

## Caregiving in the U.S. 2020 - 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
- 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 does not 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 (not me) ..... 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 (not me) ..... 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 Q2.**

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 BEFORE Q2.**

**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...?

- 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: CLASSIFY TYPE OF HOUSEHOLD AND INDIVIDUAL**

**COMPUTE CGHHf “Caregiver in Household Field Version”**

- 1 = Caregiver of adult only in HH (SC1A=1 or 2 AND SC1B=3 or REFUSED)
- 2 = Caregiver of adult and caregiver of child in HH (SC1A=1 or 2 AND SC1B=1 or 2)
- 3 = Caregiver of child only in HH (SC1A=3 or REFUSED AND SC1B=1 or 2)
- 4 = No caregiver in Household (SC1A=3 or REFUSED AND SC1B=3 or REFUSED)

IF NO ONE IS CAREGIVER (CGHHf=4): TERMINATE AS “NO CAREGIVER”.

**COMPUTE CGTYPEf “Caregiver Type Field Version”**

- 1 = Caregiver of adult only (SC1A=1 AND SC1B≠1)
- 2 = Caregiver of adult and child (SC1A=1 AND SC1B=1)
- 3 = Caregiver of child only (SC1A≠1 AND SC1B=1)
- 4 = Not a caregiver (SC1A≠1 AND SC1B≠1)

IF RESPONDENT IS NOT CAREGIVER (CGTYPEf=4): TERMINATE AS “CG HOUSEHOLD BUT R NOT CG”.

**CHARACTERISTICS OF THE RELATIONSHIP**

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

**IF CARES FOR ADULT AND CHILD:** For the rest of this survey, please think only about the adult or adults age 18 or older for whom you have provided unpaid care to in the past 12 months.

2. **IF CARES FOR ADULT:** How many adults did you care for in the past 12 months?

**IF CARES FOR CHILD ONLY:** How many children under the age of 18 did you care for in the past 12 months, because that child or children had some sort of medical, behavioral, or other condition or disability?

\_\_\_\_\_ [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]** Were all of these **[IF CARES FOR ADULT: adults / IF CARES FOR CHILD ONLY: children]** together in an institutional or group setting, like a nursing home, senior center, daycare, group home, 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 **[IF CARES FOR ADULT: adults / IF CARES FOR CHILD ONLY: children]** you helped care for had some sort of special need that 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. **IF CARES FOR ADULT:** How many adults with some sort of special need did you provide care for in the past 12 months?
- IF CARES FOR CHILD ONLY:** How many children with some sort of special need 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 **[IF CARES FOR ADULT: adult / IF CARES FOR CHILD ONLY: child]** for whom you provided care.

**[IF MORE THAN ONE (Q2=2 thru 97 OR Q2b=2 thru 97):** For the next set of questions, please think about the **[IF CARES FOR ADULT: adult / IF CARES FOR CHILD ONLY: child]** for whom you provided the most assistance in the past year.

1. Are you currently providing unpaid help to **[IF CARES FOR ADULT: that adult relative or friend / IF CARES FOR CHILD ONLY: that child]**, 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): USE PRESENT TENSE, first verb in {BRACKETS}**  
**IF PAST 12 MONTHS (Q1=2 or REFUSED): USE PAST TENSE, second verb in {BRACKETS}**

5. How old {is/was} that **[IF CARES FOR ADULT: adult / IF CARES FOR CHILD ONLY: child]** **[IF Q1=2 or REFUSED: at the time you provided care]**?
- Your best estimate is fine. [IF CARES FOR CHILD ONLY: If the child is less than 1 year old, please enter '0'.]*
- \_\_\_\_\_ years old **[RECORD AGE IN YEARS; ALLOW 0 - 130]**

9. And {is/was} the person you {care/cared} for...
- Male ..... 1  
 Female..... 2  
 Non-Binary..... 3

**PROGRAMMING NOTE: Use Gender neutral pronouns throughout irrespective of answer to Q9 (1,2,3, OR REFUSED) “they/theirs/them”.**

7. Who {are you caring/did you care} for?  
*Please select one relationship.*

<p><b>[SHOW IF Q9=1, 3, or REFUSED]:</b></p> <p><b>RELATIVE:</b></p> <p>Brother.....2          Brother-In-Law .....3          Companion/Partner .....4          Father.....6          Father-In-Law .....7          Grandfather.....9          Grandfather-In-Law.....11          Grandson .....12          Husband.....20          Nephew.....15          Same-sex partner.....30          Son .....19          Uncle.....21</p> <p><b>NON-RELATIVE:</b></p> <p>Foster child .....23          Friend.....24          Neighbor .....26          Other [SPECIFY ___].....22</p>	<p><b>[SHOW IF Q9=2, 3, or REFUSED]:</b></p> <p><b>RELATIVE:</b></p> <p>Aunt ..... 1          Companion/Partner .....4          Daughter .....5          Granddaughter .....8          Grandmother.....10          Grandmother-In-Law .....11          Mother .....13          Mother-In-Law .....14          Niece.....16          Same-sex partner.....30          Sister .....17          Sister-In-Law .....18          Wife.....20</p> <p><b>NON-RELATIVE:</b></p> <p>Foster child .....23          Friend.....24          Neighbor .....26          Other [SPECIFY ___].....22</p>
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**INSERT RESPONSE FROM Q7 ANYWHERE IT SAYS [Q7 CODE], EXCEPT FOR:**  
**IF Q7=4 or 30 [Use “partner”]**  
**IF Q7=22 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 OR REFUSED)]:** 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 OR REFUSED)]**: Which of the following best describes where your **[Q7 CODE]** {lives/lived at the time you provided care}?
- Their own home **[IF CARES FOR CHILD ONLY: (with parent or guardian)]** ..... 1  
 Someone else's home ..... 2 **[SKIP TO Q15]**  
**IF CARES FOR ADULT: An independent living or retirement community**..... 3  
**IF CARES FOR ADULT: 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]**  
**IF CARES FOR CHILD ONLY: A group home**..... 10 **[SKIP TO Q15]**  
**IF CARES FOR CHILD ONLY: Foster care**..... 11 **[SKIP TO Q15]**  
 Or somewhere else? **[SPECIFY \_\_\_\_\_]**..... 8

**IF CARES FOR CHILD ONLY, SKIP TO Q15.**

- 14c. **IF CARES FOR ADULT RECIPIENT AND IN OWN HOME, INDEPENDENT LIVING, ELSE, REFUSED (Q13: 1 OR 3 OR 6 OR REFUSED)**, ASK: {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

## CHARACTERISTICS OF RECIPIENT

**CHECKPOINT TWO - CREATE A SPLIT SAMPLE VARIABLE FOR USE IN Q17 (50%/50% SPLIT)**  
**VARIABLE NAME = SPLIT17**  
**1 = SPLIT SAMPLE 17A**  
**2 = SPLIT SAMPLE 17B**

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.	<b>IF SPLIT17=1: Developmental or intellectual disorder or mental retardation / IF SPLIT17=2: Developmental or intellectual disorder or delay</b>	1	2
f.	Behavioral issue	1	2
g.	Memory problem	1	2

**CHECKPOINT THREE – CREATE A SPLIT SAMPLE VARIABLE FOR USE IN Q18 (50%/50% SPLIT)**

**VARIABLE NAME = SPLIT18**

**1 = SPLIT SAMPLE 18A (trended Alzheimer’s wording)**

**2 = SPLIT SAMPLE 18B**

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

**IF CARES FOR CHILD ONLY:** ADD, ADHD, Attention deficit disorder..... 1

**IF CARES FOR ADULT AND SPLIT18=1:** Alzheimer’s, confusion, dementia, forgetfulness / **IF CARES FOR ADULT AND SPLIT18=2:** Alzheimer’s, dementia ..... 3

