

THE PITTSBURGH REGIONAL CAREGIVERS SURVEY
BREAKOUTS BY CAREGIVER AGE

Contents (click to jump to section)

Notes.....	1
Types of Caregiving.....	2
Caregiving Situation / Context.....	3
Care Activities.....	8
Aspects of Caregiving.....	24
Support Environment.....	28
Participation.....	32
Health.....	35
Health Literacy and Numeracy.....	40
Employment and Caregiving.....	42
Demographics.....	46
Information / Services / Policy.....	49
Health Insurance and Income.....	52

Notes

All entries are column percentages.

Percentages for single response items may not add to 100 due to rounding.

Some items allowed for multiple responses. For these items, percentages add to more than 100.

CR = care recipient; CG = caregiver

Sample sizes:

20 - 49 n = 182

50 - 64 n = 508

65 and older n = 316

Missing data (i.e., “don’t know” and “refused”) are not presented.

TYPES OF CAREGIVING

SCRNPC. Do you currently help with PERSONAL CARE TASKS, such as bathing, dressing, grooming, eating, moving from bed to chair, or going to the toilet?

	20 – 49	50 – 64	65 and older
Yes	56	46	54
No	45	54	46

SCRNHT. Do you currently help with HOUSEHOLD TASKS, such as shopping, managing personal finances, arranging for outside services, or providing transportation?

	20 – 49	50 – 64	65 and older
Yes	98	98	97
No	2	2	3

SCRNMNT. Do you currently help with MEDICAL OR NURSING TASKS, such as managing medications, changing dressing on wounds, or monitoring equipment like oxygen tanks?

	20 – 49	50 – 64	65 and older
Yes	60	62	67
No	40	38	33

Respondents were required to say YES to at least one of the three questions above to qualify. These tables present the responses of the 1,008 respondents who qualified.

CAREGIVING SITUATION / CONTEXT

QCS1. What is your relationship to the person you help with their personal care, routine household needs and/or medical/nursing tasks? Are you taking care of:

	20 – 49	50 – 64	65 and older
Your mother or mother-in-law	48	51	23
Your father or father-in-law	17	15	6
Your wife / partner	0	3	14
Your husband / partner	1	9	33
Your daughter or daughter-in-law	1	0	2
Your son or son-in-law	0	0	1
Some other relative	27	13	10
A non-relative	6	8	11

QCS2. Is the person you care for:

	20 – 49	50 – 64	65 and older
Male	29	32	47
Female	71	69	53

QCS4. How old is [he / she]? Your best estimate is fine. *(Results categorized for display.)*

	20 – 49	50 – 64	65 and older
50 – 64	26	16	10
65 – 74	29	10	24
75 – 84	26	26	25
85 +	19	48	42

QCS5. Where does [he/she] live?

	20 – 49	50 – 64	65 and older
In your household → QCS9	32	35	64
Within 20 minutes of your home	52	49	27
Between 20 minutes and an hour from your home	11	13	8
One to two hours from your home	1	2	0
More than two hours away	4	2	0

QCS6. Which of the following best describes where [he/she] lives?

	20 – 49	50 – 64	65 and older
His or her own home	77	69	69
Someone else's home → QCS9	9	9	8
An independent living or retirement community	8	12	15
In an assisted living facility where some care may be provided → QCS9	7	10	8
Somewhere else	0	1	0

Note: Persons providing care to a CR in a nursing home were not eligible for the survey.

QCS7. Does [he/she] live alone?

	20 – 49	50 – 64	65 and older
Yes	57	70	75
No	43	31	25

QCS9. Does [he/she] need care because of a... (*multiple responses allowed therefore percentages add to more than 100*)

	20 – 49	50 – 64	65 and older
Short-term physical condition	13	12	12
Long-term physical condition	81	77	77
Emotional or mental health problem	24	17	20
Developmental or intellectual disorder or mental retardation	2	6	5
Behavioral issue	7	5	11
Memory problem	32	44	47
None of the above	6	6	2

QCS10. Does [he/she] suffer from Alzheimer's disease or other types of dementia?

	20 – 49	50 – 64	65 and older
Yes	17	27	22
No	83	73	78

Has a doctor ever told [him / her] that [he / she] had...

QCS11. a heart attack or myocardial infarction?

	20 – 49	50 – 64	65 and older
Yes	23	22	23
No	77	78	77

QCS12. any other heart disease including angina or congestive heart failure?

	20 – 49	50 – 64	65 and older
Yes	35	32	34
No	65	68	66

QCS13. high blood pressure or hypertension?

	20 – 49	50 – 64	65 and older
Yes	66	68	62
No	34	32	38

QCS14. arthritis?

	20 – 49	50 – 64	65 and older
Yes	62	67	65
No	38	33	36

QCS15. osteoporosis or thinning of the bones?

	20 – 49	50 – 64	65 and older
Yes	32	37	36
No	69	63	65

QCS16. diabetes?

	20 – 49	50 – 64	65 and older
Yes	33	24	31
No	67	76	69

QCS17. lung disease, such as emphysema, asthma, or chronic bronchitis?

	20 – 49	50 – 64	65 and older
Yes	25	24	22
No	75	76	78

QCS18. cancer?

	20 – 49	50 – 64	65 and older
Yes	27	29	25
No	73	71	75

QCS18a. a stroke?

	20 – 49	50 – 64	65 and older
Yes	25	21	22
No	75	79	78

QCS19. serious difficulty seeing?

	20 – 49	50 – 64	65 and older
Yes	25	30	30
No	75	70	70

QCS20. serious difficulty hearing?

	20 – 49	50 – 64	65 and older
Yes	23	40	40
No	77	60	60

In the last month has [he / she] used...

QCS22A. glasses or other vision aids such as a magnifying glass?

	20 – 49	50 – 64	65 and older
Yes	88	88	83
No	12	12	17

QCS22B. a hearing aid?

	20 – 49	50 – 64	65 and older
Yes	10	20	20
No	90	80	80

QCS22C. a cane?

	20 – 49	50 – 64	65 and older
Yes	41	42	44
No	59	59	56

QCS22D. a walker?

	20 – 49	50 – 64	65 and older
Yes	44	44	44
No	56	56	56

QCS22E. a wheelchair?

	20 – 49	50 – 64	65 and older
Yes	33	31	38
No	67	69	62

QCS22F. a scooter?

	20 – 49	50 – 64	65 and older
Yes	8	6	10
No	92	94	91

QCS22G. a reacher or grabber to pick things up more easily?

	20 – 49	50 – 64	65 and older
Yes	44	34	28
No	56	66	72

QCS22H. special items to help with dressing, such as button hooks or clothes that are designed to get on and off easily?

	20 – 49	50 – 64	65 and older
Yes	33	20	14
No	67	80	86

QCS22I. adaptive utensils to help to eat or cut food? IF NEEDED: Adapted utensils include things like easy-to-grip silverware, knives that rock, and plates with high sides.

	20 – 49	50 – 64	65 and older
Yes	7	4	7
No	93	96	93

QCS23. Does the CR's residence have features to make it easier for older adults such as a railing or a ramp, grab bars in the bathroom, a seat for the shower or tub, or an emergency call system?

	20 – 49	50 – 64	65 and older
Yes	73	82	82
No → next section	27	18	18

QCS24. Which of these features does the CR's residence have? (*multiple responses accepted*)

	20 – 49	50 – 64	65 and older
A railing or ramp	69	63	61
Grab bars in the bathroom	74	80	74
A seat for the shower or tub	68	70	75
An emergency call system	44	47	38
Other	35	29	40

CARE ACTIVITIES

Caregivers of *persons living in assisted living* were not asked QCA1 through QCA4B if they indicated they did not help the care recipient with household tasks (household tasks screener question SCRNHT).

QCA1PRE. Next we have a few questions about CR's needs for assistance and ways you may have helped CR in the last month because of [his/her] health and functioning. Let's start with chores you may do around CR's home. This includes laundry, cleaning, or making hot meals.

QCA1. In the last month, how often did [he/she] need help with laundry, cleaning, or making hot meals due to poor health and functioning?

	20 – 49	50 – 64	65 and older
Every day	46	47	57
Most days	18	16	13
Some days	22	21	17
Rarely	4	7	6
Never → QCA2	8	7	4
Does not do, but not because of poor health and functioning → QCA2	2	2	3

QCA1A. In the last month, how often did you help CR with laundry, cleaning, or making hot meals or do these chores for [him/her]?

