INFORMATION/SERVICES/POLICY**

45. In your experience as a caregiver, have you ever.... [READ LIST; RANDOMIZE ORDER A-F]

		Yes	No	(VOL) DK	(VOL) RF
a.	Requested information about how to get financial help for your [Q7 CODE]?	1	2	3	4
b.	Used respite services where someone would take care of your [Q7 CODE] to give you a break?	1	2	3	4
c.	Had an outside service provide transportation for your [Q7 CODE] instead of you providing the transportation?	1	2	3	4
d.	Had modifications made in the house or apartment where your [Q7 CODE] {lives/lived} to make things easier for him/her?	1	2	3	4
e.	Had a doctor, nurse, or social worker ask you about what you {need/needed} to help care for your [Q7 CODE]?	1	2	3	4
f.	Had a doctor, nurse, or social worker ask you what you {need/needed} to take care of yourself?	1	2	3	4

N19. On a scale of 1 to 5, where 1 is “not at all difficult” and 5 is “very difficult”, How difficult {is/was} it to get affordable services in your [Q7 CODE]’s local area or community that {could help/would have helped} you care for your [Q7 CODE], like delivered meals, transportation, or in-home health services?

- Not at all difficult ..... 1
- 2 ..... 2
- 3 ..... 3
- 4 ..... 4
- Very difficult..... 5
- (VOL) Don't know ..... 6
- (VOL) Refused ..... 7

N20. Various organizations are thinking about ways to help caregivers like you. Which of the following do you think would {be/have been} helpful to you? **[RANDOMIZE ITEMS A-F; PROMPT YES OR NO IF NEEDED]**

		Yes	No	(VOL) DK	(VOL) RF
a.	Requiring health care providers to include your name on your <b>[Q7 CODE]</b> 's medical chart, so you {are/were} part of conversations or decisions about his/her care	1	2	3	4
b.	Requiring hospitals to {keep/have kept} you informed about major decisions, like transferring or discharging your <b>[Q7 CODE]</b>	1	2	3	4
c.	Requiring hospitals or facilities to instruct or demonstrate any medical-nursing tasks you might {need/have needed} to do	1	2	3	4
d.	Having respite services available, where someone would {take/have taken} care of your <b>[Q7 CODE]</b> to give you a break	1	2	3	4
e.	Requiring a doctor, nurse, or social worker ask you about what you {need/needed} to help care for your <b>[Q7 CODE]</b>	1	2	3	4
f.	Requiring a doctor, nurse, or social worker ask you what you {need/needed} to take care of <u>yourself</u>	1	2	3	4

47a. I am going to read you a list of ways that some people are proposing to help caregivers financially. Please tell me which one you would {find/have found} most helpful. **[ROTATE ITEMS; READ LIST]**

Which one would you {find/have found} most helpful?

- An income tax credit to caregivers, to help offset the cost of care ..... 2
- A partially paid leave of absence from work, for caregivers who are employed..... 3
- A program where caregivers could be paid for at least some of the hours they provide care ..... 4
- (VOL) Don't know ..... 7
- (VOL) Refused ..... 8
- (VOL) None of the above..... 9

48. Which of the following topics do you feel you [need/needed] more help or information? **[RANDOMIZE A-N AND READ LIST; PROMPT YES OR NOT IF NEEDED]**

		Yes	No	(VOL) DK	(VOL) RF
a.	Keeping your <b>[Q7 CODE]</b> safe at home	1	2	3	4
b.	Managing his/her challenging behaviors, such as wandering	1	2	3	4
d.	Managing his/her incontinence or toileting problems	1	2	3	4
l.	Managing your emotional and physical stress	1	2	3	4
m.	Making end-of-life decisions	1	2	3	4
n.	Finding non-English language educational materials	1	2	3	4

N21. {Does/Did} your [Q7 CODE] have plans in place for his/her future care, such as instructions for handling financial matters, healthcare decisions, or living arrangements? **[PROMPT YES OR NO IF NEEDED]**

- Yes ..... 1
- No..... 2
- Don't know..... 3
- (VOL)** Refused..... 4

N22. Do you have your own plans for your future care, such as handling financial matters, healthcare decisions, or living arrangements? **[PROMPT YES OR NO IF NEEDED]**

- Yes ..... 1
- No..... 2
- (VOL)** Don't know..... 3
- (VOL)** Refused..... 4

**K. DEMOGRAPHICS**

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And finally, just a few questions for classification purposes only....

D1. {How would you describe your own health?/When you were last caregiving, was your health...}? **[READ RESPONSES]**

- Excellent ..... 5
- Very good ..... 4
- Good ..... 3
- Fair, or ..... 2
- Poor ..... 1
- (VOL)** Don't know ..... 6
- (VOL)** Refused ..... 7

D2. How would you say taking care of your [Q7 CODE] {has affected/affected} your health? {Has/Did} it... **[READ RESPONSES]** ?

