

THE PITTSBURGH REGIONAL CAREGIVERS SURVEY
BREAKOUTS BY CAREGIVER RELATIONSHIP TO CARE RECIPIENT

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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:

Adult child n = 546

Spouse n = 214

Other n = 248

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?

	Adult Child	Spouse	Other
Yes	47	59	51
No	53	41	49

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

	Adult Child	Spouse	Other
Yes	97	99	96
No	3	1	4

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

	Adult Child	Spouse	Other
Yes	61	80	54
No	39	20	46

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:

	Adult Child	Spouse	Other
Your mother or mother-in-law	77	0	0
Your father or father-in-law	23	0	0
Your wife / partner	0	28	0
Your husband / partner	0	72	0
Your daughter or daughter-in-law	0	0	3
Your son or son-in-law	0	0	2
Some other relative	0	0	60
A non-relative	0	0	35

QCS2. Is the person you care for:

	Adult Child	Spouse	Other
Male	23	73	32
Female	77	27	69

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

	Adult Child	Spouse	Other
50 – 64	6	25	30
65 – 74	11	35	18
75 – 84	26	30	22
85 +	57	10	30

QCS5. Where does [he/she] live?

	Adult Child	Spouse	Other
In your household → QCS9	30	99	26
Within 20 minutes of your home	53	1	57
Between 20 minutes and an hour from your home	14	1	14
One to two hours from your home	2	0	1
More than two hours away	2	0	2

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

	Adult Child	Spouse	Other
His or her own home	71	67	70
Someone else's home → QCS9	6	0	14
An independent living or retirement community	13	0	9
In an assisted living facility where some care may be provided → QCS9	9	0	7
Somewhere else	0	33	1

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

QCS7. Does [he/she] live alone?

	Adult Child	Spouse	Other
Yes	66	50	73
No	35	50	27

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

	Adult Child	Spouse	Other
Short-term physical condition	13	11	10
Long-term physical condition	76	83	77
Emotional or mental health problem	17	17	27
Developmental or intellectual disorder or mental retardation	2	3	12
Behavioral issue	5	10	10
Memory problem	45	42	38
None of the above	7	1	4

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

	Adult Child	Spouse	Other
Yes	27	19	21
No	73	81	79

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

QCS11. a heart attack or myocardial infarction?

	Adult Child	Spouse	Other
Yes	24	22	21
No	76	78	79

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

	Adult Child	Spouse	Other
Yes	37	28	29
No	63	72	71

QCS13. high blood pressure or hypertension?

	Adult Child	Spouse	Other
Yes	67	70	59
No	34	30	41

QCS14. arthritis?

	Adult Child	Spouse	Other
Yes	70	66	55
No	31	34	45

QCS15. osteoporosis or thinning of the bones?

	Adult Child	Spouse	Other
Yes	44	17	32
No	56	83	68

QCS16. diabetes?

	Adult Child	Spouse	Other
Yes	24	38	27
No	76	62	74

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

	Adult Child	Spouse	Other
Yes	21	31	22
No	79	69	78

QCS18. cancer?

	Adult Child	Spouse	Other
Yes	28	30	25
No	72	70	76

QCS18a. a stroke?

	Adult Child	Spouse	Other
Yes	24	23	18
No	77	77	82

QCS19. serious difficulty seeing?

	Adult Child	Spouse	Other
Yes	30	25	30
No	70	75	70

QCS20. serious difficulty hearing?

	Adult Child	Spouse	Other
Yes	41	30	34
No	59	70	66

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

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

	Adult Child	Spouse	Other
Yes	89	84	83
No	11	16	17

QCS22B. a hearing aid?

	Adult Child	Spouse	Other
Yes	22	12	15
No	78	88	85

QCS22C. a cane?

	Adult Child	Spouse	Other
Yes	40	44	45
No	60	56	55

QCS22D. a walker?

	Adult Child	Spouse	Other
Yes	50	29	44
No	51	71	56

QCS22E. a wheelchair?

	Adult Child	Spouse	Other
Yes	34	35	33
No	67	65	68

QCS22F. a scooter?

	Adult Child	Spouse	Other
Yes	6	13	7
No	94	87	94

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

	Adult Child	Spouse	Other
Yes	34	30	37
No	66	70	63

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

	Adult Child	Spouse	Other
Yes	23	13	23
No	77	87	77

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.