	20 – 49	50 – 64	65 and older
Every day	26	35	55
Most days	24	17	14
Some days	37	33	20
Rarely	9	9	6
Never	4	6	5

QCA1B. Does anyone else help CR with laundry, cleaning, or making hot meals or do these chores for [him/her]? (*Unpaid and paid could be both be selected therefore percentages may add to more than 100*)

	20 – 49	50 – 64	65 and older
Yes, another unpaid family member / friend	77	55	33
Yes, a paid helper	20	27	21
No	17	30	52

QCA2. In the last month, how often did [he/she] need help with shopping for groceries or personal items due to poor health and functioning?

	20 – 49	50 – 64	65 and older
Every day	35	40	45
Most days	24	22	18
Some days	28	23	22
Rarely	4	10	6
Never → QCA3	6	4	5
Does not do, but not because of poor health and functioning → QCA3	3	1	4

QCA2A. In the last month, how often did you shop with CR for groceries or personal items or do [his/her] shopping for [him/her]?

	20 – 49	50 – 64	65 and older
Every day	18	21	35
Most days	21	24	20
Some days	41	37	30
Rarely	10	12	6
Never	9	6	9

QCA2B. Does anyone else help CR with shopping for groceries or personal items? (*Unpaid and paid could be both be selected*)

	20 – 49	50 – 64	65 and older
Yes, another unpaid family member / friend	73	55	39
Yes, a paid helper	7	8	7
No	26	41	57

QCA3. In the last month, did CR need help with ordering medicines due to poor health and functioning?

	20 – 49	50 – 64	65 and older
Yes	50	60	59
No → QCA4	46	39	37
Does not do, but not because of poor health and functioning → QCA4	4	1	4

QCA3A. In the last month, did you ever help CR order [his/her] prescribed medicines or order these for [him/her]?

	20 – 49	50 – 64	65 and older
Yes	66	72	87
No	34	28	14

QCA3B. Does anyone else help CR with ordering medicines? (*Unpaid and paid could be both be selected*)

	20 – 49	50 – 64	65 and older
Yes, another unpaid family member / friend	53	37	20
Yes, a paid helper	7	13	7
No	40	52	74

QCA4. In the last month, did CR need help with handling bills or banking due to poor health and functioning?

	20 – 49	50 – 64	65 and older
Yes	56	71	67
No → QCA5	42	26	27
Does not do, but not because of poor health and functioning → QCA5	2	3	6

QCA4A. In the last month, did you ever help CR with handling bills or banking or do this for [him/her]?

	20 – 49	50 – 64	65 and older
Yes	63	79	85
No	37	21	15

QCA4B. Does anyone else help CR with handling bills or banking? (*Unpaid and paid could be both be selected*)

	20 – 49	50 – 64	65 and older
Yes, another unpaid family member / friend	63	41	29
Yes, a paid helper	1	2	1
No	35	58	70

Caregivers of persons living in assisted living were not asked QCA5 through QCA12C if they indicated they did not help the care recipient with personal care (personal care screener question SCRNPC).

QCA5PRE. Now, a few questions about personal care.

QCA5. In the last month, how often did CR need help with eating due to poor health and functioning?

	20 – 49	50 – 64	65 and older
Every day	7	10	11
Most days	5	4	4
Some days	8	6	6
Rarely	9	10	12
Never → QCA6	72	70	67

QCA5A. In the last month, how often did you help [him/her] with eating?

	20 – 49	50 – 64	65 and older
Every day	18	22	33
Most days	16	12	13
Some days	35	28	18
Rarely	20	22	28
Never	10	17	8

QCA5B. Does anyone else help [him/her] with eating? (*Unpaid and paid could be both be selected*)

	20 – 49	50 – 64	65 and older
Yes, another unpaid family member / friend	65	47	22
Yes, a paid helper	16	18	12
No	29	42	69

QCA6. In the last month, how often did CR need help with showering or bathing due to poor health and functioning?

	20 – 49	50 – 64	65 and older
Every day	22	23	26
Most days	12	10	9
Some days	13	10	14
Rarely	13	10	9
Never → QCA7	40	47	43

QCA6A. In the last month, how often did you help [him/her] with showering or bathing?

	20 – 49	50 – 64	65 and older
Every day	16	18	30
Most days	12	14	12
Some days	22	23	23
Rarely	26	14	15
Never	26	32	21

QCA6B. Does anyone else help [him/her] with showering or bathing? (*Unpaid and paid could be both be selected*)

	20 – 49	50 – 64	65 and older
Yes, another unpaid family member / friend	52	41	16
Yes, a paid helper	22	33	28
No	36	34	60

QCA7. In the last month, how often did CR need help with dressing or grooming due to poor health and functioning?

	20 – 49	50 – 64	65 and older
Every day	22	22	25
Most days	10	8	8
Some days	15	16	14
Rarely	16	12	14
Never → QCA8	38	43	40

QCA7A. In the last month, how often did you help CR with dressing or grooming?

	20 – 49	50 – 64	65 and older
Every day	15	18	31
Most days	19	13	15
Some days	32	33	26
Rarely	21	21	23
Never	14	15	4

QCA7B. Does anyone else help [him/her] with dressing or grooming? (*Unpaid and paid could be both be selected*)

	20 – 49	50 – 64	65 and older
Yes, another unpaid family member / friend	61	46	17
Yes, a paid helper	20	29	19
No	35	34	68

QCA8. In the last month, how often CR need help with using the toilet due to poor health and functioning?

	20 – 49	50 – 64	65 and older
Every day	14	16	19
Most days	5	3	3
Some days	11	5	6
Rarely	14	9	9
Never → QCA9	57	67	64

QCA8A. In the last month, how often did you help CR with using the toilet?

	20 – 49	50 – 64	65 and older
Every day	21	25	41
Most days	14	12	9
Some days	22	26	16
Rarely	26	18	26
Never	18	20	8

QCA8B. Does anyone else help [him/her] with using the toilet? (*Unpaid and paid could be both be selected*)

	20 – 49	50 – 64	65 and older
Yes, another unpaid family member / friend	62	54	25
Yes, a paid helper	25	37	26
No	34	23	58

QCA9. In the last month, how often did CR need help getting in and out of bed due to poor health and functioning?

	20 – 49	50 – 64	65 and older
Every day	13	16	17
Most days	6	3	3
Some days	16	6	7
Rarely	15	12	14
Never → QCA10	50	62	59

QCA9A. In the last month, how often did you help CR get in and out of bed?

	20 – 49	50 – 64	65 and older
Every day	11	19	30
Most days	12	11	8
Some days	31	25	17
Rarely	34	29	30
Never	13	17	16

QCA9B. Does anyone else help [him/her] get in and out of bed? (*Unpaid and paid could be both be selected*)

	20 – 49	50 – 64	65 and older
Yes, another unpaid family member / friend	63	54	23
Yes, a paid helper	22	28	17
No	31	31	64

QCA10. In the last month, how often did CR need help getting around [his/her] home due to poor health and functioning?

	20 – 49	50 – 64	65 and older
Every day	19	16	17
Most days	6	5	3
Some days	16	13	10
Rarely	21	16	17
Never → QCA11	38	50	53

QCA10A. In the last month, how often did you help CR get around [his/her] home?

	20 – 49	50 – 64	65 and older
Every day	19	17	27
Most days	13	12	10
Some days	36	33	27
Rarely	28	29	28
Never	4	9	8

QCA10B. Does anyone else help [him/her] get around [his/her] home? (*Unpaid and paid could be both be selected*)

	20 – 49	50 – 64	65 and older
Yes, another unpaid family member / friend	71	61	28
Yes, a paid helper	13	23	21
No	27	29	57

QCA11. In the last month, how often did CR need help leaving [his/her] home to go outside due to poor health and functioning?

	20 – 49	50 – 64	65 and older
Every day	26	25	22
Most days	16	13	7
Some days	21	18	21
Rarely	11	14	14
Never → skip logic prior to QCA12A	27	31	36

QCA11A. In the last month, how often did you help CR leave [his/her] home to go outside?

	20 – 49	50 – 64	65 and older
Every day	15	18	28
Most days	21	18	11
Some days	39	38	36
Rarely	18	18	20
Never	7	8	6

QCA11B. Does anyone else help [him/her] leave [his/her] home to go outside? (*Unpaid and paid could be both be selected*)

	20 – 49	50 – 64	65 and older
Yes, another unpaid family member / friend	77	63	40
Yes, a paid helper	10	19	11
No	21	29	51

Skip logic: QCA12A, QCA12B, and QCA12C were asked if CG responded he / she ever provided care on QCA5A, QCA6A, QCA7A, QCA8A, QCA9A, QCA10A, or QCA11A (i.e., response of every day, most days, some days, or rarely on one or more of these items)

QCA12A. In the last month when you helped CR with personal care, did you ever lift [him/her] from a seated or lying position?

