CAREGIVING (CGQ)

*There are situations in which people provide regular **unpaid care or assistance** to a family member **(including children)** or 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 Questionnaire)**
Refused	77	**(End of Questionnaire)**
Don't Know	99	

CGQ.020.   Are you <u>currently</u> 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	
Refused	77	**(End of Questionnaire)**
Don't Know	99	

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

CGQ02010 |___|___|
FMT_NUMERIC .   Enter months **(Skip to CGQ.130)**

Refused	77	**(Skip to CGQ.130)**
Don't Know	99	**(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 .   Enter number of people

Refused	77
Don't Know	99

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

CAREGIVING (CGQ)

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

Spouse	1	
Mother	2	**(Skip to CGQ.060)**
Father	3	**(Skip to CGQ.060)**
Mother-in-law	4	**(Skip to CGQ.060)**
Father-in-law	5	**(Skip to CGQ.060)**
Son	6	**(Skip to CGQ.060)**
Daughter	8	**(Skip to CGQ.060)**
Brother	10	**(Skip to CGQ.060)**
Sister	11	**(Skip to CGQ.060)**
Brother-in-law	12	**(Skip to CGQ.060)**
Sister-in-law	13	**(Skip to CGQ.060)**
Grandmother	14	**(Skip to CGQ.060)**
Grandfather	15	
Grandparent-in-law	16	
Aunt/uncle	17	
Other family member (Specify:_____)	18	
Friend/non-family member/neighbor	19	
Companion/partner	20	
Refused	77	
Don't Know	99	

CGQ040   FMT_CGQ_RELATIONSHIP.
CGQ040_OTHER $FMT_CHAR.

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

CGQ050	Male	1
FMT_GENDER.	Female	2
	Refused	77
	Don't Know	99

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

CGQ060	|___|___|___]	
FMT_NUMERIC .	Enter years	
	Refused	777
	Don't Know	999

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

CGQ070	In your household	1
FMT_CGQ_DISTANCE.	Within twenty minutes of your home	2
	Between 20 minutes and one hour from your home	3
	A one to two hour drive from your home	4
	More than two hours away	5
	Refused	77
	Don't Know	99

CAREGIVING (CGQ)

CGQ.080. What would you say is the **main** problem or illness this person has? (Choose only one.)

Aids	1
Alzheimer's/ confusion/ dementia/ forgetfulness	2
Amputee	3
Arthritis	4
Asthma	5
Attention deficit hyperactivity disorder (ADHD)	6
Autism, Asperger's, pervasive developmental disorder (PDD)	8
Blindness/vision loss, can't see well	10
Blood pressure/hypertension	11
Broken bones	12
Cancer	13
Cerebral palsy	14
Cognitive disabilities	15
Deafness/hearing loss	16
Developmental disabilities	17
Diabetes	18
Down syndrome	19
Epilepsy	20
Feeble, unsteady, falling	21
Fragile x syndrome	22
Heart disease	23
Juvenile diabetes	24
Learning disabilities (i.e., dyslexia, dyspraxia, and central auditory disorder)	25
Lung disease, emphysema	26
Mental retardation	27
Mental illness, emotional illness, depression (including Bipolar disorder, schizophrenia, and substance abuse)	28
Mobility (can't get around)	29
Muscular dystrophy	30
Old age, just old	31
Osteoporosis	32
Paraplegia	33
Parkinson's	34
Sickle cell anemia	35
Speaking, can't speak	36
Spina bifida	37
Stroke	38
Other (Specify:_____)	39
Refused	77
Don't Know	99

CGQ080   FMT_CGQ_PROBLEM.
CGQ080_OTHER $FMT_CHAR.