	Adult Child	Spouse	Other
Yes	4	7	7
No	96	93	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?

	Adult Child	Spouse	Other
Yes	84	76	77
No → next section	17	24	23

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

	Adult Child	Spouse	Other
A railing or ramp	63	65	63
Grab bars in the bathroom	81	67	76
A seat for the shower or tub	72	71	71
An emergency call system	47	23	51
Other	33	37	33

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?

	Adult Child	Spouse	Other
Every day	49	62	42
Most days	14	16	19
Some days	21	12	23
Rarely	7	3	8
Never → QCA2	8	1	7
Does not do, but not because of poor health and functioning → QCA2	2	5	2

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]?

	Adult Child	Spouse	Other
Every day	32	75	27
Most days	17	14	20
Some days	35	10	36
Rarely	9	2	10
Never	7	0	7

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*)

	Adult Child	Spouse	Other
Yes, another unpaid family member / friend	65	14	59
Yes, a paid helper	26	14	27
No	22	75	28

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?

	Adult Child	Spouse	Other
Every day	40	50	34
Most days	21	17	25
Some days	24	17	30
Rarely	9	5	9
Never → QCA3	5	7	2
Does not do, but not because of poor health and functioning → QCA3	2	5	1

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]?

	Adult Child	Spouse	Other
Every day	22	48	13
Most days	21	25	22
Some days	37	22	43
Rarely	13	2	11
Never	8	3	11

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

	Adult Child	Spouse	Other
Yes, another unpaid family member / friend	62	19	61
Yes, a paid helper	9	3	8
No	34	78	36

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

	Adult Child	Spouse	Other
Yes	58	61	53
No → QCA4	40	35	43
Does not do, but not because of poor health and functioning → QCA4	2	4	4

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

	Adult Child	Spouse	Other
Yes	73	96	63
No	27	4	37

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

	Adult Child	Spouse	Other
Yes, another unpaid family member / friend	41	4	48
Yes, a paid helper	14	3	9
No	47	94	44

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

	Adult Child	Spouse	Other
Yes	71	60	64
No → QCA5	27	30	34
Does not do, but not because of poor health and functioning → QCA5	2	10	2

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

	Adult Child	Spouse	Other
Yes	76	99	67
No	24	1	33

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

	Adult Child	Spouse	Other
Yes, another unpaid family member / friend	48	5	52
Yes, a paid helper	1	0	4
No	52	95	45

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?

	Adult Child	Spouse	Other
Every day	9	9	11
Most days	4	4	5
Some days	7	3	9
Rarely	9	15	8
Never → QCA6	71	69	67

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

	Adult Child	Spouse	Other
Every day	22	38	19
Most days	11	9	21
Some days	31	12	27
Rarely	24	27	21
Never	12	14	13

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

	Adult Child	Spouse	Other
Yes, another unpaid family member / friend	54	5	50
Yes, a paid helper	18	9	17
No	37	88	41

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

	Adult Child	Spouse	Other
Every day	27	22	19
Most days	9	11	11
Some days	10	13	15
Rarely	10	12	10
Never → QCA7	44	44	45

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

	Adult Child	Spouse	Other
Every day	17	37	16
Most days	12	18	9
Some days	22	23	22
Rarely	16	17	18
Never	33	5	36

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

	Adult Child	Spouse	Other
Yes, another unpaid family member / friend	43	6	44
Yes, a paid helper	34	17	30
No	32	79	33

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

	Adult Child	Spouse	Other
Every day	23	28	17
Most days	6	8	13
Some days	15	17	11
Rarely	12	12	17
Never → QCA8	43	36	42

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

	Adult Child	Spouse	Other
Every day	17	40	13
Most days	13	15	19
Some days	34	29	25
Rarely	23	16	25
Never	13	1	18

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

	Adult Child	Spouse	Other
Yes, another unpaid family member / friend	51	4	50
Yes, a paid helper	29	12	26
No	32	85	35

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

	Adult Child	Spouse	Other
Every day	16	18	14
Most days	4	2	4
Some days	7	5	7
Rarely	9	11	10
Never → QCA9	64	65	65

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

	Adult Child	Spouse	Other
Every day	25	53	16
Most days	11	5	18
Some days	25	12	23
Rarely	19	29	23
Never	19	1	21

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

	Adult Child	Spouse	Other
Yes, another unpaid family member / friend	60	7	51
Yes, a paid helper	33	16	39
No	22	80	29