	20 – 49	50 – 64	65 and older
Yes	45	37	30
No	55	64	70

QCA12B. [In the last month when you helped CR with personal care,] did you ever let [him/her] lean on you or support [his/her] weight?

	20 – 49	50 – 64	65 and older
Yes	85	71	65
No	15	29	35

QCA12C. [In the last month when you helped CR with personal care,] did you ever hold [him/her] steady while [he/she] walked or stood?

	20 – 49	50 – 64	65 and older
Yes	81	73	66
No	19	27	35

QCA13. In the last month, how often did you drive CR places?

	20 – 49	50 – 64	65 and older
Every day	7	11	16
Most days	17	14	20
Some days	33	40	33
Rarely	20	17	14
Never	24	19	17

QCA14. In the last month, how often did you go with CR in a van, shuttle or cab, or take public transportation -- the bus, subway, train, or light rail -- with [him/her]?

	20 – 49	50 – 64	65 and older
Every day	1	1	3
Most days	4	2	3
Some days	4	4	3
Rarely	8	4	5
Never	56	62	57
Do not use	28	27	29

Caregivers of **persons living in assisted living** were not asked QCA15A through QCA19 if they indicated they did not help the care recipient with medical / nursing task care (medical / nursing tasks screener question SCRNMENT).

QCA15PRE. The next few questions are about help related to CR's health care.

QCA15A. In the last month, did you ever help CR keep track of [his/her] medications?

	20 – 49	50 – 64	65 and older
Yes	54	59	68
No	46	41	32

QCA15A1. In the last month, did you ever actually give CR [his/her] medications?

	20 – 49	50 – 64	65 and older
Yes	42	43	54
No	58	57	46

QCA15A2. How are these drugs administered? (multiple responses could be selected)

	20 – 49	50 – 64	65 and older
Orally (by mouth as pills, capsules, liquid)	97	99	99
Insulin injection	14	11	14
Other injection	4	8	3
Infusion pump	0	1	1
Inhaler	15	14	11
Suppository	8	2	2
Medication patch	6	5	5
Spray	3	5	3
Eye/Ear drops	11	17	20
Other	7	9	6

QCA15B. [In the last month, did you ever help CR] take shots or injections?

	20 – 49	50 – 64	65 and older
Yes	7	6	6
No	93	94	94

QCA15C. [In the last month, did you ever help CR] manage medical tasks like ostomy care, IVs, or testing blood?

	20 – 49	50 – 64	65 and older
Yes	7	10	9
No	93	90	91

QCA15D. [In the last month, did you ever help CR] with exercises [he/she] was supposed to do?

	20 – 49	50 – 64	65 and older
Yes	36	25	28
No	64	75	72

QCA15E. [In the last month, did you ever help CR] with a special diet?

	20 – 49	50 – 64	65 and older
Yes	30	26	29
No	70	74	71

QCA15F. [In the last month, did you ever help CR] care for [his/her] teeth or dentures?

	20 – 49	50 – 64	65 and older
Yes	22	19	19
No	78	81	81

QCA15G. [In the last month, did you ever help CR] care for [his/her] feet, like clipping nails?

	20 – 49	50 – 64	65 and older
Yes	33	28	29
No	67	72	71

QCA15H. [In the last month, did you ever help CR] with skin care related to wounds or sores?

	20 – 49	50 – 64	65 and older
Yes	29	23	34
No	71	77	66

QCA15I. [In the last month, did you ever help CR] with assistive devices for mobility like canes or walkers?

	20 – 49	50 – 64	65 and older
Yes	51	47	45
No	49	53	55

Caregivers were only asked QCA15J through QCA19 if they indicated they did help the care recipient with medical / nursing task care (medical / nursing task screener question SCRNMNT).

You indicated at the beginning of the survey that you perform some medical/nursing tasks. Many different tasks are considered medical/nursing tasks even though they are done at home. Some require equipment; others do not. Which of the following additional medical tasks do you perform?

QCA15J. [In the last month, did you ever] use incontinence equipment like catheters, supplies like adult diapers, or administer enemas?

	20 – 49	50 – 64	65 and older
Yes	44	37	39
No	56	63	61

QCA15K. [In the last month, did you ever] use meters/monitors (e.g., thermometer, glucometer, stethoscope, weight scales, blood pressure monitors, oxygen saturation monitors)?

	20 – 49	50 – 64	65 and older
Yes	57	47	53
No	43	53	47

QCA15L. [In the last month, did you ever] administer test kits (bladder infection test, for example)?

	20 – 49	50 – 64	65 and older
Yes	5	5	2
No	96	95	98

QCA15M. [In the last month, did you ever] operate durable medical equipment (hospital beds, lifts, wheelchairs, scooters, toilet or bath chairs, geri-chairs, for example)?

	20 – 49	50 – 64	65 and older
Yes	60	44	45
No	40	57	56

QCA15N. [In the last month, did you ever] operate mechanical ventilators, oxygen, tube feeding equipment, or home dialysis equipment?

	20 – 49	50 – 64	65 and older
Yes	22	16	18
No	78	85	83

QCA15O. [In the last month, did you ever] use telehealth equipment (cameras, sensors, phone lines to collect medical data in the home and transmit it to doctor or nurse)?

	20 – 49	50 – 64	65 and older
Yes	10	9	7
No	90	91	93

(If YES to any of QCA15A – QCA15O, ask QCA16 – QCA19; otherwise skip to QCA21)

QCA16. How difficult is it for you to do the medical and nursing tasks that are required to help CR?
Please answer by choosing a number between 1 and 5, where 1 means not at all difficult and 5 means very difficult.

	20 – 49	50 – 64	65 and older
1. Not at all difficult	45	55	59
2.	28	20	16
3.	15	16	14
4.	7	6	8
5. Very difficult	5	3	4

QCA17. Did anyone prepare you to do these tasks?

	20 – 49	50 – 64	65 and older
Yes	26	25	24
No → QCA21	74	75	76

QCA18. Who prepared you to do the medical and nursing tasks needed to help CR? (*multiple responses could be selected*)

	20 – 49	50 – 64	65 and older
Hospital nurse	23	20	27
Hospital doctor	5	8	5
Primary care doctor	20	15	11
Nurse in doctor's office or outpatient setting	13	14	9
Home care nurse	23	25	26
Social worker/geriatric care manager	3	3	3
Physical or occupational therapist	10	17	24
Pharmacist	5	9	3
Medical supply technician	3	11	8
Friend or neighbor	3	6	12
You learned on your own	23	31	23
Other	53	41	42

QCA19. How well do you feel that person prepared you to take on these medical and nursing tasks?

	20 – 49	50 – 64	65 and older
Very well	68	80	85
Somewhat well	28	19	14
Not well	5	1	2

QCA21. During that last 12 months, how many times has [he/she] been hospitalized overnight?

	20 – 49	50 – 64	65 and older
None → QCA24PRE	37	45	47
One time	19	22	22
2 times	21	14	16
3 or more times	24	19	16

QCA22. When [he/she] was in the hospital, were you included by health care workers, like nurses, doctors, or social workers, in discussions about CR's care? Would you say...

	20 – 49	50 – 64	65 and older
Yes, all the time	48	62	58
Only some of the time	25	23	25
No, and you should have been	8	4	5
No, but you did not need to be	19	11	13

QCA23. Before CR left the hospital or was discharged, did you receive clear instructions about any medical or nursing tasks you would need to perform for [him/her]?

	20 – 49	50 – 64	65 and older
Yes	61	74	78
No	31	18	17
Not applicable	8	8	5

QCA23b. How prepared did you feel to take on any medical and nursing tasks after CRs hospitalization?

	20 – 49	50 – 64	65 and older
Very well	51	53	59
Somewhat well	33	36	35
Not well	17	11	7

QCA24PRE. Now think about the last YEAR.

QCA24A. In the last year, did you ever make appointments for CR with a medical provider?

	20 – 49	50 – 64	65 and older
Yes	55	66	70
No	45	34	30

QCA24B. [In the last year, did you ever] speak to or email CR's medical provider about [his/her] care?

	20 – 49	50 – 64	65 and older
Yes	51	69	70
No	49	31	30

QCA24B1. [In the last year, did you ever] go with the CR to appointments with a medical provider?