CAREGIVING (CGQ)

CGQ.090.   When did this person's illness or disability begin?

|___|___|_-_|___|___|___|___|

Enter month and year

            Refused   777777
            Don't Know   999999

CGQ090_M   *FMT_NUMCAT.*
CGQ090_Y   *FMT_NUMCAT.*

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 enter response below if less than one year or occasionally.]**

|___|___|

Enter years

            Six months to one year   1
            Less than six months   2
            Occasionally, on and off   3
            Refused   77
            Don't Know   99

CGQ100_A   *FMT_NUMCAT.*
CGQ100_B   *FMT_CGQ_DURATION.*

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.

|___|___|___]

Enter hours per week
[If less than 1 hour per week, enter "1."]
[If SP provides constant care, enter "168."]
            Refused   777
            Don't Know   999

CGQ110   *FMT_NUMERIC.*

CAREGIVING (CGQ)

CGQ.120.   I have a list of things that other people have found to be difficult about giving care (e.g. to sick, disabled, elderly family members, friends, etc.). **Do these apply to you because of care-giving? Please answer yes or no. [Each individual method below is asked and answered with yes/no/refused/don't know response options]**

a.   Your sleep is disturbed (e.g., because the person you give care to requires care at night).
b.   It is inconvenient to you (e.g., because care-giving takes so much time).
c.   It is a physical strain for you (e.g., because of lifting the person you give care to in and out of a chair).
d.   It is confining to you (e.g., you have little free time or cannot go visiting).
e.   There have been family adjustments for you (e.g., because care-giving has disrupted your routine or there is little privacy).
f.   You have made changes in personal plans (e.g., had to turn down a job; could not go on vacation).
g.   You have had to make emotional adjustments.
h.   Some behavior (of the person you give care to) is upsetting to you.
i.   It is upsetting to find the person you give care to has changed so much from {his/her} former self.
j.   You have had to make work adjustments (e.g., because of having to take time off).
k.   It is a financial strain for you.
l.   You feel overwhelmed (e.g., because concerns about how you will manage, or concerns about health of the person you give care to).

CGQ120_A   FMT_YES_NO.
CGQ120_B   FMT_YES_NO.
CGQ120_C   FMT_YES_NO.
CGQ120_D   FMT_YES_NO.
CGQ120_E   FMT_YES_NO.
CGQ120_F   FMT_YES_NO.
CGQ120_G   FMT_YES_NO.
CGQ120_H   FMT_YES_NO.
CGQ120_I   FMT_YES_NO.
CGQ120_J   FMT_YES_NO.
CGQ120_K   FMT_YES_NO.
CGQ120_L   FMT_YES_NO.

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

QUESTIONS FOR THOSE CAREGIVERS WHO ARE NOT CURRENTLY IN THIS ROLE (CGQ. 130 – CGQ.210 only)

CGQ.130.   To how many people did you provide this care in the past 12 months?
CGQ130   FMT_NUMERIC. |___|___|
                                 Enter number of people
                                 Refused   77
                                 Don't Know   99

CAREGIVING (CGQ)

> *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?

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

CGQ140   FMT_CGQ_RELATIONSHIP.
CGQ140_OTHER $FMT_CHAR.

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

CGQ150   Male   1
FMT_GENDER.   Female   2
                   Refused   77
                   Don't Know   99

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

CGQ160 |___|___|___]
FMT_NUMERIC.   Enter years
                   Refused   777
                   Don't Know   999

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

CGQ170   In your household   1
FMT_CGQ_DISTANCE. Within twenty minutes of your home   2
                   Between 20 minutes and an hour from your home   3
                   A one to two hour drive from your home   4
                   More than two hours away   5
                   Refused   77

CAREGIVING (CGQ)

Don't Know   99

CAREGIVING (CGQ)

