

CAREGIVING (CGQ)

SPID#: _____ Date: _____ Interviewer#: _____

There are situations in which people provide regular **unpaid care or assistance** to a family member (**including children**) or a friend who has a **long-term illness or a disability**.

CGQ.010. In the past 12 months, did you provide any such care or assistance to a family member or friend living with you or living elsewhere? (Include only unpaid care activities and only those care activities made necessary by the illness or disability of the recipient.)

CGQ010 FMT_YES_NO.

Yes 1

No 2 (End of Caregiving Questionnaire)

Don't Know (d)

Refused (r) (End of Caregiving Questionnaire)

CGQ.020. Are you currently giving unpaid help to a family member or friend? (Include only unpaid care activities and only those care activities made necessary by the illness or disability of the recipient.)

CGQ020 FMT_YES_NO.

Yes 1 (Skip to CGQ.030)

No 2

Don't Know (d)

Refused (r) (End of Caregiving Questionnaire)

CGQ.020.10. How many months ago did you last provide care?

CGQ02010 FMT_NUMERIC.

|_|_|

Enter months (Skip to CGQ.130)

Don't Know (d) (Skip to CGQ.130)

Refused (r) (Skip to CGQ.130)

QUESTIONS FOR THOSE CURRENTLY PROVIDING CARE (CGQ.030-CGQ.120 only)

CGQ.030. To how many people do you currently provide care?

CGQ030 FMT_NUMERIC.

|_|_| (0-76 are allowed)

Enter number of people

Don't Know (d)

Refused (r)

CAREGIVING (CGQ)

SPID#: _____

Date: _____

Interviewer#: _____

The next questions are about the person who receives your care.

** If you care for one person, I'd like you to focus on that person.*

** If you care for more than one person, please focus on the one with whom you live.*

** If you live with more than one person you care for, please focus on the person to whom you provide the most assistance.*

CGQ.040. What is this person's relationship to you?

- | | <i>CGQ040</i> | <i>FMT_CGQ_RELATIONSHIP., CGQ040_OTHER</i> | <i>\$FMT_CHAR.</i> |
|-------------|--------------------------------------|--|--------------------|
| 1. | Spouse | | |
| 2. | Mother | (Skip to CGQ.060) | |
| 3. | Father | (Skip to CGQ.060) | |
| 4. | Mother-in-law | (Skip to CGQ.060) | |
| 5. | Father-in-law | (Skip to CGQ.060) | |
| 6. | Son | (Skip to CGQ.060) | |
| 8. | Daughter | (Skip to CGQ.060) | |
| 10. | Brother | (Skip to CGQ.060) | |
| 11 | Sister | (Skip to CGQ.060) | |
| 12. | Brother-in-law | (Skip to CGQ.060) | |
| 13 | Sister-in-law | (Skip to CGQ.060) | |
| 14. | Grandmother | (Skip to CGQ.060) | |
| 15. | Grandfather | (Skip to CGQ.060) | |
| 16. | Grandparent-in-law | | |
| 17. | Aunt/uncle | | |
| 18. | Other family member (Specify: _____) | | |
| 19. | Friend/non-family member/neighbor | | |
| 20. | Companion/partner | | |
| (d). | Don't Know | | |
| (r). | Refused | | |

CAREGIVING (CGQ)

SPID#: _____ **Date:** _____ **Interviewer#:** _____

CGQ.050. Is the person you care for a male or female?

CGQ050 FMT_GENDER

Male **1**

Female **2**

Don't Know **(d)**

Refused **(r)**

CGQ.060. How old is this person? Your best estimate is fine.

CGQ060 FMT_NUMERIC

[][][]
Enter years

Don't Know **(d)**

Refused **(r)**

CGQ.070. Does this person live...? (Choose one.)

CGQ070

FMT_CGQ_DISTANCE

- 1. In your household
- 2. Within twenty minutes of your home
- 3. Between 20 minutes and one hour from your home
- 4. A one to two hour drive from your home
- 5. More than two hours away.
- (d).** Don't Know
- (r)** Refused

CAREGIVING (CGQ)

SPID#: _____ **Date:** _____ **Interviewer#:** _____

CGQ.080. What would you say is the **main** problem or illness this person has? **(Choose only one.)**
CGQ080_FMT_CGQ_PROBLEM, CGQ080_OTHER \$FMT_CHAR.