	20 – 49	50 – 64	65 and older
Yes	77	85	89
No	23	15	11

QCA24C. [In the last year, did you ever] help [him/her] change or add a health insurance or prescription drug plan? [IF NEEDED: For example, changed or helped [him/her] change a Medicare supplemental plan or prescription drug plan , or helped [him/her] decide to join or leave a managed care plan.]

	20 – 49	50 – 64	65 and older
Yes	18	28	29
No	82	73	71

QCA24D. [In the last year, did you ever] handle any other health insurance matters related to [his/her] medical care? [IF NEEDED: This includes contacting Medicare or another insurer to find out what is covered, comparing plans or providers, finding out about bills, or filing a claim.]

	20 – 49	50 – 64	65 and older
Yes	28	40	42
No	72	60	59

QCA25. About how many hours per week on average do you help this person with personal care, routine household needs and/or medical/nursing tasks?

	20 – 49	50 – 64	65 and older
8 hours or less per week	46	43	37
9 to 19 hours per week	22	28	24
20 to 39 hours per week	21	15	15
40 or more hours per week	12	14	25

QCA25b. Thinking about all of the ways you helped CR in the last month, did you help on a regular basis or did it vary? By regular schedule, we mean the same days or times every week.

	20 – 49	50 – 64	65 and older
Regular schedule	42	52	60
Varied	58	48	40

QCA26. For how long have you been helping this person with personal care routine household needs and/or medical/nursing tasks?

	20 – 49	50 – 64	65 and older
3 months or less	5	5	7
4 to 12 months	12	11	10
1 - 2 years	25	20	15
3 - 5 years	24	29	30
More than 5 years	35	35	38

QCA27. Over the past month, has the amount you helped CR increased, decreased, or been about the same as before?

	20 – 49	50 – 64	65 and older
Increased in the past month	33	37	36
Been about the same in the past month	55	56	55
Decreased in the past month	12	8	10

QCA28. Thinking ahead to next few months, do you think the amount you will help CR will increase, decrease, or be about the same as the past month?

	20 – 49	50 – 64	65 and older
Will increase	35	35	28
Will be about the same	59	59	60
Will decrease	6	7	12

QCA29. Do you feel you had a choice in taking on this responsibility for caring for CR?

	20 – 49	50 – 64	65 and older
Yes	52	45	43
No	48	55	57

QCA30. In general, how worried are you about making a mistake or error, or unintentionally hurting CR while caring for him / her?

	20 – 49	50 – 64	65 and older
Very worried	7	5	4
Somewhat worried	15	11	11
Only a little	30	29	26
Not at all	48	55	59

Illness, disability, and life circumstances may cause some people to suffer either physically or psychologically.

QCA31. I'd like to ask you to the degree to which you think CR has been suffering physically during the past month on a scale from 1 to 10 where 1 equals "CR has not been suffering physically," and 10 equals "CR has been suffering terribly".)

	20 – 49	50 – 64	65 and older
1 CR has not been suffering physically	10	14	14
2	6	10	12
3	8	16	16
4	14	9	7
5	17	14	14
6	10	8	8
7	15	10	12
8	11	9	10
9	4	4	5
10 CR has been suffering terribly	6	7	4

QCA32. Now, please rate the degree to which you think CR has been suffering psychologically or emotionally during the past month on a scale from 1 to 10 where 1 equals “CR has not been suffering psychologically / emotionally,” and 10 equals “CR has been suffering terribly”.)

	20 – 49	50 – 64	65 and older
1 CR has not been suffering physically	11	14	12
2	12	8	10
3	10	11	11
4	6	7	8
5	9	15	19
6	9	11	9
7	13	10	7
8	14	11	12
9	7	6	4
10 CR has been suffering terribly	9	7	7

ASPECTS OF CAREGIVING

QAC1PRE. Now we have a few questions about your relationship with CR.

QAC1. How much do you enjoy being with [him/her]?

	20 – 49	50 – 64	65 and older
A lot	72	71	68
Some	22	22	26
A little	6	5	5
Not at all	1	1	1

QAC2. How much does [he/she] argue with you?

	20 – 49	50 – 64	65 and older
A lot	25	20	13
Some	21	23	33
A little	28	29	29
Not at all	27	28	25

QAC3. How much does CR appreciate what you do for [him/her]?

	20 – 49	50 – 64	65 and older
A lot	82	81	77
Some	9	11	14
A little	6	6	6
Not at all	3	2	3

QAC4. How often does [he/she] get on your nerves?

	20 – 49	50 – 64	65 and older
A lot	20	19	21
Some	27	30	34
A little	34	32	33
Not at all	20	18	12

QAC4b. How would you say the quality of your relationship with CR has changed, if at all, since you began helping him/her? Would you say your relationship has...

	20 – 49	50 – 64	65 and older
Gotten much better	25	18	11
Gotten somewhat better	23	23	15
Stayed about the same	44	45	54
Gotten somewhat worse	7	12	16
Gotten much worse	2	2	5

QAC5PRE. Next we have a few questions about your experience helping CR. For each statement I read, please tell me whether this describes your situation very much, somewhat, or not so much.

QAC5A. Helping [him/her] has made you more confident about your abilities.

	20 – 49	50 – 64	65 and older
Very much	35	38	39
Somewhat	35	37	38
Not so much	29	25	23

QAC5B. Helping [him/her] has taught you to deal with difficult situations.

	20 – 49	50 – 64	65 and older
Very much	49	47	48
Somewhat	35	38	35
Not so much	16	15	17

QAC5C. Helping CR has brought you closer to [him/her].

	20 – 49	50 – 64	65 and older
Very much	47	50	44
Somewhat	39	35	35
Not so much	14	16	21

QAC5D. Helping CR gives you satisfaction that [he/she] is well cared for.

	20 – 49	50 – 64	65 and older
Very much	75	79	78
Somewhat	20	18	19
Not so much	5	3	2

QAC6A. Is helping CR financially difficult for you?

	20 – 49	50 – 64	65 and older
Yes	24	24	19
No	76	76	81

QAC6B. Is helping [him/her] emotionally difficult for you?

	20 – 49	50 – 64	65 and older
Yes	58	61	62
No	42	39	39

QAC6C. Is helping [him/her] physically difficult for you?

	20 – 49	50 – 64	65 and older
Yes	26	28	32
No	74	72	68

QAC7A. Please tell me how difficult helping is by picking a number from 1 to 5. The number 5 means very difficult and the number 1 means a little difficult. How financially difficult is helping CR? (*Asked if “yes” to QAC6A*)

	20 – 49	50 – 64	65 and older
1. A little difficult	19	12	5
2.	12	9	14
3.	19	30	41
4.	30	23	24
5. Very difficult	21	26	17

QAC7B. How emotionally difficult is helping [him/her]? (*Asked if “yes” to QAC6B*)

	20 – 49	50 – 64	65 and older
1. A little difficult	10	10	17
2.	18	16	20
3.	24	31	27
4.	29	23	19
5. Very difficult	19	21	18

QAC7C. How physically difficult is helping [him/her]? (*Asked if “yes” to QAC6C*)

	20 – 49	50 – 64	65 and older
1. A little difficult	6	13	6
2.	15	18	19
3.	38	39	31
4.	23	20	27
5. Very difficult	17	11	18

QAC8. In general, how much has your family disagreed over the details of [his/her] care? (*Asked if CR was related to CG*)

	20 – 49	50 – 64	65 and older
Very much	13	8	6
Somewhat	23	24	17
Not so much	64	68	77

QAC9PRE. Please listen to a few more statements and answer whether this describes your situation very much, somewhat, or not so much.

QAC9A. You are exhausted when you go to bed at night.

	20 – 49	50 – 64	65 and older
Very much	34	34	27
Somewhat	28	29	33
Not so much	39	37	40

QAC9B. You have more things to do than you can handle.

	20 – 49	50 – 64	65 and older
Very much	25	27	17
Somewhat	34	33	35
Not so much	41	40	48

QAC9C. You don't have time for yourself.

	20 – 49	50 – 64	65 and older
Very much	30	27	23
Somewhat	31	34	33
Not so much	39	39	44

QAC9D. As soon as you get a routine going, CR's needs change.

	20 – 49	50 – 64	65 and older
Very much	11	11	11
Somewhat	21	28	30
Not so much	68	61	60

SUPPORT ENVIRONMENT

QSE1PRE. The next questions are about support you may be getting.

QSE1. Do you have friends or family that you talk to about important things in your life?

	20 – 49	50 – 64	65 and older
Yes	92	89	90
No	8	11	11

QSE2. Do you have friends or family that help you with your daily activities, such as running errands, or helping you with things around the house?