**IF CARES FOR ADULT:** Arthritis ..... 5

**IF CARES FOR CHILD ONLY:** Asthma ..... 6

**IF CARES FOR CHILD ONLY:** Autism or Autism Spectrum Disorder ..... 7

**IF CARES FOR ADULT:** Back problems ..... 8

**IF CARES FOR ADULT:** Blood pressure, hypertension..... 11

Brain damage or injury ..... 12

Broken bones ..... 13

Cancer ..... 14

Developmental or intellectual disorder or disability ..... 21

Diabetes ..... 16

**IF CARES FOR ADULT:** Feeble, unsteady, falling ..... 18

**IF CARES FOR ADULT:** Hearing loss, deafness ..... 15

**IF CARES FOR ADULT:** Heart disease, heart attack ..... 19

**IF CARES FOR ADULT:** Lung disease, emphysema, COPD ..... 20

Mental illness, emotional illness, depression ..... 22

**IF CARES FOR ADULT:** Mobility problem, can’t get around..... 23

**IF CARES FOR ADULT:** Old age, Aging ..... 24

**IF CARES FOR ADULT:** Parkinson’s ..... 27

**IF CARES FOR ADULT:** Stroke ..... 30

Substance, drug, alcohol abuse ..... 31

Surgery, wounds ..... 32

**IF CARES FOR ADULT:** Vision loss, blindness, can’t see well ..... 10

Other [**SPECIFY REQUIRED:** \_\_\_\_\_] ..... 33

Not sure..... 34

19. **[IF CARES FOR CHILD ONLY, ASK]:** As a result of your [Q7 CODE]’s condition {is/was} your [Q7 CODE] limited in any way in their ability to do the things that most children of the same age do?

Yes ..... 1

No ..... 2

**[IF CARES FOR CHILD ONLY AND NO LIMIT (Q19=2) AND NO CONDITIONS (Q17A=2 and Q17B=2 and Q17c=2 and q17d=2 and q17e=2 and Q17F=2), TERMINATE.]**

20. **[IF CARES FOR ADULT AND 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

## LENGTH OF CARE AND TASKS

21. **IF CARES FOR ADULT:** How long {have you been providing/did you provide} care to your [Q7 CODE]?  
**IF CARES FOR CHILD ONLY:** How long {have you been providing/did you provide} care to your [Q7 CODE], over and above normal childcare needs?

*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. **IF CARES FOR ADULT:** Which of these {do/did} you help your [Q7 CODE] with?  
**IF CHILD RECIPIENT (IF CARES FOR CHILD ONLY):** Which of these {do/did} you help your [Q7 CODE] with, because they {are/were} less able to do this task than children of the same age without their condition?

[RANDOMIZE A-F ORDER; ALWAYS SHOW G LAST]

	ADL list	Yes	No
a.	[IF CARE RECIPIENT IS 3+ YEARS (Q5>2): Getting in and out of beds and chairs	1	2
b.	[IF CARE RECIPIENT IS 4+ YEARS (Q5>3): Getting dressed	1	2
c.	[IF CARE RECIPIENT IS 4+ YEARS (Q5>3): Getting to and from the toilet	1	2
d.	[IF CARE RECIPIENT IS 6+ YEARS (Q5>5): Bathing or showering	1	2
e.	[IF CARE RECIPIENT IS 4+ YEARS (Q5>3): By dealing with incontinence or diapers	1	2
f.	[IF CARE RECIPIENT IS 3+ YEARS (Q5>2): By feeding them	1	2
g.	By giving medicines, like pills, eye drops, or injections for their 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]

1 - Not at all difficult ..... 1  
 2 ..... 2  
 3 ..... 3  
 4 ..... 4  
 5 - Very difficult ..... 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.	<b>IF CARES FOR ADULT:</b> Grocery or other shopping	1	2
c.	<b>IF CARES FOR ADULT:</b> Housework, such as doing dishes, laundry, or straightening up	1	2
d.	<b>IF CARES FOR ADULT:</b> Preparing meals	1	2
e.	<b>IF CARES FOR ADULT:</b> Transportation, either by driving them, or helping them get transportation	1	2
f.	Arranging outside services, such as nurses, home care aides, or meals-on-wheels	1	2



M8. **[IF HELPS MANAGE PAPERWORK (Q23A= 1), ASK]:** How time consuming {is/was} it for you to help your **[Q7 CODE]** with their finances, bills, or insurance claims? **[ROTATE 1-5/5-1]**

- 1 - Not at all time consuming..... 1
- 2..... 2
- 3..... 3
- 4..... 4
- 5 - Very time consuming..... 5

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

		Yes	No
g.	Advocating for them with health care providers, community services, <b>[IF CARES FOR CHILD ONLY: schools,]</b> or government agencies	1	2
i.	Monitoring the severity of their condition so that you {can/could} adjust care accordingly	1	2
j.	Communicating with health care professionals like doctors, nurses, or social workers about their 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 them?

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

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

25Z. **[IF CONSTANT CARE (Q25= 168 or 170), ASK]:** We would like to understand a little bit more about people like you who have {to provide/provided} constant care.

Which of the following best describes how much care or help you {have to give/gave} your **[Q7 CODE]**, because of their condition(s) in a normal week? {Do/Did} you provide care...

- All the time: 24 hours a day, 7 days a week ..... 1
- Almost all the time, with only small breaks here or there..... 2
- Almost all the time, with just breaks to sleep ..... 3
- On and off around the clock ..... 4
- Other **[SPECIFY: \_\_\_\_\_]** ..... 5

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

**IF CARES FOR ADULT AND 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.**

- N9. In the last 12 months **[IF Q1=2 or refused: that you were caring for them]**, 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

**OTHER CAREGIVERS – PAID AND UNPAID**

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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
- 29Z. **IF HAS OTHER UNPAID HELP (Q28= 1):** Of all the people who {help provide/provided} care to your **[Q7 CODE]**, {are/were} any of them children under the age of 18?  
 They might {help or assist/have helped or assisted} you with the care you {provide/provided}. The child(ren) may also {help/have helped} with things like bringing items to or from your **[Q7 CODE]**, doing chores or other housework, running errands, or just generally helping watch over your **[Q7 CODE]**.  
 Yes..... 1  
 No..... 2
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 them?  
 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. **IF CARES FOR ADULT:** 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?  
**IF CARES FOR CHILD ONLY:** Do you expect to have some responsibility for the care of {your **[Q7 CODE]** or another person/another person} in the next five years?  
 Yes..... 1  
 No..... 2  
 Not sure..... 3

## PHYSICAL, EMOTIONAL AND FINANCIAL STRESS OF CAREGIVING

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]

- 1 - Not a strain at all ..... 1
- 2 ..... 2
- 3 ..... 3
- 4 ..... 4
- 5 - Very much a strain ..... 5

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

- 1 - Not at all stressful ..... 1
- 2 ..... 2
- 3 ..... 3
- 4 ..... 4
- 5 - Very stressful ..... 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]

- 1 - Not a strain at all ..... 1
- 2 ..... 2
- 3 ..... 3
- 4 ..... 4
- 5 - Very much a strain ..... 5

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

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

M5. How much do you agree or disagree with each statement below about being a caregiver for your [Q7 CODE]? [RANDOMIZE ORDER OF ITEMS A-C]

		<b>Strongly disagree</b>	<b>Disagree</b>	<b>Neither</b>	<b>Agree</b>	<b>Strongly agree</b>
a.	My role as a caregiver {gives/gave} me a sense of purpose or meaning in my life	1	2	3	4	5
b.	I {find/found} it difficult to take care of my own health	1	2	3	4	5
c.	I {feel/felt} alone	1	2	3	4	5

## WORKING CAREGIVERS/STUDENT CAREGIVERS

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 M2]

**[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?  
\_\_\_\_ hours a week [ALLOW 1-80]

- 33Z. **[IF CURRENTLY EMPLOYED AND CAREGIVING (Q1=1 and Q32A=1)]:** Are you...?