1. AIDS
2. Alzheimer's/ confusion/ dementia/ forgetfulness
3. Amputee
4. Arthritis
5. Asthma
6. Attention deficit hyperactivity disorder (ADHD)
8. Autism, Asperger's, pervasive developmental disorder (PDD)
10. Blindness/vision loss, can't see well
11. Blood pressure/hypertension
12. Broken bones
13. Cancer
14. Cerebral palsy
15. Cognitive disabilities
16. Deafness/hearing loss
17. Developmental disabilities
18. Diabetes
19. Down syndrome
20. Epilepsy
21. Feeble, unsteady, falling
22. Fragile X syndrome
23. Heart disease
24. Juvenile diabetes
25. Learning disabilities (i.e., dyslexia, dyspraxia and central auditory disorder)

CAREGIVING (CGQ)

SPID#: _____ **Date:** _____ **Interviewer#:** _____

[CONTINUED FROM PREVIOUS PAGE: CGQ.080. What would you say is the main problem or illness this person has? (Choose only one.)

- 26. Lung disease, emphysema
- 27. Mental retardation
- 28. Mental illness, emotional illness, depression (including Bipolar disorder, schizophrenia, and substance abuse)
- 29. Mobility (can't get around)
- 30. Muscular dystrophy
- 31. Old age, just old
- 32. Osteoporosis
- 33. Paraplegia
- 34. Parkinson's
- 35. Sickle cell anemia
- 36. Speaking, can't speak
- 37. Spina bifida
- 38. Stroke
- 39. Other (Specify: _____)
- (d) Don't Know
- (r) Refused

CGQ.090. When did this person's illness or disability begin? {If more than one year since start of illness, it is allowed to enter just the year that the illness started}

CGQ090_M, CGQ090_Y FMT_NUMCAT.

____|____| - ____|____|____|____|
Enter month and year

Don't Know **(d)**

Refused **(r)**

CAREGIVING (CGQ)

SPID#: _____ Date: _____ Interviewer#: _____

CGQ.100. How long have you cared for this person? Your best estimate is fine. **[Interviewer: Enter number of years if one or more years, or mark response below if less than one year or occasionally.]**

CGQ100_A FMT_NUMCAT, CGQ100_B FMT_CGQ_DURATION

____|____|
Enter years

- 91. Six months to one year
- 92. Less than six months
- 93. Occasionally, on and off

Don't Know (d)

Refused (r)

CGQ.110. Thinking now of all the kinds of help you provide for this person, about how many hours do you spend in an average week doing these things? Your best estimate is fine.

CGQ110 FMT_NUMERIC.

____|____|____|
Enter hours per week
[If less than 1 hour per week, enter "1."]
[If SP provides constant care, enter "168."]

Don't Know (d)

Refused (r)

CAREGIVING (CGQ)

SPID#: _____ **Date:** _____ **Interviewer#:** _____

CGQ.120. I have a list of things that other people have found to be difficult about giving care (for example to sick, disabled, elderly family members, friends, etc.). Do these apply to you **because of care-giving**? Please answer yes or no. **[Interviewer: Check Yes or No box for each item.]**

		Yes	No
a.	Your sleep is disturbed (for example, because the person you give care to requires care at night). <i>CGQ120_A FMT_YES_NO.</i>		
b.	It is inconvenient to you (for example, because care-giving takes so much time). <i>CGQ120_B FMT_YES_NO.</i>		
c.	It is a physical strain for you (for example, because of lifting the person you give care to in and out of a chair). <i>CGQ120_C FMT_YES_NO.</i>		
d.	It is confining to you (for example, you have little free time or cannot go visiting). <i>CGQ120_D FMT_YES_NO.</i>		
e.	There have been family adjustments for you (for example, because care-giving has disrupted your routine or there is little privacy). <i>CGQ120_E FMT_YES_NO.</i>		
f.	You have made changes in personal plans (for example, had to turn down a job; could not go on vacation). <i>CGQ120_F FMT_YES_NO.</i>		
g.	You have had to make emotional adjustments. <i>CGQ120_G FMT_YES_NO.</i>		
h.	Some behavior (of the person you give care to) is upsetting to you. <i>CGQ120_H FMT_YES_NO.</i>		
i.	It is upsetting to find the person you give care to has changed so much from {his/her} former self. <i>CGQ120_I FMT_YES_NO.</i>		
j.	You have had to make work adjustments (for example, because of having to take time off). <i>CGQ120_J FMT_YES_NO.</i>		
k.	It is a financial strain for you. <i>CGQ120_K FMT_YES_NO.</i>		
l.	You feel overwhelmed (for example, because concerns about how you will manage, or concerns about health of the person you give care to). <i>CGQ120_L FMT_YES_NO.</i>		