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

	Adult Child	Spouse	Other
Every day	17	17	12
Most days	2	3	7
Some days	7	8	12
Rarely	11	20	13
Never → QCA10	63	52	56

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

	Adult Child	Spouse	Other
Every day	20	36	7
Most days	9	7	15
Some days	25	19	26
Rarely	28	36	28
Never	18	2	25

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

	Adult Child	Spouse	Other
Yes, another unpaid family member / friend	63	8	51
Yes, a paid helper	27	11	28
No	23	84	35

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

	Adult Child	Spouse	Other
Every day	17	16	16
Most days	5	3	6
Some days	12	13	14
Rarely	16	19	17
Never → QCA11	51	48	47

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

	Adult Child	Spouse	Other
Every day	17	33	14
Most days	12	9	14
Some days	34	26	34
Rarely	31	29	24
Never	7	3	14

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

	Adult Child	Spouse	Other
Yes, another unpaid family member / friend	66	13	63
Yes, a paid helper	23	14	20
No	24	76	28

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

	Adult Child	Spouse	Other
Every day	25	21	26
Most days	14	6	10
Some days	20	18	19
Rarely	12	18	14
Never → skip logic prior to QCA12A	30	37	31

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

	Adult Child	Spouse	Other
Every day	17	37	15
Most days	20	8	15
Some days	40	29	39
Rarely	15	25	22
Never	9	2	9

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

	Adult Child	Spouse	Other
Yes, another unpaid family member / friend	69	25	64
Yes, a paid helper	16	9	16
No	24	68	29

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?

	Adult Child	Spouse	Other
Yes	38	36	32
No	62	64	68

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?

	Adult Child	Spouse	Other
Yes	76	68	66
No	25	32	34

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?

	Adult Child	Spouse	Other
Yes	77	65	68
No	23	36	32

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

	Adult Child	Spouse	Other
Every day	8	28	8
Most days	13	23	16
Some days	42	25	34
Rarely	18	10	19
Never	20	14	23

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]?

	Adult Child	Spouse	Other
Every day	1	5	2
Most days	2	4	1
Some days	3	3	5
Rarely	4	5	6
Never	61	52	62
Do not use	28	31	25

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 SCRNMNT).

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?

	Adult Child	Spouse	Other
Yes	59	79	52
No	42	22	48

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

	Adult Child	Spouse	Other
Yes	43	60	41
No	57	40	60

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

	Adult Child	Spouse	Other
Orally (by mouth as pills, capsules, liquid)	98	99	99
Insulin injection	12	16	8
Other injection	6	6	3
Infusion pump	0	2	0
Inhaler	12	16	12
Suppository	4	2	3
Medication patch	6	5	2
Spray	4	4	4
Eye/Ear drops	16	23	12
Other	9	9	2

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

	Adult Child	Spouse	Other
Yes	6	12	3
No	94	88	98

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

	Adult Child	Spouse	Other
Yes	10	12	5
No	90	88	95

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

	Adult Child	Spouse	Other
Yes	25	35	28
No	75	65	73

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

	Adult Child	Spouse	Other
Yes	23	40	26
No	77	60	74

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

	Adult Child	Spouse	Other
Yes	20	21	17
No	80	79	83

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

	Adult Child	Spouse	Other
Yes	28	41	22
No	72	59	78

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

	Adult Child	Spouse	Other
Yes	24	42	22
No	76	58	78

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

	Adult Child	Spouse	Other
Yes	49	40	48
No	51	60	52

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?

	Adult Child	Spouse	Other
Yes	43	30	42
No	57	70	58

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

	Adult Child	Spouse	Other
Yes	53	56	38
No	47	44	62

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

	Adult Child	Spouse	Other
Yes	5	4	2
No	96	96	99

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)?

	Adult Child	Spouse	Other
Yes	49	42	46
No	51	58	54

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

	Adult Child	Spouse	Other
Yes	17	19	16
No	83	81	84

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)?

	Adult Child	Spouse	Other
Yes	11	8	4
No	89	92	96

(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.

	Adult Child	Spouse	Other
1. Not at all difficult	56	54	53
2.	21	15	22
3.	14	15	16
4.	5	11	7
5. Very difficult	4	5	3

QCA17. Did anyone prepare you to do these tasks?