- 33Z\_1. **[IF EMPLOYED CAREGIVER IN LAST YEAR (Q33=1)]:** Were you...?
- Paid a salary ..... 1  
Paid hourly for the time you work ..... 2  
Some other arrangement [SPECIFY: \_\_\_\_\_] ..... 3

- 13B. **[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 at your work in a similar role or job as yours, 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 at your work in a similar role or job as yours, which of the following did your employer offer?

**[RANDOMIZE ITEMS A-C; KEEP E-D-F LAST AND IN THAT ORDER]**

		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 family leave, where you could take <u>extended paid</u> time off from work (in weeks) to care for an ill family member	1	2
e.	Paid sick days, where you can take limited paid hours or days off from work to care for or go to appointments with an ill family member	1	2
f.	Unpaid family leave, where you could take extended time off (in weeks) without pay to care for an ill family member	1	2

34. **[IF WORKING CAREGIVER (Q32A= 1 OR Q33= 1), ASK]**: As a result of caregiving, did you ever experience any of these things at work? **[RANDOMIZE ITEMS A-I]**

		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

M2. **[IF NOT WORKING OR NOT WORKED IN PAST YEAR (Q33 NE 1)]**: At any time while you {have been providing/provided} care to your **[Q7 CODE]**, have you worked or had a job?

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

N15. **[IF LEFT (Q34b= 1 OR Q34f= 1 OR Q34g= 1)] OR HAD A JOB AT SOME POINT IN THE FAR PAST (M2= 1)**: Why did you leave your job, take a leave of absence, or otherwise decide to not work while also providing car? **[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

M3. Have you ever felt that your responsibilities as a caregiver led to you being penalized or discriminated against at work?

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

**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 them?	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]**

- 1 - Not at all difficult ..... 1
- 2 ..... 2
- 3 ..... 3
- 4 ..... 4
- 5 - Very difficult ..... 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 4-6; ALLOW MULTIPLE RESPONSE]**

*Select all answers that apply.*

- 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

M1. Where {do/did} you go for help or information about caring for your [Q7 CODE]? Please select all that apply.

- Doctor or health care professional ..... 1
- Friends or family ..... 2
- Government agencies or organizations (local, state, or federal)..... 3
- Local hospital or other care facility ..... 4
- Online or social media ..... 5
- Organization or non-profit for aging, caregiving, or specific condition .... 6
- Somewhere else [SPECIFY: \_\_\_\_\_] ..... 98
- Not applicable: you never got help or information..... 99

M7. In your experience as a caregiver for your [Q7 CODE], have you ever done the following things online? [RANDOMIZE ITEMS A-H]

		Yes	No	Not Applicable
a.	Had a virtual or online visit with a healthcare provider who could care for your [Q7 CODE]	1	2	3
b.	Created an online or shared calendar to organize caregiving schedules or activities	1	2	3
c.	Managed your [Q7 CODE]'s prescription refills or delivery on an app or website	1	2	3
d.	Placed an online order for groceries or household supplies for your [Q7 CODE]	1	2	3
e.	Used a ride service like Lyft or Uber for your [Q7 CODE]	1	2	3
f.	Searched online for support services, aides, facilities, or other help for your [Q7 CODE]	1	2	3
g.	Connected with other caregivers online using social media or support groups	1	2	3
h.	Watched videos to learn how to do different things you need to do to care for your [Q7 CODE]	1	2	3

M11. In your experience as a caregiver for your [Q7 CODE], have you ever done the following things using technology or software? [RANDOMIZE ITEMS A-E]

		Yes	No	Not Applicable
a.	Created electronic lists or spreadsheets to track activities related to providing care for your [Q7 CODE]	1	2	3
b.	Checked up on your [Q7 CODE] using an app, video, wearable device, or other remote monitoring	1	2	3
c.	Tracked your [Q7 CODE]'s personal health records	1	2	3
d.	Tracked your [Q7 CODE]'s finances	1	2	3
e.	Got or used assistive devices for things like your [Q7 CODE]'s low vision or hearing problems	1	2	3

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

Select all that apply.

		Yes
a.	Keeping your [Q7 CODE] safe at home	<input type="checkbox"/> 1
b.	Managing your [Q7 CODE]'s challenging behaviors, such as wandering	<input type="checkbox"/> 1
c.	Activities you {could do/could have done} with your [Q7 CODE]	<input type="checkbox"/> 1
d.	Choosing a home care agency, assisted living facility or nursing home	<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
e.	Figuring out forms, paperwork, or eligibility for services or support for your [Q7 CODE]	<input type="checkbox"/> 1
f.	Managing or handling your own personal finances	<input type="checkbox"/> 1
g.	Using technology to care for your [Q7 CODE]	<input type="checkbox"/> 1
s.	Something else? [SPECIFY: _____]	<input type="checkbox"/> 1
t.	None of the above	<input type="checkbox"/> 1

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

**IF CARES FOR CHILD ONLY BUT NOT CARING FOR OWN CHILD (Q7 NE 5 AND Q7 NE 19):** {Does/Did} your [Q7 CODE]'s family have plans in place for their future care, such as instructions for handling financial matters, healthcare decisions, or living arrangements?

**IF CARES FOR CHILD ONLY AND CARING FOR OWN CHILD (Q7=5 OR Q7=19):** {Do/Did} you have plans in place for your [Q7 CODE]'s 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

M6. As a result of providing care to your [Q7 CODE], have you ever experienced any of these financial things? **[KEEP ORDER AS SHOWN]**

		Yes	No	Not Applicable
a.	Took on more debt (credit cards, loans, lines of credit)	1	2	3
b.	Missed or was late paying for a student loan	1	2	3
c.	Borrowed money from family or friends	1	2	3
d.	Filed for bankruptcy (medical or personal)	1	2	3
e.	Been unable to afford basic expenses like food	1	2	3



		Yes	No	Not Applicable
f.	Left your bills unpaid or paid them late	1	2	3
g.	Used up your personal short-term savings	1	2	3
h.	Used long-term savings, like retirement or education, to pay for other things	1	2	3
i.	Stopped saving	1	2	3
j.	Moved to a less expensive home, apartment, or other living arrangement	1	2	3
k.	Was evicted or had a home foreclosed	1	2	3
l.	Put off when you planned to retire or decided to never retire	1	2	3
m.	Had to start working, work more, or find a second job	1	2	3

M9. Below are some ways that people are proposing to help caregivers financially. How helpful would you {find/have found} each? **[RANDOMIZE ORDER OF ITEMS A-C]**

		Very helpful				Not at all helpful
a.	An income tax credit to caregivers, to help offset the cost of care	5	4	3	2	1
b.	A partially paid leave of absence from work, for caregivers who are employed	5	4	3	2	1
c.	A program where caregivers could be paid for at least some of the hours they provide care	5	4	3	2	1

**PROGRAMMING NOTE: CREATE A COUNT VARIABLE COUNTM9 OF ALL MENTIONS IN M9 WHERE ITEM IS 3 OR HIGHER.**

**IF NONE OR JUST ONE HELPFUL (COUNTM9=0 or 1), SKIP TO TEXT BEFORE M10.**

47a. **IF MULTIPLE HELPFUL (COUNTM9=2 or 3), ASK:** Below are some ways that people are proposing to help caregivers financially. Which one would you {find/have found} most helpful? **[MATCH ORDER OF ITEMS 2-3-4 AS SHOWN IN QUESTION M9]**