- {Made/Make} it better ..... 1
- Not affected it, or ..... 2
- {Made/Make} it worse ..... 3
- (VOL)** Don't know ..... 4
- (VOL)** Refused ..... 5

**IF CARING FOR HUSBAND/WIFE (Q7=20), AUTOPUNCH D3=1 AND SKIP TO D4.**

D3. {Are you currently/When you were last caregiving, were you}... **[READ LIST]**

- Married ..... 1
- Living with a partner ..... 2
- Widowed ..... 3
- Separated..... 4
- Divorced ..... 5
- Single, never married ..... 6
- (VOL)** Don't know..... 7
- (VOL)** Refused..... 8

- D4. Did you ever serve on active duty in the US Armed Forces?  
**[IF NEEDED: Army, Navy, Air Force, Marines, Coast Guard or Women’s Armed Forces]**  
 Yes ..... 1  
 No..... 2  
 (VOL) Don't know..... 3  
 (VOL) Refused..... 4
- D5. Did your **[Q7 CODE]** serve in the US Armed Forces?  
 Yes ..... 1  
 No..... 2  
 (VOL) Don't know..... 3  
 (VOL) Refused..... 4
- D5B. **[IF CR IS VET (D5=1), ASK]:** Did your **[Q7 CODE]** serve before September 11<sup>th</sup>, 2001?  
 Yes (served before 9/11)..... 1  
 No (served after 9/11) ..... 2  
 (VOL) Don't know..... 3  
 (VOL) Refused..... 4
- D6. {Are/When you were last caregiving, were} there any children or grandchildren living in your household under 18 years of age?  
 Yes ..... 1  
 No..... 2  
 (VOL) Don't know..... 3  
 (VOL) Refused..... 4
- D7. What is the last grade of school you completed? **[IF NEEDED, READ LIST]**  
 Less than high school ..... 1  
 High school grad/GED ..... 2  
 Some college ..... 3  
 Technical school or Associates degree..... 4  
 College graduate with Bachelor’s degree ..... 5  
 Graduate or Professional degree (or more) ..... 6  
 (VOL) Don't know..... 7  
 (VOL) Refused..... 8
- D8a. Last year, was your total annual household income from all sources, before taxes over or under \$50,000?  
 Over ..... 1 **[GO TO d]**  
 Under ..... 2 **[GO TO b]**  
 (VOL) Don't know..... 3 **[SKIP TO D10]**  
 (VOL) Refused..... 4 **[SKIP TO D10]**
- b. **[IF UNDER \$50,000:]** Over or under \$30,000?  
 Over..... 1 **[SKIP TO D10]**  
 Under..... 2 **[GO TO c]**  
 (VOL) Don't know..... 3 **[SKIP TO D10]**  
 (VOL) Refused..... 4 **[SKIP TO D10]**

- c. **[IF UNDER \$30,000:]** Over or under \$15,000?
- Over..... 1 **[SKIP TO D10]**
  - Under..... 2 **[SKIP TO D10]**
  - (VOL) Don't know ..... 3 **[SKIP TO D10]**
  - (VOL) Refused ..... 4 **[SKIP TO D10]**

- d. **[IF OVER 50,000:]** Over or under \$100,000?
- Over..... 1 **[SKIP TO D10]**
  - Under..... 2 **[GO TO e]**
  - (VOL) Don't know ..... 3 **[SKIP TO D10]**
  - (VOL) Refused ..... 4 **[SKIP TO D10]**

- e. **[IF UNDER 100,000:]** Over or under \$75,000?
- Over..... 1 **[SKIP TO D10]**
  - Under..... 2 **[SKIP TO D10]**
  - (VOL) Don't know ..... 3 **[SKIP TO D10]**
  - (VOL) Refused ..... 4 **[SKIP TO D10]**

D10. If the situation arose, would you be interested in participating in future research on caregivers?

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

D11. Also, the results of this survey are totally confidential. However if a reporter writing a story about the results of the overall survey wanted to interview you for a news story, would you like to get a call back or not? It is completely optional.

- Yes ..... 1
- No **[SKIP TO C2]** ..... 2
- (VOL) Don't know **[SKIP TO C2]** ..... 3
- (VOL) Refused **[SKIP TO C2]** ..... 4

**[IF D10=1 OR D11=1, ASK:]** What is the best number to call you on **[IF D10=1: for future research]?**

- [ ] ..... 98
- The number we called ..... 98
- (VOL) Refused ..... 99

C2. And what name and address can we use to send you your \$15 check?

**[COLLECT NAME AND FULL MAILING ADDRESS]**

**NAME (first and last):** \_\_\_\_\_

**STREET ADDRESS:** \_\_\_\_\_

**CITY:** \_\_\_\_\_

**STATE:** \_\_\_\_\_

**ZIP:** \_\_\_\_\_

- (VOL) Declines \$15 check ..... 99

**[THANK YOU]:** Thank you very much for your time. Your responses have been very helpful to this research.