	20 – 49	50 – 64	65 and older
Yes	66	52	46
No	34	48	54

QSE3. Do you have friends or family that help you care for CR?

	20 – 49	50 – 64	65 and older
Yes	81	69	56
No	19	31	44

QSE4. In the last year, have you gone to a support group for people who give care?

	20 – 49	50 – 64	65 and older
Yes	3	7	5
No	97	93	95

QSE4a. In the last year, have you used any service that took care of CR so that you could take some time away from helping?

	20 – 49	50 – 64	65 and older
Yes	15	22	19
No	85	79	81

QSE5. In the last year, have you received any training to help you take care of CR?

	20 – 49	50 – 64	65 and older
Yes	9	11	8
No	91	89	92

QSE6. In the last year, have you found financial help for CR, including helping [him/her] apply for Medicaid?

	20 – 49	50 – 64	65 and older
Yes	21	19	13
No	79	81	87

QSE7. Have you ever looked for [A support group for people who provide care] or [A service to care for CR so you could take time away] or [Training to help you care for CR] or [Information about how to get financial help for CR]? *(Asked regarding items the respondent did not say YES to)*

	20 – 49	50 – 64	65 and older
Yes	15	19	20
No	85	81	80

QSE8. In the last year, have you helped [him/her] to get devices to get around more easily, such as a cane, walker, wheelchair, or scooter?

	20 – 49	50 – 64	65 and older
Yes	48	42	42
No	52	58	59

QSE9. In the last year, have you [made your home safer] [helped CR make [his/her] home safer] by adding features such as a railing or a ramp, grab bars in the bathroom, a seat for the shower or tub, or an emergency call system?

	20 – 49	50 – 64	65 and older
Yes	48	43	42
No	52	57	58

QSE10. In the last year, have you helped [him/her] find a paid helper to do household chores or personal care?

	20 – 49	50 – 64	65 and older
Yes	16	21	24
No	84	79	76

Shared Caregiving *(Questions QSE11 through QSE16 were asked if the respondent indicated that he/she has family or friends to help care for CR in QSE3)*

You mentioned that you have other family or friends that help you care for CR. I'd now like to ask a few questions about that.

QSE11. First, how many other family and friends help you care for CR?

	20 – 49	50 – 64	65 and older
One	25	22	24
Two	27	27	28
Three or more	48	51	49

QSE11A. Who is that (are they)? (multiple responses accepted)

	20 – 49	50 – 64	65 and older
Caregiver’s Brother(s)	24	32	19
CG’s Sister(s)	27	49	27
CG’s husband	22	20	16
CG’s wife	7	9	6
CG’s other relative(s) / in-law(s)	65	45	63
CG’s friend(s)	11	13	12
Other	26	24	24

QSE12. Which of the following best describes where this/these additional helper(s) live(s)? (multiple responses accepted)

	20 – 49	50 – 64	65 and older
Live(s) with you	54	38	30
Within twenty minutes of your home	57	66	68
Between twenty minutes and an hour from your home	22	25	28
One to two hours from your home	9	6	4
Two to four hours away	6	4	3
More than four hours away	10	12	10

QSE13. Which of the following best describes how you divide the tasks of caring for CR?

	20 – 49	50 – 64	65 and older
We complement each other – we each help CR with different tasks.	29	29	29
We help with the same things but we divide the help over time.	17	18	16
We share some tasks, and others we do separately	54	53	55

QSE14. Would you say that you or someone else is the “primary caregiver,” or the person that provides MOST of the help for your CR?

	20 – 49	50 – 64	65 and older
Respondent is the primary caregiver	41	52	75
Someone else is the primary caregiver	43	32	15
Care is equally shared	16	16	10

QSE15. To what extent would you say that you and the other caregiver(s) experience conflict or disagreement over coordinating care for the CR?

	20 – 49	50 – 64	65 and older
To a great extent	5	2	0
To a moderate extent	8	9	8
Only a little	33	30	24
Not at all	55	59	69

QSE16. Overall, how satisfied or dissatisfied are you with the care coordination between you and your family / friends?

	20 – 49	50 – 64	65 and older
Very satisfied	61	67	75
Moderately satisfied	29	26	20
Moderately dissatisfied	8	5	4
Very dissatisfied	3	2	2

PARTICIPATION

QPP1PRE. Now let's talk about other activities you may have done in the last month.

QPP1. In the last month, did you ever visit in person with friends or family NOT living with you, either at your home or theirs?

	20 – 49	50 – 64	65 and older
Yes	87	85	84
No	13	15	17

QPP2. In the last month, did helping CR ever keep you from doing this [visiting in person with friends or family NOT living with you]?

	20 – 49	50 – 64	65 and older
Yes	29	33	28
No	71	67	72

QPP3. How important is it to you to visit in person with friends or family NOT living with you?

	20 – 49	50 – 64	65 and older
Very important	57	50	55
Somewhat important	30	35	32
Not so important	13	15	14

QPP4. In the last month, did you ever attend religious services?

	20 – 49	50 – 64	65 and older
Yes	51	62	64
No	50	38	36

QPP5. In the last month, did helping CR ever keep you from doing this [attending religious services]?

	20 – 49	50 – 64	65 and older
Yes	11	13	13
No	89	87	87

QPP6. How important is it to you to attend religious services?

	20 – 49	50 – 64	65 and older
Very important	33	48	52
Somewhat important	26	24	22
Not so important	41	29	26

QPP7. In the last month, [besides religious services,] did you ever participate in club meetings or group activities? [IF NEEDED: These could be any ongoing group activity including dinner or bridge clubs, neighborhood or political organizations, knitting or regular exercise groups.]

	20 – 49	50 – 64	65 and older
Yes	45	46	53
No	55	54	47

QPP8. In the last month, did helping CR ever keep you from doing this [participating in club meetings or group activities [other than religious services]]? [IF NEEDED: These could be any ongoing group activity including dinner or bridge clubs, neighborhood or political organizations, knitting or regular exercise groups.]

	20 – 49	50 – 64	65 and older
Yes	17	22	21
No	83	79	79

QPP9. How important is it to you to participate in club meetings or group activities [other than religious services]? [IF NEEDED: These could be any ongoing group activity including dinner or bridge clubs, neighborhood or political organizations, knitting or regular exercise groups.]

	20 – 49	50 – 64	65 and older
Very important	26	31	33
Somewhat important	29	32	30
Not so important	45	37	37

QPP10. In the last month, [besides for club or group activities,] did you ever go out for enjoyment? This includes things like going out to dinner, a movie, to gamble, or to hear music or see a play.

	20 – 49	50 – 64	65 and older
Yes	87	84	80
No	13	16	20

QPP11. In the last month, did helping CR ever keep you from doing this [going out for enjoyment]? [IF NEEDED: This includes things like going out to dinner, a movie, to gamble, or to hear music or see a play.]

	20 – 49	50 – 64	65 and older
Yes	22	25	25
No	78	75	75

QPP12. How important is it to you to go out for enjoyment? [IF NEEDED: This includes things like going out to dinner, a movie, to gamble, or to hear music or see a play.]

	20 – 49	50 – 64	65 and older
Very important	49	48	47
Somewhat important	35	39	36
Not so important	17	13	17

QPP13. In the last month, did you ever do volunteer work?

	20 – 49	50 – 64	65 and older
Yes	36	34	39
No	64	66	61

QPP14. In the last month, did helping CR ever keep you from doing this [volunteer work]?

	20 – 49	50 – 64	65 and older
Yes	10	15	21
No	90	85	79

QPP15. In the last month, [besides as a job or volunteer work,] did you ever provide care to or look after a child or adult who cannot care for themselves? We mean someone besides CR.

	20 – 49	50 – 64	65 and older
Yes	47	41	37
No	53	59	63

QPP16. In the last month, did helping CR ever keep you from doing this [caring for a child or other adult]?

	20 – 49	50 – 64	65 and older
Yes	7	7	9
No	93	93	91

HEALTH

QHE1. Would you say that in general, your health is excellent, very good, good, fair, or poor?

	20 – 49	50 – 64	65 and older
Excellent	20	15	14
Very good	30	30	33
Good	26	33	32
Fair	21	18	19
Poor	3	4	3

QHE2. Has a doctor ever told you that you had a heart attack or myocardial infarction?

	20 – 49	50 – 64	65 and older
Yes	2	5	13
No	98	95	87

QHE3. Has a doctor ever told you that you had any other heart disease including angina or congestive heart failure?