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

Aids	1
Alzheimer's/ confusion/ dementia/ forgetfulness	2
Amputee	3
Arthritis	4
Asthma	5
Attention deficit hyperactivity disorder (ADHD)	6
Autism, Asperger's, pervasive developmental disorder (PDD)	8
Blindness/vision loss, can't see well	10
Blood pressure/hypertension	11
Broken bones	12
Cancer	13
Cerebral palsy	14
Cognitive disabilities	15
Deafness/hearing loss	16
Developmental disabilities	17
Diabetes	18
Down syndrome	19
Epilepsy	20
Feeble, unsteady, falling	21
Fragile x syndrome	22
Heart disease	23
Juvenile diabetes	24
Learning disabilities (i.e., dyslexia, dyspraxia, and central auditory disorder)	25
Lung disease, emphysema	26
Mental retardation	27
Mental illness, emotional illness, depression (including Bipolar disorder, schizophrenia, and substance abuse)	28
Mobility (can't get around)	29
Muscular dystrophy	30
Old age, just old	31
Osteoporosis	32
Paraplegia	33
Parkinson's	34
Sickle cell anemia	35
Speaking, can't speak	36
Spina bifida	37
Stroke	38
Other (Specify:_____)	39
Refused	77
Don't Know	99

CGQ180   FMT_CGQ_PROBLEM.
CGQ180_OTHER $FMT_CHAR.

CAREGIVING (CGQ)

CGQ.190.   When did this person's illness or disability begin?

|___|___|_-_|___|___|___|___|

Enter month and year

Refused	777777
Don't Know	999999

CGQ190_M   FMT_NUMCAT.
CGQ190_Y   FMT_NUMCAT.

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 enter response below if less than one year or occasionally.]**

|___|___|

Enter years

Six months to one year	1
Less than six months	2
Occasionally, on and off	3
Refused	77
Don't Know	99

CGQ200_A   FMT_NUMCAT.
CGQ200_B   FMT_CGQ_DURATION.

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.

|___|___|___]

Enter hours per week

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

Refused	777
Don't Know	999

CGQ210   FMT_NUMERIC.

CAREGIVING (CGQ)

CGQ. 220. I have a list of things that other people have found to be difficult about giving care (e.g. to sick, disabled, elderly family members, friends, etc.). **Did these apply to you <u>because of care-giving</u>? Please answer yes or no. [Each individual method below is asked and answered with yes/no/refused/don't know response options]**

   a. Your sleep is disturbed (e.g., because the person you give care to requires care at night).
   m. It is inconvenient to you (e.g., because care-giving takes so much time).
   n. It is a physical strain for you (e.g., because of lifting the person you give care to in and out of a chair).
   o. It is confining to you (e.g., you have little free time or cannot go visiting).
   p. There have been family adjustments for you (e.g., because care-giving has disrupted your routine or there is little privacy).
   q. You have made changes in personal plans (e.g., had to turn down a job; could not go on vacation).
   r. You have had to make emotional adjustments.
   s. Some behavior (of the person you give care to) is upsetting to you.
   t. It is upsetting to find the person you give care to has changed so much from {his/her} former self.
   u. You have had to make work adjustments (e.g., because of having to take time off).
   v. It is a financial strain for you.
   w. You feel overwhelmed (e.g., because concerns about how you will manage, or concerns about health of the person you give care to).

CGQ220_A	FMT_YES_NO.	[REFERS TO QUESTION (A)]
CGQ220_B	FMT_YES_NO.	[REFERS TO QUESTION (M)]
CGQ220_C	FMT_YES_NO.	[REFERS TO QUESTION (N)]
CGQ220_D	FMT_YES_NO.	[REFERS TO QUESTION (O)]
CGQ220_E	FMT_YES_NO.	[REFERS TO QUESTION (P)]
CGQ220_F	FMT_YES_NO.	[REFERS TO QUESTION (Q)]
CGQ220_G	FMT_YES_NO.	[REFERS TO QUESTION (R)]
CGQ220_H	FMT_YES_NO.	[REFERS TO QUESTION (S)]
CGQ220_I	FMT_YES_NO.	[REFERS TO QUESTION (T)]
CGQ220_J	FMT_YES_NO.	[REFERS TO QUESTION (U)]
CGQ220_K	FMT_YES_NO.	[REFERS TO QUESTION (V)]
CGQ220_L	FMT_YES_NO.	[REFERS TO QUESTION (W)]

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