[This is the end of the Caregiving Questionnaire for Current Caregivers.]

CAREGIVING (CGQ)

SPID#: _____ **Date:** _____ **Interviewer#:** _____

QUESTIONS FOR THOSE CAREGIVERS WHO ARE NOT CURRENTLY IN THIS ROLE
(CGQ.130 – CGQ.220 only)

CGQ.130. To how many people did you provide this care in the past 12 months?

CGQ130

FMT_NUMERIC.

|__| |__| (0-50 is option here)
Enter number of people

Don't Know **(d)**

Refused **(r)**

CAREGIVING (CGQ)

SPID#: _____ **Date:** _____ **Interviewer#:** _____

The next questions are about the person who received your care.

** If you cared for one person, I'd like you to focus on that person.*

** If you cared for more than one person, please focus on the one with whom you lived.*

** If you lived with more than one person you cared for, please focus on the person to whom you provided the most assistance.*

CGQ.140. What was this person's relationship to you?

CGQ140 FMT_CGQ_RELATIONSHIP, CGQ140_OTHER \$FMT_CHAR

1. Spouse
2. Mother **(Skip to CGQ.160)**
3. Father **(Skip to CGQ.160)**
4. Mother-in-law **(Skip to CGQ.160)**
5. Father-in-law **(Skip to CGQ.160)**
6. Son **(Skip to CGQ.160)**
8. Daughter **(Skip to CGQ.160)**
10. Brother **(Skip to CGQ.160)**
11. Sister **11(Skip to CGQ.160)**
12. Brother-in-law **(Skip to CGQ.160)**
13. Sister-in-law **(Skip to CGQ.160)**
14. Grandmother **(Skip to CGQ.160)**
15. Grandfather **(Skip to CGQ.160)**
16. Grandparent-in-law
17. Aunt/uncle
18. Other family member (Specify: _____)
19. Friend/non-family member/neighbor
20. Companion/partner
99. Don't Know
77. Refused

CAREGIVING (CGQ)

SPID#: _____ **Date:** _____ **Interviewer#:** _____

CGQ.150. Was the person you cared for a male or female?

CGQ150

FMT_GENDER

Male **1**

Female **2**

Don't Know **(d)**

Refused **(r)**

CGQ.160. How old was this person (when you last provided care)? Your best estimate is fine.

CGQ160

FMT_NUMERIC

[][][]
Enter years

Don't Know **(d)**

Refused **(r)**

CGQ.170. Did this person live...? (Choose one.)

CGQ170 FMT_CGQ_DISTANCE.

1. In your household
2. Within twenty minutes of your home
3. Between 20 minutes and one hour from your home
4. A one to two hour drive from your home
5. More than two hours away

Don't Know **(d)**

Refused **(r)**

CAREGIVING (CGQ)

SPID#: _____ **Date:** _____ **Interviewer#:** _____

CGQ.180. What would you say was the **main** problem or illness this person had? (**Choose only one.**)

*CGQ180**FMT_CGQ_PROBLEM.,**CGQ180_OTHER \$FMT_CHAR.*

1. AIDS
2. Alzheimer's/ confusion/ dementia/ forgetfulness
3. Amputee
4. Arthritis
5. Asthma
6. Attention deficit hyperactivity disorder (ADHD)
8. Autism, Asperger's, pervasive developmental disorder (PDD)
10. Blindness/vision loss, can't see well
11. Blood pressure/hypertension
12. Broken bones
13. Cancer
14. Cerebral palsy
15. Cognitive disabilities
16. Deafness/hearing loss
17. Developmental disabilities
18. Diabetes
19. Down syndrome
20. Epilepsy
21. Feeble, unsteady, falling
22. Fragile X syndrome
23. Heart disease
24. Juvenile diabetes
25. Learning disabilities (i.e., dyslexia, dyspraxia and central auditory disorder)
26. Lung disease, emphysema

CAREGIVING (CGQ)

SPID#: _____ **Date:** _____ **Interviewer#:** _____

[CONTINUED FROM PREVIOUS PAGE: CGQ.180. What would you say was the main problem or illness this person had? (Choose only one.)]