	Adult Child	Spouse	Other
Yes	23	27	27
No → QCA21	77	74	73

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

	Adult Child	Spouse	Other
Hospital nurse	21	32	17
Hospital doctor	4	11	6
Primary care doctor	15	15	13
Nurse in doctor's office or outpatient setting	14	9	11
Home care nurse	26	30	17
Social worker/geriatric care manager	2	4	4
Physical or occupational therapist	19	28	6
Pharmacist	8	7	2
Medical supply technician	8	13	4
Friend or neighbor	4	7	13
You learned on your own	26	22	32
Other	49	33	44

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

	Adult Child	Spouse	Other
Very well	82	78	77
Somewhat well	17	20	21
Not well	2	2	2

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

	Adult Child	Spouse	Other
None → QCA24PRE	45	45	42
One time	22	24	18
2 times	15	13	19
3 or more times	19	18	22

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...

	Adult Child	Spouse	Other
Yes, all the time	64	68	35
Only some of the time	24	25	25
No, and you should have been	5	4	6
No, but you did not need to be	7	3	33

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]?

	Adult Child	Spouse	Other
Yes	77	83	54
No	18	16	30
Not applicable	5	1	16

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

	Adult Child	Spouse	Other
Very well	52	57	56
Somewhat well	35	38	33
Not well	12	5	11

QCA24PRE. Now think about the last YEAR.

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

	Adult Child	Spouse	Other
Yes	68	78	50
No	32	22	50

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

	Adult Child	Spouse	Other
Yes	70	77	49
No	30	24	51

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

	Adult Child	Spouse	Other
Yes	85	97	76
No	15	3	24

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.]

	Adult Child	Spouse	Other
Yes	25	38	18
No	75	62	82

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.]

	Adult Child	Spouse	Other
Yes	39	49	27
No	61	51	73

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?

	Adult Child	Spouse	Other
8 hours or less per week	43	29	48
9 to 19 hours per week	28	22	24
20 to 39 hours per week	16	15	17
40 or more hours per week	14	33	11

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.

	Adult Child	Spouse	Other
Regular schedule	50	68	44
Varied	50	32	57

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

	Adult Child	Spouse	Other
3 months or less	4	6	9
4 to 12 months	11	8	13
1 - 2 years	22	16	15
3 - 5 years	28	25	31
More than 5 years	34	45	31

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

	Adult Child	Spouse	Other
Increased in the past month	37	36	33
Been about the same in the past month	54	53	59
Decreased in the past month	9	11	9

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?

	Adult Child	Spouse	Other
Will increase	37	26	28
Will be about the same	57	59	64
Will decrease	6	16	8

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

	Adult Child	Spouse	Other
Yes	42	34	64
No	58	67	37

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

	Adult Child	Spouse	Other
Very worried	4	6	6
Somewhat worried	13	9	13
Only a little	32	27	21
Not at all	51	58	61

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".)

	Adult Child	Spouse	Other
1 CR has not been suffering physically	13	10	16
2	10	8	10
3	15	15	11
4	9	6	12
5	15	15	12
6	8	8	10
7	11	13	10
8	9	10	10
9	3	8	4
10 CR has been suffering terribly	5	8	5

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”.)

	Adult Child	Spouse	Other
1 CR has not been suffering physically	11	13	18
2	12	5	8
3	13	10	8
4	9	5	6
5	14	22	12
6	9	11	10
7	10	10	10
8	12	14	11
9	5	3	8
10 CR has been suffering terribly	6	7	11

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]?

	Adult Child	Spouse	Other
A lot	69	73	71
Some	24	20	25
A little	6	5	3
Not at all	1	1	1

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

	Adult Child	Spouse	Other
A lot	21	19	13
Some	24	33	24
A little	28	33	27
Not at all	27	16	36

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

	Adult Child	Spouse	Other
A lot	80	77	83
Some	12	15	9
A little	6	4	6
Not at all	2	3	2

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

	Adult Child	Spouse	Other
A lot	19	25	19
Some	32	36	24
A little	36	30	28
Not at all	14	8	29

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...

	Adult Child	Spouse	Other
Gotten much better	17	7	26
Gotten somewhat better	21	14	24
Stayed about the same	50	51	38
Gotten somewhat worse	10	20	11
Gotten much worse	2	8	0

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.