	Q47a: MOST
<b>IF HELPFUL (M9a&gt;2):</b> An income tax credit to caregivers, to help offset the cost of care	2
<b>IF HELPFUL (M9b&gt;2):</b> A partially paid leave of absence from work, for caregivers who are employed	3
<b>IF HELPFUL (M9c&gt;2):</b> A program where caregivers could be paid for at least some of the hours they provide care	4
Not sure	7

## DEMOGRAPHICS

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

- M10. At any time in the past year while you were providing care to your [Q7 CODE], were you also a student, either full-time or part-time?
- Yes..... 1  
 No..... 2
- 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
- M12. {Are you, yourself, currently/At the time you last provided care, were you, yourself} covered by any form of health insurance or a health plan?
- Yes..... 1  
 No..... 2
- M13. [IF YES (M12= 1)]: What type of health insurance or health coverage {do/did} you have? Please select your main source of health insurance.
- An employer plan (yours or a family member's)..... 1  
 Plan bought directly (from an insurance company, using an agent, or using an exchange/marketplace)..... 2  
 Medicare (standard, supplemental, and/or Medicare Advantage)..... 3  
 Medicaid coverage provided by your state..... 4  
 Military health care (Tricare, VA, Champ)..... 5  
 Some other type of coverage [SPECIFY: \_\_\_\_\_]..... 6  
 Not sure..... 7  
 No health insurance..... 8
- 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

D6. {Are/When you were last caregiving, were} there any children or grandchildren living in your household under 18 years of age [IF CARING FOR CHILD LIVING IN CG'S HOME (Q11=1), INSERT: in addition to your [DOV\_CODE]]?

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

D5. **IF CARES FOR ADULT:** Did your [Q7 CODE] ever serve in the US Armed Forces?

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

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

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

By agreeing to be contacted, Ipsos will provide your phone number to AARP and the National Alliance for Caregiving's third-party research firm, who may contact you if and when they undertake 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, Ipsos will provide your phone number to AARP and the National Alliance for Caregiving, if and when they have a reporter 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. The results of this research should be released to the public in spring 2020 on both [caregiving.org](http://caregiving.org) and [aarp.org](http://aarp.org), if you are interested in seeing the results.

# PHONE VERSION

## SCREENER

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### 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. The survey is for research purposes only.

[IF LANDLINE (sample= 1)]:

If you qualify and complete this important research survey, we'll provide you with a \$15 check. 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 (sample=2): If you qualify and complete this important research survey, we will provide you with a \$15 check. Is now a safe time to talk?]

**[IF NOT ARRANGE FOR CALLBACK.]**

**[IF NEEDED REASSURE RESPONDENT:** This research company will never try to sell you anything]

**[IF NEEDED REASSURE RESPONDENT:** The survey is completely confidential]

**[IF ASK:** The survey takes about 20 minutes]

**[IF NEEDED:** This study is sponsored by A-A-R-P and the National Alliance for Caregiving.]

## 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 (not the person on the phone) ..... 2

No..... 3

**(VOL)** Don't know ..... 4

**(VOL)** Refused..... 5

SC1b. (new 2019) 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.

**[IF NEEDED:** This could include care for an ongoing medical condition, a serious short-term condition, emotional or behavioral problems, or developmental problems.]

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

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

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

**IF INITIAL RESPONDENT IS CAREGIVER (SC1a=1 OR SC1b=1), SKIP TO INTRO STATEMENT BEFORE SC2.**

**IF NO CAREGIVERS ((SC1a=3 or 4 or 5) AND (SC1b=3 or 4 or 5)), TERMINATE**

**IF ANOTHER IN HOUSEHOLD IS CG ((SC1a=2 AND SC1b NE 1) OR (SC1b=2 and SC1a NE 1)) AND CELL SAMPLE, TERMINATE.**

**IF ANOTHER IN HOUSEHOLD IS CG ((SC1a=2 AND SC1b NE 1) OR (SC1b=2 and SC1a NE 1)) AND LANDLINE SAMPLE, CONTINUE.**

SC13. May I please speak to the person in your household who is providing unpaid care?

**[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
- No..... 2
- (VOL)** Don’t know ..... 3
- (VOL)** Refused..... 4

SC14b. **(new 2019) [IF NEW CAREGIVER COMES TO PHONE (SC13= 1)]** In the last 12 months, have you 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.

**[IF NEEDED:** This could include care for an ongoing medical condition, a serious short-term condition, emotional or behavioral problems, or developmental problems.]

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

**IF NEW PERSON ON PHONE IS A CAREGIVER (SC14a= 1 or SC14b= 1), SKIP TO INTRO BEFORE SC2.**

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. Are you...? **[READ RESPONSES 1-3]**
- Male ..... 1
  - Female..... 2
  - Non-Binary..... 3
  - (VOL) Don't know** ..... 8
  - (VOL) Refused** ..... 9
- 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 CHECKPOINT]**
  - (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 TO KNOW IF THEY ARE 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 CHECKPOINT]**
- No..... 2 **[SKIP TO CHECKPOINT]**
- (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/RENTS, WE MEAN 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]**



**CHECKPOINT: CLASSIFY TYPE OF HOUSEHOLD AND INDIVIDUAL**

**COMPUTE CGHHf “Caregiver in Household Field Version”**

- 1 = Caregiver of adult only in Household (SC1A=1 or 2 AND SC1B=3 or REFUSED or DON'T KNOW)
- 2 = Caregiver of adult and caregiver of child in Household (SC1A=1 or 2 AND SC1B=1 or 2)
- 3 = Caregiver of child only in Household (SC1A=3 or REFUSED or DON'T KNOW AND SC1B=1 or 2)
- 4 = No caregiver in Household (SC1A=3 or REFUSED or DON'T KNOW AND SC1B=3 or REFUSED or DON'T KNOW)

**IF NO ONE IS CAREGIVER (CGHHf=4): TERMINATE AS “NO CAREGIVER”.**

**COMPUTE CGTYPEf “Caregiver Type Field Version”**

- 1 = Caregiver of adult only (SC1A=1 AND SC1B≠1) OR (SC14A=1 AND SC14B≠1)
- 2 = Caregiver of adult and child (SC1A=1 AND SC1B=1) OR (SC14A=1 AND SC14B=1)
- 3 = Caregiver of child only (SC1A≠1 AND SC1B=1) OR (SC14A≠1 AND SC14B=1)
- 4 = Not a caregiver (SC1A≠1 AND SC1B≠1) OR (SC14A≠1 AND SC14B≠1)

**IF RESPONDENT IS NOT CAREGIVER (CGTYPEf=4): TERMINATE AS “CG HOUSEHOLD BUT R NOT CG”.**

## ALL CAREGIVERS

### 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.

**IF CARES FOR ADULT:** For the rest of this survey, please think only about the adult or adults age 18 or older for whom you have provided unpaid care to in the past 12 months.

2. **IF CARES FOR ADULT:** How many adults did you provide care for in the past 12 months? **[RECORD NUMBER]**

**(new 2019) IF CARES FOR CHILD ONLY:** How many children under the age of 18 did you care for in the past 12 months, because that child or children had some sort of medical, behavioral, or other condition or disability? **[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]** Were all of these **[IF CARES FOR ADULT: adults/IF CARES FOR CHILD ONLY: children]** together in an institutional or group setting, like a nursing home, senior center, daycare, group home, or school where you work or volunteer?