	20 – 49	50 – 64	65 and older
Yes	3	7	16
No	97	93	84

QHE4. [Has a doctor ever told you that you had] high blood pressure or hypertension?

	20 – 49	50 – 64	65 and older
Yes	21	42	51
No	79	58	49

QHE5. [Has a doctor ever told you that you had] arthritis?

	20 – 49	50 – 64	65 and older
Yes	23	45	67
No	78	55	34

QHE6. [Has a doctor ever told you that you had] osteoporosis or thinning of the bones?

	20 – 49	50 – 64	65 and older
Yes	4	16	35
No	96	84	65

QHE7. [Has a doctor ever told you that you had] diabetes?

	20 – 49	50 – 64	65 and older
Yes	6	17	16
No	95	83	84

QHE8. [Has a doctor ever told you that you had] lung disease, such as emphysema, asthma, or chronic bronchitis?

	20 – 49	50 – 64	65 and older
Yes	17	14	19
No	84	86	81

QHE9. [Has a doctor ever told you that you had] cancer?

	20 – 49	50 – 64	65 and older
Yes	2	13	22
No	98	87	78

QHE10PRE. Now I have a few questions about health problems.

QHE10. In the last month, have you been bothered by pain?

	20 – 49	50 – 64	65 and older
Yes	55	59	71
No	45	41	29

QHE12. In the last month, did you have any breathing problems, including shortness of breath or difficulty breathing?

	20 – 49	50 – 64	65 and older
Yes	14	16	20
No	86	84	80

QHE14. In the last month, did you have limited strength or movement in your shoulders, arms, or hands?

	20 – 49	50 – 64	65 and older
Yes	22	29	37
No	78	71	63

QHE16. In the last month, did you have limited strength in your hips, legs, knees, or feet?

	20 – 49	50 – 64	65 and older
Yes	26	40	46
No	74	60	54

QHE18. In the last month, did you have low energy or were you easily exhausted?

	20 – 49	50 – 64	65 and older
Yes	48	54	51
No	52	46	50

QHE20. In the last month, on nights when you woke up before you wanted to, how often did you have trouble falling back asleep?

	20 – 49	50 – 64	65 and older
Every night	10	9	9
Most nights	17	16	13
Some nights	26	33	36
Rarely	26	26	26
Never	21	16	16

QHE21. In the last month, how often did helping CR cause your sleep to be interrupted?

	20 – 49	50 – 64	65 and older
Every night	1	2	4
Most nights	4	5	6
Some nights	16	18	22
Rarely	21	24	24
Never	58	52	44

QHE23a. How tall are you? (*see BMI below*)

QHE23b. How tall are you? (*see BMI below*)

QHE22. How much do you currently weigh? (*see BMI below*)

BMI categories:

	20 – 49	50 – 64	65 and older
< 18.5 (underweight)	1	1	1
18.5 – 24.9 (normal)	29	27	26
25.0 – 29.9 (overweight)	33	36	39
30.0 – 34.9 (moderately obese)	20	23	22
35.0 – 39.9 (severely obese)	9	7	7
40.0 + (very severely obese)	8	7	5

QHE24. Have you lost 10 or more pounds in the last 12 months?

	20 – 49	50 – 64	65 and older
Yes	37	30	27
No → QHE25A	63	71	73

QHE24a. Were you trying to lose weight?

	20 – 49	50 – 64	65 and older
Yes	70	73	58
No	30	27	42

QHE25a. Thinking about the last month, how often did you feel cheerful?

	20 – 49	50 – 64	65 and older
Every day	14	14	17
Most days	46	47	44
Some days	32	30	28
Rarely	8	8	10
Never	1	1	1

QHE25b. Thinking about the last month, how often did you feel calm and peaceful?

	20 – 49	50 – 64	65 and older
Every day	12	11	15
Most days	37	39	40
Some days	32	34	33
Rarely	16	14	11
Never	4	2	2

QHE25c. [Thinking about the last month,] how often did you feel full of life?

	20 – 49	50 – 64	65 and older
Every day	15	15	18
Most days	35	33	30
Some days	31	32	31
Rarely	17	15	19
Never	3	5	3

QHE25d. [Thinking about the last month,] how often did you feel bored?

	20 – 49	50 – 64	65 and older
Every day	3	3	2
Most days	7	5	6
Some days	21	23	19
Rarely	28	33	32
Never	40	37	42

QHE25e. [Thinking about the last month,] how often did you feel lonely?

	20 – 49	50 – 64	65 and older
Every day	3	3	1
Most days	9	8	6
Some days	20	21	20
Rarely	27	28	29
Never	41	40	44

QHE25f. [Thinking about the last month,] how often did you feel upset?

	20 – 49	50 – 64	65 and older
Every day	2	4	4
Most days	12	8	9
Some days	45	46	50
Rarely	36	36	32
Never	6	6	6

QHE26a. Over the last month, how often have you had little interest or pleasure doing things?

	20 – 49	50 – 64	65 and older
Not at all	57	55	56
Several days	32	32	32
More than half the days	7	9	7
Nearly every day	5	4	5

QHE26b. [Over the last month, how often have you] felt down, depressed, or hopeless?

	20 – 49	50 – 64	65 and older
Not at all	55	56	59
Several days	32	34	28
More than half the days	8	6	9
Nearly every day	4	4	4

QHE26c. [Over the last month, how often have you] felt nervous, anxious, or on edge?

	20 – 49	50 – 64	65 and older
Not at all	37	41	43
Several days	43	45	43
More than half the days	11	8	7
Nearly every day	9	6	7

QHE26d. [Over the last month, how often have you] been unable to stop or control worrying?

	20 – 49	50 – 64	65 and older
Not at all	50	51	50
Several days	25	32	34
More than half the days	11	9	7
Nearly every day	14	8	10

HEALTH LITERACY AND NUMERACY

QLN1PRE. The next few questions are about your abilities and skills in understanding medical information when you have a health problem.

QLN1. How confident are you filling out medical forms by yourself?

	20 – 49	50 – 64	65 and older
Not at all	1	3	4
A little bit	3	4	5
Somewhat	9	10	8
Quite a bit	27	30	25
Extremely	60	53	58

QLN2. How often do you need to have someone help you when you read instructions, pamphlets, or other written material from a doctor or pharmacy?

	20 – 49	50 – 64	65 and older
Never	71	69	65
Rarely	23	22	25
Sometimes	5	8	9
Often	1	1	1
Always	1	0	1

QLN3. How often do you have problems learning about a medical condition because of difficulty understanding written information?

	20 – 49	50 – 64	65 and older
Never	76	65	59
Rarely	18	25	27
Sometimes	4	9	11
Often	1	0	2
Always	1	1	1

QLN4PRE. As a caregiver, you might be asked to help CR understand medical information like test results, diagnoses, or the likelihood of side effects of various medications. This can sometimes involve working with and understanding numbers. The next few questions are designed to measure your ability to work with numbers. Many people have trouble with some of these questions, so don't worry if you find any of them difficult. Just do the best you can.

QLN4. Which of the following numbers represents the biggest risk of getting a disease (1 in 100; 1 in 1,000; or 1 in 10)?

	20 – 49	50 – 64	65 and older
Correct	78	69	58
Incorrect	23	31	43

QLN5. If the chance of getting a disease is 10%, how many people out of 1000 would be expected to get the disease? (*open-ended question; responses categorized for presentation*)

	20 – 49	50 – 64	65 and older
Correct	85	82	81
Incorrect	15	18	20

QLN6. If the chance of getting a disease is 20 out of 100, this would be the same as having a what percent chance of getting the disease? (*open-ended question; responses categorized for presentation*)

	20 – 49	50 – 64	65 and older
Correct	81	75	76
Incorrect	19	25	24

EMPLOYMENT AND CAREGIVING

QEC1PRE. Now I'd like to ask you some questions about work and jobs you may have had.

QEC1. Did you do any work for pay in the last week? By the last week, I mean the last full week beginning on a Sunday and ending on a Saturday.

	20 – 49	50 – 64	65 and older
Yes → QEC4	76	54	18
No	20	23	22
Retired / don't work anymore → QEC16	4	22	60

QEC2. Do you have a job from which you were absent last week because of illness, vacation, or some other reason?

	20 – 49	50 – 64	65 and older
Yes → QEC4	11	9	3
No	78	71	60
Retired / don't work anymore → QEC16	11	20	37

QEC3. In the last week, were you looking for a job or were you on layoff from a job?