	Adult Child	Spouse	Other
Very much	32	48	43
Somewhat	41	33	33
Not so much	28	19	24

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

	Adult Child	Spouse	Other
Very much	46	57	44
Somewhat	38	34	37
Not so much	17	10	19

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

	Adult Child	Spouse	Other
Very much	43	49	56
Somewhat	39	29	34
Not so much	18	23	10

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

	Adult Child	Spouse	Other
Very much	78	78	77
Somewhat	19	19	18
Not so much	3	3	5

QAC6A. Is helping CR financially difficult for you?

	Adult Child	Spouse	Other
Yes	21	32	18
No	79	68	82

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

	Adult Child	Spouse	Other
Yes	64	64	49
No	36	36	51

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

	Adult Child	Spouse	Other
Yes	27	37	26
No	73	63	74

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)

	Adult Child	Spouse	Other
1. A little difficult	14	4	14
2.	13	9	9
3.	30	29	34
4.	18	31	32
5. Very difficult	25	27	11

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

	Adult Child	Spouse	Other
1. A little difficult	9	12	19
2.	18	15	18
3.	29	30	25
4.	24	19	24
5. Very difficult	21	24	13

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

	Adult Child	Spouse	Other
1. A little difficult	11	3	14
2.	18	17	19
3.	39	34	31
4.	22	25	23
5. Very difficult	10	22	14

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

	Adult Child	Spouse	Other
Very much	8	6	14
Somewhat	22	14	31
Not so much	70	80	56

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.

	Adult Child	Spouse	Other
Very much	32	35	29
Somewhat	29	38	24
Not so much	39	27	47

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

	Adult Child	Spouse	Other
Very much	24	22	23
Somewhat	33	38	32
Not so much	43	40	45

QAC9C. You don't have time for yourself.

	Adult Child	Spouse	Other
Very much	26	30	24
Somewhat	35	38	25
Not so much	39	31	51

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

	Adult Child	Spouse	Other
Very much	13	9	9
Somewhat	26	36	23
Not so much	61	55	68

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?

	Adult Child	Spouse	Other
Yes	91	85	91
No	9	15	9

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?

	Adult Child	Spouse	Other
Yes	59	34	54
No	41	66	46

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

	Adult Child	Spouse	Other
Yes	78	38	67
No	22	62	33

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

	Adult Child	Spouse	Other
Yes	5	8	5
No	95	92	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?

	Adult Child	Spouse	Other
Yes	25	10	16
No	75	90	84

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

	Adult Child	Spouse	Other
Yes	8	13	10
No	92	87	90

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

	Adult Child	Spouse	Other
Yes	19	11	20
No	82	89	80

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)*

	Adult Child	Spouse	Other
Yes	20	20	14
No	80	80	86

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?

	Adult Child	Spouse	Other
Yes	43	46	38
No	57	54	62

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?

	Adult Child	Spouse	Other
Yes	47	49	33
No	53	51	68

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

	Adult Child	Spouse	Other
Yes	24	22	15
No	76	79	86

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?

	Adult Child	Spouse	Other
One	22	22	25
Two	28	31	24
Three or more	50	47	51

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

	Adult Child	Spouse	Other
Caregiver's Brother(s)	35	7	14
CG's Sister(s)	49	7	26
CG's husband	24	0	17
CG's wife	10	0	5
CG's other relative(s) / in-law(s)	48	90	54
CG's friend(s)	9	13	20
Other	22	23	31

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

	Adult Child	Spouse	Other
Live(s) with you	43	22	39
Within twenty minutes of your home	62	82	61
Between twenty minutes and an hour from your home	27	20	23
One to two hours from your home	6	1	9
Two to four hours away	4	4	4
More than four hours away	13	8	6

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

	Adult Child	Spouse	Other
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.	16	17	19
We share some tasks, and others we do separately	55	54	52

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?

	Adult Child	Spouse	Other
Respondent is the primary caregiver	51	100	47
Someone else is the primary caregiver	33	0	37
Care is equally shared	16	0	16

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

	Adult Child	Spouse	Other
To a great extent	2	0	2
To a moderate extent	9	4	8
Only a little	32	21	26
Not at all	57	75	63

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

	Adult Child	Spouse	Other
Very satisfied	64	71	75
Moderately satisfied	27	28	19
Moderately dissatisfied	6	1	4
Very dissatisfied	3	0	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?

	Adult Child	Spouse	Other
Yes	84	81	90
No	16	19	10

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]?