Yes **[TERMINATE]** ..... 1

No ..... 2

**(VOL)** Don't know/Refused **[TERMINATE]** ..... 3

4. **[IF Q2 >=5]** How many of the **[IF CARES FOR ADULT: adults/IF CARES FOR CHILD ONLY: children]** you helped care for had some sort of special need that 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/Refused **[TERMINATE]** ..... 4

2b. **IF SOME HAVE SPECIAL NEEDS (Q4=2) AND CARES FOR ADULT:** How many adults with some sort of special need did you provide care for in the past 12 months? **[RECORD NUMBER]**

**IF SOME HAVE SPECIAL NEEDS (Q4=2) AND CARES FOR CHILD ONLY:** How many children with some sort of special need 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 **[IF CARES FOR ADULT: adult/IF CARES FOR CHILD ONLY: child]** for whom you provided care.]

**[IF MORE THAN ONE (Q2=2 thru 97 OR Q2b=2 thru 97):** Let's focus on the **[IF CARES FOR ADULT: adult/IF CARES FOR CHILD ONLY: child]** for whom you provided the most assistance in the past year.]

1. Are you currently providing unpaid help to **[IF CARES FOR ADULT: that adult relative or friend /IF CARES FOR CHILD ONLY: that child]**, 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
- (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}**

5. How old {is/was} that **[IF CARES FOR ADULT: adult/IF CARES FOR CHILD ONLY: child]**? **[PROMPT: Your best estimate is fine]**

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

**[IF CARES FOR CHILD ONLY, SHOW: NOTE: IF CHILD IS LESS THAN 1 YEAR OLD, ENTER 0]**

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

9. And {is/was} the person you {care/cared} for...? **[READ RESPONSES 1-3]**

- Male ..... 1
- Female..... 2
- Non-Binary..... 3
- (VOL)** Refused..... 9

**Use Gender neutral pronouns throughout irrespective of answer to Q9 (1, 2, 3, OR REFUSED) "they/theirs/them".**

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? They are your \_\_\_\_?]**

<b>RELATIVE:</b>	<i>[IF Q9 &gt; 1]:</i> Aunt .....	1
	<i>[IF Q9 = 1 or 3 or 9]:</i> Brother.....	2
	<i>[IF Q9 = 1 or 3 or 9]:</i> Brother-In-Law.....	3
	Companion/Partner .....	4 <b>[Use “Partner”]</b>
	<i>[IF Q9 &gt; 1]:</i> Daughter.....	5
	<i>[IF Q9 = 1 or 3 or 9]:</i> Father.....	6
	<i>[IF Q9 = 1 or 3 or 9]:</i> Father-In-Law .....	7
	<i>[IF Q9 &gt; 1]:</i> Granddaughter.....	8
	<i>[IF Q9 = 1 or 3 or 9]:</i> Grandfather.....	9
	<i>[IF Q9 &gt; 1]:</i> Grandmother .....	10
	Grandparent-In-Law .....	11
	<i>[IF Q9 = 1 or 3 or 9]:</i> Grandson .....	12
	<i>[IF Q9 &gt; 1]:</i> Mother.....	13
	<i>[IF Q9 &gt; 1]:</i> Mother-In-Law .....	14
	<i>[IF Q9 = 1 or 3 or 9]:</i> Nephew.....	15
	<i>[IF Q9 &gt; 1]:</i> Niece .....	16
	Same-sex partner .....	30 <b>[Use “Partner”]</b>
	<i>[IF Q9 &gt; 1]:</i> Sister .....	17
	<i>[IF Q9 &gt; 1]:</i> Sister-In-Law.....	18
	<i>[IF Q9 = 1 or 3 or 9]:</i> 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>	
	<i>[IF Q9 = 1 or 3 or 9]:</i> Uncle.....	21
<b>NON-RELATIVE:</b>	Foster child.....	23
	Friend .....	24
	Neighbor.....	26
	Other <b>[SPECIFY _____]</b> .....	22 <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
<b>(VOL)</b> Don’t know .....	7
<b>(VOL)</b> 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]**
- Their own home **[IF CARES FOR CHILD ONLY: (with parent or guardian)]** .... 1  
 Someone else's home ..... 2 **[SKIP TO Q15]**  
**IF CARES FOR ADULT: An independent living or retirement community...** 3  
**IF CARES FOR ADULT: 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]**  
**IF CARES FOR CHILD ONLY A group home.....** 10 **[SKIP TO Q15]**  
**IF CARES FOR CHILD ONLY): Foster care.....** 11 **[SKIP TO Q15]**  
 Or somewhere else? **[SPECIFY \_\_\_\_\_]**..... 8  
**(VOL) Don't know** ..... 98  
**(VOL) Refused**..... 99

**IF ADULT RECIPIENT AND LIVING WITH OTHERS AND (Q13=2 or 4 or 5 or 10 or 11) OR CHILD RECIPIENT, SKIP TO Q15.**

- 14c. **IF CARES FOR ADULT AND OWN HOME, INDEPENDENT LIVING, ELSE, REF (Q13=1 OR 3 OR 8 OR 98OR 99), ASK:** {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

## CHARACTERISTICS OF RECIPIENT

### CHECKPOINT TWO – CREATE A SPLIT SAMPLE VARIABLE FOR USE IN Q17 (50%/50% SPLIT)

VARIABLE NAME = SPLIT17

1 = SPLIT SAMPLE 17A

2 = SPLIT SAMPLE 17B

17. {Does/Did} your [Q7 CODE] need care because of a...[READ ITEMS A-F 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.	(edited 2019) IF SPLIT17= 1: Developmental or intellectual disorder or mental retardation / IF SPLIT17=2: Developmental or intellectual disorder or delay?	1	2	3	4
e.	Behavioral issue?	1	2	3	4
f.	A memory problem?	1	2	3	4

### CHECKPOINT THREE – CREATE A SPLIT SAMPLE VARIABLE FOR USE IN Q18 (50%/50% SPLIT)

VARIABLE NAME = SPLIT18

1 = SPLIT SAMPLE 18A (trended Alzheimer's wording)

2 = SPLIT SAMPLE 18B

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

[DO NOT READ RESPONSE LIST. CODE BASED ON RESPONDENT ANSWER. ACCEPT ONLY ONE. IF NOT CLEAR, TYPE AS MUCH INFORMATION AS POSSIBLE IN THE OTHER SPECIFY RESPONSE]

[IF "DISABLED", PROBE: "What kind of disability would that be?"]

**IF CHILD RECIPIENT (CARES FOR CHILD ONLY):** ADD, ADHD,

Attention deficit disorder ..... 1

**IF ADULT RECIPIENT (CARES FOR ADULT) AND SPLIT18= 1:**

Alzheimer's, dementia, confusion, forgetfulness / **IF ADULT**

**RECIPIENT (CARES FOR ADULT) AND SPLIT18=2:** Alzheimer's, dementia..... 3

**IF ADULT RECIPIENT (CARES FOR ADULT):** Arthritis ..... 5

**IF CHILD RECIPIENT (CARES FOR CHILD ONLY):** Asthma ..... 6

**IF CHILD RECIPIENT (CARES FOR CHILD ONLY):** Autism or Autism Spectrum Disorder..... 7

**IF ADULT RECIPIENT (CARES FOR ADULT):** Back problems ..... 8

**IF ADULT RECIPIENT (CARES FOR ADULT):** Blindness, vision loss, can't see well ..... 10

**IF ADULT RECIPIENT (CARES FOR ADULT):** Blood pressure, hypertension ..... 11

Brain damage or injury..... 12

Broken bones ..... 13

Cancer..... 14

<b>IF ADULT RECIPIENT (CARES FOR ADULT):</b> Deafness, hearing loss .....	15
Diabetes .....	16
<b>IF ADULT RECIPIENT (CARES FOR ADULT):</b> Feeble, unsteady, falling .....	18
<b>IF ADULT RECIPIENT (CARES FOR ADULT):</b> Heart disease, heart attack .....	19
<b>IF ADULT RECIPIENT (CARES FOR ADULT):</b> Lung disease, emphysema, COPD .....	20
Developmental or intellectual disorder or disability .....	21
Mental illness, emotional illness, depression .....	22
<b>IF ADULT RECIPIENT (CARES FOR ADULT):</b> Mobility problem, can't get around.....	23
<b>IF ADULT RECIPIENT (CARES FOR ADULT):</b> Old age, just old, Aging.....	24
<b>IF ADULT RECIPIENT (CARES FOR ADULT):</b> Parkinson's .....	27
<b>IF ADULT RECIPIENT (CARES FOR ADULT):</b> Stroke .....	30
Substance/drug/alcohol abuse .....	31
Surgery, wounds .....	32
Other [ <b>SPECIFY</b> _____] .....	33
<b>(VOL)</b> Don't know .....	34
<b>(VOL)</b> Refused.....	35