	20 – 49	50 – 64	65 and older
Yes, looking for a job → QEC16	38	11	7
Yes, on layoff → QEC16	0	8	2
No → QEC16	62	80	68
Retired / don't work anymore → QEC16	0	1	22

QEC4. Last week, did you have more than one job, including part-time, evening, or weekend work?

	20 – 49	50 – 64	65 and older
Yes	23	22	18
No	78	78	82

QEC5. How many total hours per week do you usually work? (*open-ended question; categorized for display*)

	20 – 49	50 – 64	65 and older
20 or fewer	18	19	47
21 – 39	18	20	16
40 or more	64	61	38

QEC6. [On your main job do / Do] you have flexible work hours that allow you to vary or make changes in the time you begin and end work?

	20 – 49	50 – 64	65 and older
Yes	61	55	80
No	39	45	20

QEC7. [On your main job do / Do] you usually work a daytime schedule or some other schedule?

	20 – 49	50 – 64	65 and older
Daytime	78	85	71
Some other schedule	22	15	29

If response to QEC2 was yes, skip to QEC9A

QEC8. Now thinking back over the last month, were you ever absent from work for any reason?

	20 – 49	50 – 64	65 and older
Yes	50	44	29
No → QEC12	50	56	71

QEC9A. I will read a few reasons people miss work. For each one, please say “yes” if this was a reason you missed work over the last month, and say “no” if you did not miss work for this reason.

You were on vacation.

	20 – 49	50 – 64	65 and older
Yes	36	31	26
No	64	70	74

QEC9B. You were sick.

	20 – 49	50 – 64	65 and older
Yes	36	43	42
No	64	57	58

QEC9C. You took time off to help CR.

	20 – 49	50 – 64	65 and older
Yes	41	46	47
No	59	54	53

QEC9D. Other family members were sick.

	20 – 49	50 – 64	65 and older
Yes	32	15	16
No	69	85	84

QEC9E. You took personal time for other reasons. [IF NEEDED: For example, a school visit for a child, looking for a job, taking classes.]

	20 – 49	50 – 64	65 and older
Yes	40	36	32
No	60	64	68

If response to QEC9C was yes, ask QEC10; otherwise, skip to QEC12

QEC10. You said one of the reasons you were absent from work last month was because you were helping CR. About how many days of work did you miss last month to do this?

	20 – 49	50 – 64	65 and older
One	48	52	56
Two	24	23	11
Three or more	28	25	33

QEC12. We are interested in whether helping CR affects you at work. In the last month, did helping [him/her] make it harder for you to get your work done?

	20 – 49	50 – 64	65 and older
Yes	28	24	27
No → QEC14	72	76	73

QEC13. Please tell me how much helping CR affected you at work by picking a number from 1 to 10. The number 10 means helping [him/her] made your work a lot harder and the number 1 means helping [him/her] made your work a little harder.

	20 – 49	50 – 64	65 and older
1 A little harder	8	18	13
2	13	12	0
3	18	19	25
4	13	15	13
5	20	12	25
6	13	6	6
7	5	9	0
8	13	6	13
10 A lot harder	0	4	6

QEC14. [On your main job does / Does] your supervisor know that you are caring for CR?

	20 – 49	50 – 64	65 and older
Yes	71	81	79
No	29	19	21

QEC15. For employees in your position, which of the following does your employer offer? (*multiple responses accepted*)

	20 – 49	50 – 64	65 and older
Telecommuting or working from home	37	28	32
Programs like information, referrals, counseling, or an employee assistance program, to help caregivers like yourself	38	38	18
Paid leave, where you could take paid time off from work for several weeks to care for a family member	37	34	22
Paid sick days	62	54	33
None of the above	20	27	50

QEC16. As a result of caregiving, did you ever experience any of the following things at work? (*multiple responses accepted*)

	20 – 49	50 – 64	65 and older
Went in late, left early, or took time off during the day to provide care	54	47	28
Took a leave of absence	10	14	11
Went from working full-time to part-time, or cut back your hours	13	17	11
Turned down a promotion	5	4	2
Lost any of your job benefits	4	6	3
Gave up working entirely	8	15	14
Retired early	1	13	19
Received a warning about your performance or attendance at work	6	4	2
None of the above	40	39	52

DEMOGRAPHICS

QDE1. INTERVIEWER: RECORD PERSON'S SEX

	20 – 49	50 – 64	65 and older
Male	25	24	27
Female	75	76	73

QDE2. What is your age now? *(categorized for display)*

	20 – 49	50 – 64	65 and older
44 or under	64	0	0
45 – 54	36	24	0
55 – 64	0	76	0
65 or older	0	0	100

QDE3. What is your current marital status? Are you:

	20 – 49	50 – 64	65 and older
Married	39	59	71
Living with a partner in a marital-like relationship	8	5	3
Divorced or separated	12	16	10
Widowed	0	3	10
Single/never married	42	17	6

QDE4. Are you of Hispanic or Latino descent?

	20 – 49	50 – 64	65 and older
Yes	5	1	1
No	95	99	99

QDE5. How would you describe your race or ethnicity? *(multiple responses accepted)*

	20 – 49	50 – 64	65 and older
Caucasian/White	72	82	90
Asian/Pacific Islander	3	0	0
American Indian or Alaskan Native	2	1	1
Black or African-American	24	17	10
None of the above	2	0	1

QDE6. What is the highest level of education you have completed?

	20 – 49	50 – 64	65 and older
Eighth grade or less	0	0	0
Some high school	1	1	2
High school graduate or GED	9	20	24
Some college, no degree	20	20	21
Associate's degree, occupational	9	8	5
Associate's degree, academic	9	6	4
Bachelor's degree	34	26	22
Master's degree	13	15	16
Professional degree	2	2	3
Doctoral degree	3	2	3

QDE7. What are your current living arrangements? Do you ...

	20 – 49	50 – 64	65 and older
Live alone → QDE11PRE	12	16	13
Live in a household with family or others	87	83	86
Have some other living arrangements	1	1	1

QDE8. Including you, how many adults, age 18 and older, currently live in your household?

	20 – 49	50 – 64	65 and older
One	8	4	4
Two	53	61	78
Three	26	25	15
Four	9	9	3
Five	3	1	1
Six	1	0	0

QDE9. How many children under age 18 currently live in your household?

	20 – 49	50 – 64	65 and older
Zero	41	85	97
One	26	10	1
Two	21	4	1
Three	8	1	1
Four	2	1	0
Five	2	0	0
Six	1	0	0

QDE10. What is the relationship of each of these people to you? (*multiple responses accepted*)

	20 – 49	50 – 64	65 and older
Your spouse / partner	58	76	85
Your child(ren)	61	33	14
Your grandchild(ren)	2	5	6
Your parent(s)	33	19	9
Other relatives of yours	19	10	6
Non-relatives	4	4	2

QDE11PRE. And now just a couple questions about CR.

QDE11. What is the highest level of education [he/she] completed?

	20 – 49	50 – 64	65 and older
Eighth grade or less	6	6	6
Some high school	7	6	8
High school graduate or GED	41	51	43
Some college, no degree	8	8	8
Associate's degree, occupational	10	7	5
Associate's degree, academic	4	2	4
Bachelor's degree	12	13	15
Master's degree	6	5	7
Professional degree	3	1	2
Doctoral degree	2	2	4

QDE12. Is [he/she] of Hispanic or Latino descent?

	20 – 49	50 – 64	65 and older
Yes	2	0	0
No	98	100	100

QDE13. How would you describe [his/her] race or ethnicity? (*multiple responses accepted*)

	20 – 49	50 – 64	65 and older
Caucasian/White	73	82	90
Asian/Pacific Islander	2	0	0
American Indian or Alaskan Native	4	1	1
Black or African-American	23	18	10
None of the above	2	0	0

INFORMATION / SERVICES / POLICY

QIN1. In your experience as a caregiver, have you ever had a doctor, nurse, or social worker ask you about what you need to help care for CR?

	20 – 49	50 – 64	65 and older
Yes	28	37	42
No	72	63	58

QIN2. In your experience as a caregiver, have you ever had a doctor, nurse, or social worker ask you what you need to take care of yourself?

	20 – 49	50 – 64	65 and older
Yes	13	17	23
No	87	83	77

QIN2b. How difficult is it for you to communicate when necessary with healthcare professional such as doctors, nurses, social workers, pharmacists, and rehabilitation therapists about CR’s needs for care? Please answer by using a number between 1 and 5, where 1 means not at all difficult and 5 means very difficult.