	Adult Child	Spouse	Other
Yes	32	34	24
No	68	66	77

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

	Adult Child	Spouse	Other
Very important	53	49	57
Somewhat important	35	34	28
Not so important	12	18	15

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

	Adult Child	Spouse	Other
Yes	61	58	62
No	39	42	39

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

	Adult Child	Spouse	Other
Yes	10	20	13
No	90	80	87

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

	Adult Child	Spouse	Other
Very important	44	51	47
Somewhat important	25	22	23
Not so important	31	28	30

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.]

	Adult Child	Spouse	Other
Yes	50	41	50
No	50	59	50

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.]

	Adult Child	Spouse	Other
Yes	22	24	15
No	79	76	85

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.]

	Adult Child	Spouse	Other
Very important	31	25	36
Somewhat important	33	31	27
Not so important	37	44	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.

	Adult Child	Spouse	Other
Yes	86	74	87
No	15	26	13

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.]

	Adult Child	Spouse	Other
Yes	25	31	19
No	75	69	82

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.]

	Adult Child	Spouse	Other
Very important	49	43	49
Somewhat important	39	34	38
Not so important	12	23	13

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

	Adult Child	Spouse	Other
Yes	34	29	49
No	67	72	51

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

	Adult Child	Spouse	Other
Yes	15	23	11
No	85	77	89

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.

	Adult Child	Spouse	Other
Yes	44	33	42
No	57	67	58

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

	Adult Child	Spouse	Other
Yes	7	12	6
No	93	88	94

HEALTH

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

	Adult Child	Spouse	Other
Excellent	16	12	17
Very good	34	23	32
Good	30	36	29
Fair	17	25	17
Poor	3	5	4

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

	Adult Child	Spouse	Other
Yes	5	11	8
No	95	89	92

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

	Adult Child	Spouse	Other
Yes	7	17	6
No	93	83	94

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

	Adult Child	Spouse	Other
Yes	36	51	43
No	64	49	57

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

	Adult Child	Spouse	Other
Yes	42	65	47
No	59	36	53

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

	Adult Child	Spouse	Other
Yes	15	34	19
No	85	66	82

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

	Adult Child	Spouse	Other
Yes	12	18	16
No	88	82	84

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

	Adult Child	Spouse	Other
Yes	13	21	17
No	87	79	83

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

	Adult Child	Spouse	Other
Yes	11	27	8
No	89	73	92

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

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

	Adult Child	Spouse	Other
Yes	60	71	59
No	40	29	41

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

	Adult Child	Spouse	Other
Yes	13	28	17
No	87	72	84

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

	Adult Child	Spouse	Other
Yes	26	41	32
No	74	59	69

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

	Adult Child	Spouse	Other
Yes	37	49	36
No	63	51	65

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

	Adult Child	Spouse	Other
Yes	52	59	46
No	48	41	54

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

	Adult Child	Spouse	Other
Every night	9	10	10
Most nights	15	16	14
Some nights	34	37	26
Rarely	26	20	31
Never	16	16	19

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

	Adult Child	Spouse	Other
Every night	2	7	1
Most nights	4	6	5
Some nights	17	28	14
Rarely	23	29	20
Never	54	30	61

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:

	Adult Child	Spouse	Other
< 18.5 (underweight)	1	1	0
18.5 – 24.9 (normal)	28	21	30
25.0 – 29.9 (overweight)	38	38	32
30.0 – 34.9 (moderately obese)	22	21	25
35.0 – 39.9 (severely obese)	6	13	5
40.0 + (very severely obese)	5	6	8

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

	Adult Child	Spouse	Other
Yes	30	29	31
No → QHE25A	70	71	69

QHE24a. Were you trying to lose weight?

	Adult Child	Spouse	Other
Yes	73	51	72
No	27	49	28

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

	Adult Child	Spouse	Other
Every day	13	15	21
Most days	48	37	48
Some days	32	33	22
Rarely	7	14	8
Never	1	1	1

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

	Adult Child	Spouse	Other
Every day	9	13	18
Most days	39	32	43
Some days	34	38	27
Rarely	16	14	9
Never	2	3	3

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

	Adult Child	Spouse	Other
Every day	14	13	22
Most days	34	31	32
Some days	33	30	30
Rarely	15	23	13
Never	4	4	4