19. (new 2019) **[IF CHILD RECIPIENT (CARES FOR CHILD ONLY), ASK]:** As a result of your **[Q7 CODE]**'s condition {is/was} your **[Q7 CODE]** limited in any way in their ability to do the things that most children of the same age do?

Yes.....	1
No.....	2
<b>(VOL)</b> Don't know .....	98
<b>(VOL)</b> Refused.....	99

**[IF CHILD CAREGIVER AND NO LIMIT (Q19=2) AND NO CONDITIONS (Q17A=2 and Q17B=2 and Q17c=2 and q17d=2 and q17e=2 and Q17F=2), TERMINATE.]**

20. **[IF ADULT RECIPIENT AND 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
<b>(VOL)</b> Don't know .....	4
<b>(VOL)</b> Refused.....	5

## LENGTH OF CARE AND TASKS

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

(new 2019) **IF CHILD RECIPIENT:** For how long {have you been providing/did you provide} care to your [Q7 CODE], over and above normal childcare needs?

**[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. **IF ADULT RECIPIENT:** {Do/Did} you help your [Q7 CODE]...[RANDOMIZE ALWAYS SHOW G LAST & READ LIST]

**IF CHILD RECIPIENT:** Because of your [Q7 CODE]'s condition, {do/did} you help your [Q7 CODE]...? [RANDOMIZE ALWAYS SHOW G LAST & READ LIST]

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

		Yes	No	(VOL) DK	(VOL) RF
a.	<b>IF CR AGE IS 3+ YRS (Q5&gt;2):</b> Get in and out of beds and chairs?	1	2	3	4
b.	<b>IF CR AGE IS 4+ YRS (Q5&gt;3):</b> Get dressed?	1	2	3	4
c.	<b>IF CR AGE IS 4+ YRS (Q5&gt;3):</b> Get to and from the toilet?	1	2	3	4
d.	<b>IF CR AGE IS 6+ YRS (Q5&gt;5):</b> Bathe or shower?	1	2	3	4
e.	<b>IF CR AGE IS 4+ YRS (Q5&gt;3):</b> By dealing with incontinence or diapers?	1	2	3	4
f.	<b>IF CR AGE IS 3+ YRS (Q5&gt;2):</b> By feeding them?	1	2	3	4
g.	By giving medicines, like pills, eye drops, or injections for their 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]

		Yes	No	(VOL) DK	(VOL) RF
a.	With managing finances, such as paying bills or filling out insurance claims	1	2	3	4
b.	<b>IF ADULT RECIPIENT:</b> With grocery or other shopping	1	2	3	4
c.	<b>IF ADULT RECIPIENT:</b> With housework, such as doing dishes, laundry, or straightening up	1	2	3	4
d.	<b>IF ADULT RECIPIENT:</b> With preparing meals	1	2	3	4
e.	<b>IF ADULT RECIPIENT:</b> With transportation, either by driving them, or helping them 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

M8. (new 2019) [IF HELPS MANAGE PAPERWORK (Q23A= 1), ASK]: On a scale of 1 to 5, where 1 is “not at all time consuming” and 5 is “very time consuming”, how time consuming {is/was} it for you to help your [Q7 CODE] with their finances, bills, or insurance claims?

- 1 - Not at all time consuming..... 1
- 2..... 2
- 3..... 3
- 4..... 4
- 5 - Very time consuming ..... 5
- (VOL) Don't know ..... 98
- (VOL) Refused..... 99

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 them with health care providers, community services, <b>IF CHILD RECIPIENT:</b> schools,] or government agencies	1	2	3	4
i.	(match up to Q24h) Monitoring the severity of their 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 their 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 them? [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



25Z. (new 2019) [IF CONSTANT CARE (Q25= 168 or 170), ASK]: We would like to understand a little bit more about people like you who have {to provide/provided} constant care.

Which of the following best describes how much care or help you {have to give/gave} your [Q7 CODE], because of their condition(s) in a normal week? {Do/Did} you provide care...[READ LIST]

- All the time: 24 hours a day, 7 days a week ..... 1
- Almost all the time, with only small breaks here or there..... 2
- Almost all the time, with just breaks to sleep ..... 3
- On and off around the clock; or ..... 4
- Some other situation? [SPECIFY: \_\_\_\_\_]..... 5
- (VOL) Don't know ..... 98
- (VOL) Refused..... 99

## 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

IF ADULT RECIPIENT AND 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.

N9. In the last 12 months [IF PAST (Q1> 1), INSERT: that you were caring for them], 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

## OTHER CAREGIVERS – UNPAID AND PAID

---

Now, we have a few questions about who else [provides/provided] care for your [Q7 CODE].

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. **IF HAS OTHER UNPAID HELP (Q28= 1):** 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
- 29Z. **IF HAS OTHER UNPAID HELP (Q28= 1):** Of all the people who {help provide/provided} care to your [Q7 CODE], {are/were} any of them children under the age of 18?
- [IF NEEDED: They might {help or assist/have helped or assisted} you with the care you {provide/ provided}. The child(ren) may also {help/have helped} with things like bringing items to or from your [Q7 CODE], doing chores or other housework, running errands, or just generally helping watch over your [Q7 CODE].]
- Yes ..... 1  
 No ..... 2  
 (VOL) Don't know ..... 98  
 (VOL) Refused ..... 99
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 them?
- 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 SCALE 1-4/4-1]?
- Very easy ..... 1  
 Somewhat easy ..... 2  
 Somewhat difficult ..... 3  
 Very difficult ..... 4  
 (VOL) Not applicable: someone else {does/did} that ..... 7  
 (VOL) Don't know ..... 5  
 (VOL) Refused ..... 6
- N12. **IF ADULT RECIPIENT:** 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]
- (new 2019) **IF CHILD RECIPIENT:** Do you expect to have some responsibility for the care of {your [Q7 CODE] or another person/another person} in the next five years? [PROMPT YES OR NO IF NEEDED]
- Yes ..... 1  
 No ..... 2  
 (VOL) Don't know ..... 3  
 (VOL) Refused ..... 4

## PHYSICAL, EMOTIONAL AND FINANCIAL STRESS OF CAREGIVING

---

Now, we have some questions about how caring for your [Q7 CODE] has affected you.

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. (new 2019) 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

M5. (new 2019) I am going to read you a list of statements about being a caregiver for your [Q7 CODE]. How much do you agree or disagree that...[RANDOMIZE ORDER OF ITEMS A-C AND READ ITEM.]  
Do you...[READ SCALE 1-5/5-1]  
[INTERVIEWER NOTE: REPEAT SCALE AS NEEDED.]