	20 – 49	50 – 64	65 and older
1. Not at all difficult	69	73	79
2	11	15	8
3	11	8	5
4	5	2	3
5. Very difficult	3	3	5

QIN2c. How difficult is it for you to communicate when necessary with healthcare professional such as doctors, nurses, social workers, pharmacists, and rehabilitation therapists about your own needs for information and support as a caregiver? Please answer by using a number between 1 and 5, where 1 means not at all difficult and 5 means very difficult.

	20 – 49	50 – 64	65 and older
1. Not at all difficult	67	69	73
2	9	14	11
3	10	9	9
4	9	4	4
5. Very difficult	5	5	3

QIN3. How difficult is it to locate and arrange for affordable community-based services in CR’s local area that could help you care for CR, such as like delivered meals and transportation? Please answer by using a number between 1 and 5, where 1 means not at all difficult and 5 means very difficult.

	20 – 49	50 – 64	65 and older
1. Not at all difficult	36	37	44
2	11	10	6
3	10	14	8
4	11	7	5
5. Very difficult	12	7	9
Not applicable	20	25	27

QIN3a. How difficult is it to locate and arrange for affordable paid in-home personal care such as helping with bathing, dressing, and meals? Please answer by using a number between 1 and 5, where 1 means not at all difficult and 5 means very difficult.

	20 – 49	50 – 64	65 and older
1. Not at all difficult	34	32	34
2	12	8	11
3	11	12	8
4	5	7	5
5. Very difficult	17	13	12
Not applicable	21	29	30

QIN3b. How difficult is it to locate and arrange for affordable community-based service providers that you can trust to provide good care for CR? Please answer by using a number between 1 and 5, where 1 means not at all difficult and 5 means very difficult.

	20 – 49	50 – 64	65 and older
1. Not at all difficult	31	25	29
2	10	7	8
3	10	15	12
4	13	10	7
5. Very difficult	18	15	12
Not applicable	19	27	32

QIN4. Various organizations are thinking about ways to help caregivers like you. Which of the following do you think would be helpful to you? (*multiple responses accepted*)

	20 – 49	50 – 64	65 and older
Requiring health care providers to include your name on CR’s medical chart, so you are part of conversations or decisions about [his/her] care	84	85	81
Requiring hospitals to keep you informed about major decisions, like transferring or discharging CR	84	87	85
Requiring hospitals or facilities to instruct or demonstrate any medical or nursing tasks you might need to do	88	88	85
Having respite services available, where someone would take care of CR to give you a break	69	72	70
Requiring a doctor, nurse, or social worker ask you about what you need to help care for CR	80	81	74
Requiring a doctor, nurse, or social worker ask you about what you need to take care of yourself	62	65	63
None of the above	5	6	6

QIN5. Next I’ll read three ways that people are proposing to help caregivers financially. Please tell me which ONE you would find most helpful.

	20 – 49	50 – 64	65 and older
An income tax credit to caregivers, to help offset the cost of care	30	31	43
A partially paid leave of absence from work for caregivers who are employed	22	20	13
A program where caregivers could be paid for at least some of the hours they provide care	49	50	44

HEALTH INSURANCE AND INCOME

QHI1pre. We have a few last questions.

QHI1. Are you currently covered by Medicare, a health insurance program for person 65 years and over and persons with disabilities?

	20 – 49	50 – 64	65 and older
Yes	8	21	94
No → QHI3	92	80	6

QHI2. Some people with Medicare also have a Medigap or Medicare Supplement plan. Do you have this type of health insurance coverage?

	20 – 49	50 – 64	65 and older
Yes	31	63	71
No	69	37	29

QHI3. Medicaid is a state program for low-income persons or for persons on public assistance. Are you now covered by Medicaid?

	20 – 49	50 – 64	65 and older
Yes	19	13	7
No	81	87	93

QHI4. Are you currently covered by a private health insurance plan? IF NEEDED: This may be a policy you [or your {spouse/partner}]have through a job, a labor union, or an association or organization you belong to. It may also be bought directly from an insurance agent or company.

	20 – 49	50 – 64	65 and older
Yes	75	81	68
No	25	19	32

QHI5. TRICARE and CHAMPVA are health care programs for active duty and retired members of the uniformed Armed Forces, their families, and survivors. Are you now covered by either one of these programs?

	20 – 49	50 – 64	65 and older
Yes	1	2	6
No	100	98	94

QHI7C. What kind of health insurance does the CR have? (*multiple responses accepted*)

	20 – 49	50 – 64	65 and older
Medicare	65	78	79
Medicaid	25	21	10
Private Health Insurance	42	55	66
Tricare/CHAMPVA	4	3	4

QHI8. Do you own your home? *(select “yes” if owned with spouse/partner)*

	20 – 49	50 – 64	65 and older
Yes	52	79	85
No	48	21	15

QHI9A. Do you [and your {spouse/partner}] have any checking accounts?

	20 – 49	50 – 64	65 and older
Yes	92	95	99
No	8	5	1

QHI9B. Do you [and your {spouse/partner}] have any savings or money market accounts?

	20 – 49	50 – 64	65 and older
Yes	67	76	78
No	33	24	22

QHI9C. Do you [and your {spouse/partner}] have any certificates of deposit?

	20 – 49	50 – 64	65 and older
Yes	17	18	22
No	83	82	78

QHI9D. Do you [and your {spouse/partner}] retirement plans such as IRAs, SEPs, 401K, or 403b plans?

	20 – 49	50 – 64	65 and older
Yes	63	74	72
No	37	27	28

QHI9E. Do you [and your {spouse/partner}] stocks or mutual funds that are not in retirement accounts?

	20 – 49	50 – 64	65 and older
Yes	26	35	39
No	74	65	61

QHI10. Now thinking about the income that you [and your {spouse/partner}] have from [work and] all other sources, about how much was your [and your {spouse/partner's}] total income for the last year (in the last 12 months ending in December 2016) before taxes?

	20 – 49	50 – 64	65 and older
0 – less than \$10,000	15	7	2
\$10,000 to less than \$20,000	7	11	10
\$20,000 to less than \$30,000	8	7	15
\$30,000 to less than \$40,000	12	11	15
\$40,000 to less than \$50,000	10	10	10
\$50,000 to less than \$60,000	8	9	11
\$60,000 to less than \$70,000	7	8	10
\$70,000 to less than \$80,000	3	6	7
\$80,000 to less than \$90,000	4	5	6
\$90,000 to less than \$100,000	7	5	4
\$100,000 to less than \$110,000	6	4	4
\$110,000 to less than \$120,000	1	2	1
\$120,000 to less than \$130,000	2	2	1
\$130,000 to less than \$140,000	0	0	0
\$140,000 to less than \$150,000	4	2	1
More than \$150,000	7	9	4

QHI14A. Family members often help each other out financially. In the last year have you used your own money to pay for CR's medications or medical care?

	20 – 49	50 – 64	65 and older
Yes	33	36	50
No	67	64	50

QHI14B. In the last year have you used your own money to pay for CR's Medicare premiums or copayments or other insurance premiums and copayments?

	20 – 49	50 – 64	65 and older
Yes	11	15	37
No	89	85	63

QHI14C. In the last year have you used your own money to pay for mobility devices for CR such as walkers, canes, or wheelchairs?

	20 – 49	50 – 64	65 and older
Yes	12	10	22
No	89	91	78

QHI14D. In the last year have you used your own money to pay for features that made CR's home safer such as a railing or a ramp, grab bars in the bathroom, a seat for the shower or tub, or an emergency call system?

	20 – 49	50 – 64	65 and older
Yes	25	25	34
No	75	75	66

QHI14E. In the last year have you used your own money to pay for any other assistive devices for CR that make it easier or safer for [him/her] to do activities or do them on [his/her] own? This includes devices to help [him/her] see, hear, reach, hold things, or pick things up.

	20 – 49	50 – 64	65 and older
Yes	20	19	23
No	80	81	77

QHI14f. In the last year have you used your own money to pay for a paid in-home helper for CR?

	20 – 49	50 – 64	65 and older
Yes	7	8	14
No	93	92	86

If QHI14A through QHI14F are all no, don't know, or refused skip to next section.

QHI15. Altogether last year, would you say you paid more or less than \$1,000 for CR's [medications or medical care,]

	20 – 49	50 – 64	65 and older
More than \$1,000 → QHI6	25	36	61
Less than \$1,000 → QHI7	75	64	39

QHI16. Was it more than \$2,000?

	20 – 49	50 – 64	65 and older
Yes	63	53	71
No	38	47	29

(skip to next section)

QHI17. Was it less than \$500?

	20 – 49	50 – 64	65 and older
Yes	79	76	59
No	21	24	41