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

	Adult Child	Spouse	Other
Every day	2	3	5
Most days	6	6	5
Some days	21	26	19
Rarely	33	29	31
Never	39	36	41

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

	Adult Child	Spouse	Other
Every day	2	4	2
Most days	8	8	6
Some days	20	24	20
Rarely	29	26	30
Never	42	39	43

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

	Adult Child	Spouse	Other
Every day	3	5	3
Most days	8	13	8
Some days	48	52	41
Rarely	36	26	39
Never	5	5	9

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

	Adult Child	Spouse	Other
Not at all	58	48	56
Several days	30	34	33
More than half the days	9	12	4
Nearly every day	3	6	7

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

	Adult Child	Spouse	Other
Not at all	57	51	61
Several days	33	31	30
More than half the days	6	13	5
Nearly every day	3	6	4

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

	Adult Child	Spouse	Other
Not at all	41	34	47
Several days	43	47	41
More than half the days	8	11	6
Nearly every day	7	8	5

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

	Adult Child	Spouse	Other
Not at all	51	41	58
Several days	29	39	28
More than half the days	10	8	6
Nearly every day	10	12	8

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?

	Adult Child	Spouse	Other
Not at all	3	4	3
A little bit	4	6	3
Somewhat	8	12	8
Quite a bit	29	24	29
Extremely	56	54	57

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?

	Adult Child	Spouse	Other
Never	71	58	69
Rarely	21	30	23
Sometimes	7	12	7
Often	1	1	1
Always	0	1	1

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

	Adult Child	Spouse	Other
Never	69	52	68
Rarely	23	32	21
Sometimes	7	12	10
Often	0	2	0
Always	1	1	0

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)?

	Adult Child	Spouse	Other
Correct	71	58	66
Incorrect	30	42	34

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*)

	Adult Child	Spouse	Other
Correct	85	76	82
Incorrect	15	25	18

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*)

	Adult Child	Spouse	Other
Correct	80	70	74
Incorrect	20	30	26

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.

	Adult Child	Spouse	Other
Yes → QEC4	56	22	48
No	22	20	24
Retired / don't work anymore → QEC16	22	58	27

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

	Adult Child	Spouse	Other
Yes → QEC4	8	7	7
No	72	61	70
Retired / don't work anymore → QEC16	21	33	23

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

	Adult Child	Spouse	Other
Yes, looking for a job → QEC16	15	4	21
Yes, on layoff → QEC16	5	12	2
No → QEC16	72	85	69
Retired / don't work anymore → QEC16	8	0	7

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

	Adult Child	Spouse	Other
Yes	20	6	32
No	80	94	69

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

	Adult Child	Spouse	Other
20 or fewer	19	34	23
21 – 39	19	14	21
40 or more	61	52	57

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?

	Adult Child	Spouse	Other
Yes	58	60	63
No	42	40	37

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

	Adult Child	Spouse	Other
Daytime	83	78	77
Some other schedule	17	22	23

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?

	Adult Child	Spouse	Other
Yes	46	47	39
No → QEC12	54	53	61

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.

	Adult Child	Spouse	Other
Yes	35	12	32
No	65	88	68

QEC9B. You were sick.

	Adult Child	Spouse	Other
Yes	37	40	50
No	63	60	50

QEC9C. You took time off to help CR.

	Adult Child	Spouse	Other
Yes	49	52	28
No	51	48	73

QEC9D. Other family members were sick.

	Adult Child	Spouse	Other
Yes	22	8	22
No	78	92	78

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

	Adult Child	Spouse	Other
Yes	37	24	43
No	64	76	57

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?

	Adult Child	Spouse	Other
One	49	54	57
Two	25	8	21
Three or more	25	39	21

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?

	Adult Child	Spouse	Other
Yes	26	29	23
No → QEC14	74	71	77

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.