		Strongly disagree	Disagree	Neither	Agree	Strongly agree	(VOL) Don't Know	(VOL) Refused
a.	Your role as a caregiver {gives/gave} you a sense of purpose or meaning in your life	1	2	3	4	5	98	99
b.	You {find/found} it difficult to take care of your own health	1	2	3	4	5	98	99
c.	You {feel/felt} alone	1	2	3	4	5	98	99

## 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 M2]  
(VOL) Don't know ..... 3 [SKIP TO M2]  
(VOL) Refused..... 4 [SKIP TO M2]

[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] [ALLOW 0-80]

(VOL) Don't know ..... 98  
(VOL) Refused..... 99

33Z. (new 2019) [IF CURRENTLY EMPLOYED AND CAREGIVING (Q1=1 and Q32A=1)]: Are you...?

33Z\_1. (new 2019) [IF EMPLOYED CAREGIVER IN LAST YEAR (Q33=1)]: Were you...?

**[READ LIST]**

- Paid a salary ..... 1
- Paid hourly for the time you work, or ..... 2
- Some other arrangement? [SPECIFY: \_\_\_\_\_] ..... 3
- (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 at your work in a similar role or job as yours, 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 at your work in a similar role or job as yours, which of the following did your employer offer?

**[RANDOMIZE ITEMS A-C; KEEP E-D-F LAST AND IN THAT ORDER; 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 family leave, where you could take <u>extended paid</u> time off from work, in weeks, to care for an ill family member?	1	2	3	4

		Yes	No	VOL DK	VOL RF
e.	Paid sick days, where you can take limited paid hours or days off from work to care for or go to appointments with an ill family member?	1	2	3	4
f.	(new 2019) Unpaid family leave, where you could take extended time off, in weeks, without pay to care for an ill family member	1	2	3	4

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

M2. (new 2019) [IF NOT WORKING OR NOT WORKED IN PAST YEAR (Q33 NE 1) AND (Q32A NE 1)]: At any time while you {have been providing/provided} care to your [Q7 CODE], have you worked or had a job?

- Yes..... 1
- No..... 2
- (VOL) Don't know ..... 98
- (VOL) Refused..... 99

N15. [IF LEFT (Q34b= 1 OR Q34f= 1 OR Q34g= 1) OR HAD A JOB AT SOME POINT IN FAR PAST (M2= 1)]: Why did you leave your job, take a leave of absence, or otherwise decide to not work while also providing care?

[OPEN-END RESPONSE, PROBE FOR PULL BETWEEN WORK AND CAREGIVING.]

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M3. (new 2019) Have you ever felt that your responsibilities as a caregiver led to you being penalized or discriminated against at work?

- Yes..... 1
- No..... 2
- (VOL) Don't know ..... 98
- (VOL) Refused..... 99

**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 [RESS - PIT] 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.	(was Q46a) Had modifications made in the house or apartment where your [Q7 CODE] {lives/lived} to make things easier for them?	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 D-F; PROMPT YES OR NO IF NEEDED]

		Yes	No	(VOL) DK	(VOL) RF
d.	Having respite [RESS - PIT] services available, where someone would {take/have taken} care of your [Q7 CODE] 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 [Q7 CODE]	1	2	3	4
f.	Requiring a doctor, nurse, or social worker ask you what you {need/needed} to take care of yourself	1	2	3	4

- M1. (new 2019) I am going to read you a list of places you might use for information. Where {do/did} you go for help or information about caring for your [Q7 CODE]? [KEEP ITEMS A-G IN ORDER; PROMPT YES OR NO AS NEEDED. AT FIRST MENTION OF NEVER GOT HELP OR INFORMATION (CODE 99) – SKIP TO M7]

		Yes	No	(VOL) NOT APPLICABLE - NEVER GOT HELP OR INFORMATION
a.	Doctor or health care professional	1	2	99
b.	Friends or family	1	2	99
c.	Government agencies or organizations, like local, state, or federal	1	2	99
d.	Local hospital or other care facility	1	2	99
e.	Online or social media	1	2	99
f.	Organization or non-profit for aging, caregiving, or specific condition	1	2	99

- M7. Now, I am going to read you a list of things you might have done online in your experience as a caregiver for your [Q7 CODE]. For each, please tell me if you have done it.

Have you ever ... [RANDOMIZE ITEMS A-H]? [PROMPT YES OR NO IF NEEDED. AT FIRST MENTION OF NO INTERNET (CODE 98, SKIP TO QUESTION M11)]

		Yes	No	(VOL) Not Applicable	(VOL) HAVE NO INTERNET/ DO NOT GO ONLINE	(VOL) REFUSED
a.	Had a virtual or online visit with a healthcare provider who could care for your [Q7 CODE]	1	2	3	98	99
b.	Created an online or shared calendar to organize caregiving schedules or activities	1	2	3	98	99
c.	Managed your [Q7 CODE]'s prescription refills or delivery on an app or website	1	2	3	98	99
d.	Placed an online order for groceries or household supplies for your [Q7 CODE]	1	2	3	98	99
e.	Used a ride service like Lyft or Uber for your [Q7 CODE]	1	2	3	98	99
f.	Searched online for support services, aides, facilities, or other help for your [Q7 CODE]	1	2	3	98	99
g.	Connected with other caregivers online using social media or support groups	1	2	3	98	99
h.	Watched videos to learn how to do different things you need to do to care for your [Q7 CODE]	1	2	3	98	99



M11. (new 2019) And, In your experience as a caregiver for your [Q7 CODE], have you ever done the following things using technology or software?

Have you ever... [RANDOMIZE ITEMS A-E, PROMPT YES OR NO AS NEEDED. AT FIRST MENTION OF NO TECH (CODE 98, SKIP TO Q48)]

		Yes	No	(VOL) Not Applicable	(VOL) DO NOT USE TECH	(VOL) REFUSED
a.	Created electronic lists or spreadsheets to track activities related to providing care for your [Q7 CODE]	1	2	3	98	99
b.	Checked up on your [Q7 CODE] using an app, video, wearable device, or other remote monitoring	1	2	3	98	99
c.	Tracked your [Q7 CODE]'s personal health records	1	2	3	98	99
d.	Tracked your [Q7 CODE]'s finances	1	2	3	98	99
e.	Got or used assistive devices for things like your [Q7 CODE]'s low vision or hearing problems	1	2	3	98	99

48. (edited 2014) Which of the following topics do you feel you [need/needed] more help or information?

[RANDOMIZE A-R WITH Z LAST AND READ LIST; PROMPT YES OR NOT IF NEEDED]

RE-READ PROMPT EVERY 4 ITEMS AND ON LAST ONE: [Do/Did] you need more help or information about...

		Yes	No	(VOL) DK	(VOL) RF
a.	Keeping your [Q7 CODE] safe at home	1	2	3	4
b.	Managing your [Q7 CODE]'s challenging behaviors, such as wandering	1	2	3	4
c.	(new 2019) Activities you {could do/could have done} with your [Q7 CODE]	1	2	3	4
d.	(new 2019) Choosing a home care agency, assisted living facility or nursing home	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
e.	(new 2019) Figuring out forms, paperwork, or eligibility for services or support for your [Q7 CODE]	1	2	3	4
f.	(new 2019) Managing or handling your own personal finances	1	2	3	4
g.	(new 2019) Using technology to care for your [Q7 CODE]	1	2	3	4

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

(new 2019) **IF CHILD RECIPIENT BUT NOT CARING FOR OWN CHILD (Q7 NE 5 AND Q7 NE 19):** {Does/Did} your [Q7 CODE]'s family have plans in place for their future care, such as instructions for handling financial matters, healthcare decisions, or living arrangements? **[PROMPT YES OR NO IF NEEDED]**

(new 2019) **IF CHILD RECIPIENT AND CARING FOR OWN CHILD (Q7=5 OR Q7=19):** {Do/Did} you have plans in place for your [Q7 CODE]'s future care, such as instructions for 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

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

M6. (new 2019) I am going to read you a list of financial impacts that some caregivers have experienced. For each, please tell me if this ever happened to you.