- 27. Mental retardation
- 28. Mental illness, emotional illness, depression (including Bipolar disorder, schizophrenia, and substance abuse)
- 29. Mobility (can't get around)
- 30. Muscular dystrophy
- 31. Old age, just old
- 32. Osteoporosis
- 33. Paraplegia
- 34. Parkinson's
- 35. Sickle cell anemia
- 36. Speaking, can't speak
- 37. Spina bifida
- 38. Stroke
- 39. Other (Specify: _____)
- 99. Don't Know
- 77. Refused

CGQ.190. When did this person's illness or disability begin? **{If more than one year since start of illness, it is allowed to enter just the year that the illness started}**

CGQ190_M, CGQ190_Y FMT_NUMCAT.

|_|_| - |_|_|_|_|_|
Enter month and year

Don't Know **(d)**

Refused **(r)**

CAREGIVING (CGQ)

SPID#: _____ Date: _____ Interviewer#: _____

CGQ.200. How long did you care for this person? Your best estimate is fine. **[Interviewer: Enter number of years if one or more years, or mark response below if less than one year or occasionally.]**

CGQ200_A FMT_NUMCAT., CGQ200_B FMT_CGQ_DURATION.

____|____|
Enter years

- 91. Six months to one year
- 92. Less than six months
- 93. Occasionally, on and off
- (d) Don't Know
- (r). Refused

CGQ.210. Thinking now of all the kinds of help you provided for this person, about how many hours did you spend in an average week doing these things? Your best estimate is fine.

CGQ210 FMT_NUMERIC.

____|____|____|
Enter hours per week
**[If less than 1 hour per week, enter "1."
[If SP provided constant care, enter "168."]**

- Don't Know (d)
- Refused (r)

CAREGIVING (CGQ)

SPID#: _____ **Date:** _____ **Interviewer#:** _____

CGQ 220. I have a list of things that other people have found to be difficult about giving care (for example to sick, disabled, elderly family members, friends, etc.). **Did these apply to you because of care-giving? Please answer yes or no. [Interviewer: Check Yes or No box for each item.]**

		Yes	No
a.	Your sleep was disturbed (for example, because the person you gave care to required care at night). <i>CGQ220_A FMTYES_NO.</i>		
b.	It was inconvenient to you (for example, because care-giving took so much time). <i>CGQ220_B FMTYES_NO.</i>		
c.	It was a physical strain for you (for example, because of lifting the person you gave care to in and out of a chair). <i>CGQ220_C FMTYES_NO.</i>		
d.	It was confining to you (for example, you had little free time or could not go visiting). <i>CGQ220_D FMTYES_NO.</i>		
e.	There were family adjustments for you (for example, because care-giving disrupted your routine or there was little privacy). <i>CGQ220_E FMTYES_NO.</i>		
f.	You made changes in personal plans (for example, had to turn down a job; could not go on vacation). <i>CGQ220_F FMTYES_NO.</i>		
g.	You had to make emotional adjustments. <i>CGQ220_G FMTYES_NO.</i>		
h.	Some behavior (of the person you gave care to) was upsetting to you. <i>CGQ220_H FMTYES_NO.</i>		
i.	It was upsetting to find the person you gave care to had changed so much from {his/her} former self. <i>CGQ220_I FMTYES_NO.</i>		
j.	You had to make work adjustments (for example, because of having to take time off). <i>CGQ220_J FMTYES_NO.</i>		
k.	It was a financial strain for you. <i>CGQ220_K FMTYES_NO.</i>		
l.	You felt overwhelmed (for example, because of concerns about how you would manage, or concerns about the health of the person you gave care to). <i>CGQ220_L FMTYES_NO.</i>		

[This is the end of the Caregiving Questionnaire for SPs who ended their caregiver roles in the last 12 months.]