As a result of providing care to your [Q7 CODE], have you ever...**[KEEP ORDER AS SHOWN]? [PROMPT YES OR NO IF NEEDED. RE-READ QUESTION STEM EVERY 4 ITEMS]**

		Yes	No	(VOL) Not Applicable	(VOL) DK	(VOL) RF
a.	Taken on more debt (credit cards, loans, lines of credit)?	1	2	3	98	99
b.	Missed or was late paying for a student loan?	1	2	3	98	99
c.	Borrowed money from family or friends?	1	2	3	98	99
d.	Filed for bankruptcy (medical or personal)?	1	2	3	98	99
e.	Been unable to afford basic expenses like food?	1	2	3	98	99
f.	Left your bills unpaid or paid them late?	1	2	3	98	99
g.	Used up your personal short-term savings?	1	2	3	98	99
h.	Used long-term savings, like retirement or education, to pay for other things?	1	2	3	98	99
i.	Stopped saving?	1	2	3	98	99
j.	Moved to a less expensive home, apartment, or other living arrangement?	1	2	3	98	99
k.	Was evicted or had a home foreclosed?	1	2	3	98	99
l.	Put off when you planned to retire or decided to never retire?	1	2	3	98	99
m.	Had to start working, work more, or find a second job?	1	2	3	98	99

M9. Using a scale of 1 to 5, where 1 means “not at all helpful” and 5 means “very helpful”, how helpful would you {find/have found} each of the following ways people are proposing to help caregivers financially?

First/next...[SHOW ITEMS A-C IN ORDER AND INSERT ITEM AND READ]

[INTERVIEWER NOTE: REPEAT SCALE AS NEEDED]

		Not at all helpful				Very helpful	VOL Refused
a.	An income tax credit to caregivers, to help offset the cost of care	1	2	3	4	5	9
b.	A partially paid leave of absence from work, for caregivers who are employed	1	2	3	4	5	9
c.	A program where caregivers could be paid for at least some of the hours they provide care	1	2	3	4	5	9

PROGRAMMING NOTE: CREATE A COUNT VARIABLE COUNTM9 OF ALL MENTIONS IN M9 WHERE ITEM = 3 or 4 or 5.

IF NONE OR JUST ONE HELPFUL (COUNTM9=0 or 1), SKIP TO TEXT BEFORE M10.

47a. IF MULTIPLE HELPFUL (COUNTM9=2 or 3), ASK: And Which one would you {find/have found} most helpful? [KEEP ITEMS 2-3-4 IN ORDER; READ LIST]

	Q47a: MOST
IF HELPFUL (M9a>2): An income tax credit to caregivers, to help offset the cost of care	2
IF HELPFUL (M9b>2): A partially paid leave of absence from work, for caregivers who are employed	3
IF HELPFUL (M9c>2): 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

## DEMOGRAPHICS

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

- D5. (moved up 2019) **[IF CARING FOR ADULT ASK]:** Did your **[Q7 CODE]** serve in the US Armed Forces?  
**[IF NEEDED: This includes Army, Navy, Air Force, Marines, Coast Guard, Women’s Armed Forces, National Guard, or Reserves.]**
- Yes..... 1  
 No..... 2  
**(VOL) Don’t know** ..... 3  
**(VOL) Refused**..... 4
- M10. (new 2019) At any time in the past year while you were providing care to your **[Q7 CODE]**, were you also a student, either full-time or part-time?
- Yes..... 1  
 No..... 2  
**(VOL) Don’t know** ..... 98  
**(VOL) Refused**..... 99
- 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
- M12. (new 2019) {Are you, yourself, currently/At the time you last provided care, were you, yourself} covered by any form of health insurance or a health plan?
- Yes..... 1  
 No..... 2  
**(VOL) Don’t know** ..... 98  
**(VOL) Refused**..... 99

M13. (new 2019) [IF YES (M12=1)]: What type of health insurance or health coverage {do/did} you have?

[DO NOT READ LIST UNLESS RESPONDENT NEEDS IT. CODE TO LIST.]

[INTERVIEWER NOTE: IF RESPONDENT HAS MULTIPLE TYPES OF COVERAGE, ASK THEM FOR THEIR MAIN SOURCE OF HEALTH INSURANCE.]

- An employer plan (yours or a family member's)..... 1
- Plan bought directly (from an insurance company, using an agent,  
or using an exchange/marketplace) ..... 2
- Medicare (standard, supplemental, and/or Medicare Advantage) ..... 3
- Medicaid coverage provided by your state ..... 4
- Military health care (Tricare, VA, Champ) ..... 5
- Some other type of coverage [SPECIFY: \_\_\_\_\_] ..... 6
- No health insurance..... 8
- (VOL) Don't know ..... 98
- (VOL) Refused..... 99

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

D6. (moved up 2019) {Are/When you were last caregiving, were} there any children or grandchildren living in your household under 18 years of age [IF CARING FOR CHILD LIVING IN CG'S HOME (Q11=1), INSERT: in addition to your [Q7 CODE]]?

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

D4. Did you ever serve on active duty in the US Armed Forces?

[IF NEEDED: This includes the Army, Navy, Air Force, Marines, Coast Guard, Women's Armed Forces, National Guard, or Reserves.]

- 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 Associate’s degree ..... 4
  - College graduate with Bachelor’s degree ..... 5
  - Graduate or Professional degree (or more) ..... 6
  - (VOL)** Don’t know ..... 7
  - (VOL)** Refused ..... 8
- D6B. **(new 2019)** {Do/When you were last caregiving, did} you have internet access of any kind in your home?  
Please include dial-up, broadband, cable, or internet access via smartphone.
- Yes ..... 1
  - No ..... 2
  - (VOL)** Don’t know ..... 3
  - (VOL)** Refused ..... 4
- 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 D 10]**
  - (VOL)** Refused ..... 4 **[SKIP TO D 10]**
- b. **[IF UNDER \$50,000:]** Over or under \$30,000?
- Over ..... 1 **[SKIP TO D 10]**
  - Under ..... 2 **[GO TO c]**
  - (VOL)** Don’t know ..... 3 **[SKIP TO D 10]**
  - (VOL)** Refused ..... 4 **[SKIP TO D 10]**
- c. **[IF UNDER \$30,000:]** Over or under \$15,000?
- Over ..... 1 **[SKIP TO D 10]**
  - Under ..... 2 **[SKIP TO D 10]**
  - (VOL)** Don’t know ..... 3 **[SKIP TO D 10]**
  - (VOL)** Refused ..... 4 **[SKIP TO D 10]**
- d. **[IF OVER 50,000:]** Over or under \$100,000?
- Over ..... 1 **[SKIP TO D 10]**
  - Under ..... 2 **[GO TO e]**
  - (VOL)** Don’t know ..... 3 **[SKIP TO D 10]**
  - (VOL)** Refused ..... 4 **[SKIP TO D 10]**
- e. **[IF UNDER 100,000:]** Over or under \$75,000?
- Over ..... 1 **[SKIP TO D 10]**
  - Under ..... 2 **[SKIP TO D 10]**
  - (VOL)** Don’t know ..... 3 **[SKIP TO D 10]**
  - (VOL)** Refused ..... 4 **[SKIP TO D 10]**

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]?

[ ] \_\_\_\_\_

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. The results of this research should be released to the public in spring 2020 online on both "caregiving dot O-R-G" and "A-A-R-P dot O-R-G", if you are interested in seeing the results.

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