	Adult Child	Spouse	Other
1 A little harder	15	14	10
2	10	14	10
3	16	29	24
4	14	7	17
5	14	7	28
6	11	7	0
7	9	7	0
8	10	7	7
10 A lot harder	3	7	3

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

	Adult Child	Spouse	Other
Yes	77	87	76
No	23	13	24

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

	Adult Child	Spouse	Other
Telecommuting or working from home	31	28	33
Programs like information, referrals, counseling, or an employee assistance program, to help caregivers like yourself	39	20	32
Paid leave, where you could take paid time off from work for several weeks to care for a family member	34	30	34
Paid sick days	56	46	52
None of the above	26	38	28

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

	Adult Child	Spouse	Other
Went in late, left early, or took time off during the day to provide care	49	36	34
Took a leave of absence	13	13	11
Went from working full-time to part-time, or cut back your hours	13	17	15
Turned down a promotion	4	1	4
Lost any of your job benefits	5	4	3
Gave up working entirely	12	22	8
Retired early	10	23	9
Received a warning about your performance or attendance at work	4	5	3
None of the above	39	43	54

DEMOGRAPHICS

QDE1. INTERVIEWER: RECORD PERSON'S SEX

	Adult Child	Spouse	Other
Male	26	28	23
Female	74	72	77

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

	Adult Child	Spouse	Other
44 or under	12	1	19
45 – 54	26	6	13
55 – 64	45	24	37
65 or older	17	70	31

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

	Adult Child	Spouse	Other
Married	55	92	39
Living with a partner in a marital-like relationship	3	8	7
Divorced or separated	18	0	16
Widowed	5	1	10
Single/never married	20	1	29

QDE4. Are you of Hispanic or Latino descent?

	Adult Child	Spouse	Other
Yes	2	1	2
No	98	100	98

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

	Adult Child	Spouse	Other
Caucasian/White	83	89	75
Asian/Pacific Islander	1	0	0
American Indian or Alaskan Native	1	2	1
Black or African-American	15	10	23
None of the above	1	0	1

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

	Adult Child	Spouse	Other
Eighth grade or less	0	0	1
Some high school	0	1	2
High school graduate or GED	16	31	16
Some college, no degree	18	19	27
Associate's degree, occupational	7	6	9
Associate's degree, academic	6	3	8
Bachelor's degree	30	21	23
Master's degree	19	12	10
Professional degree	2	4	2
Doctoral degree	3	2	2

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

	Adult Child	Spouse	Other
Live alone → QDE11PRE	17	1	22
Live in a household with family or others	82	97	78
Have some other living arrangements	1	1	0

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

	Adult Child	Spouse	Other
One	5	1	7
Two	57	83	63
Three	27	12	21
Four	9	2	7
Five	1	1	2
Six	0	0	0

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

	Adult Child	Spouse	Other
Zero	75	95	77
One	13	2	12
Two	8	1	7
Three	3	1	2
Four	0	0	3
Five	1	0	0
Six	0	0	0

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

	Adult Child	Spouse	Other
Your spouse / partner	71	99	62
Your child(ren)	39	14	37
Your grandchild(ren)	4	4	7
Your parent(s)	31	0	9
Other relatives of yours	9	1	23
Non-relatives	2	1	7

QDE11PRE. And now just a couple questions about CR.

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

	Adult Child	Spouse	Other
Eighth grade or less	7	2	7
Some high school	8	5	6
High school graduate or GED	49	40	47
Some college, no degree	7	9	9
Associate's degree, occupational	7	7	6
Associate's degree, academic	2	5	4
Bachelor's degree	11	19	14
Master's degree	5	7	6
Professional degree	2	2	1
Doctoral degree	2	5	1

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

	Adult Child	Spouse	Other
Yes	1	0	0
No	99	100	100

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

	Adult Child	Spouse	Other
Caucasian/White	84	88	75
Asian/Pacific Islander	1	1	0
American Indian or Alaskan Native	1	1	1
Black or African-American	15	11	23
None of the above	1	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?

	Adult Child	Spouse	Other
Yes	37	48	30
No	64	52	71

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?

	Adult Child	Spouse	Other
Yes	15	30	16
No	85	70	85

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.

	Adult Child	Spouse	Other
1. Not at all difficult	73	79	71
2	14	8	13
3	8	8	8
4	2	3	3
5. Very difficult	3	3	4

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.

	Adult Child	Spouse	Other
1. Not at all difficult	69	67	74
2	14	10	9
3	8	11	9
4	4	6	4
5. Very difficult	4	5	4

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.

	Adult Child	Spouse	Other
1. Not at all difficult	39	37	43
2	9	7	11
3	13	9	9
4	7	5	8
5. Very difficult	9	10	7
Not applicable	23	32	22

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.

	Adult Child	Spouse	Other
1. Not at all difficult	32	29	36
2	11	8	9
3	12	8	10
4	6	5	6
5. Very difficult	14	14	11
Not applicable	25	36	29

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.

	Adult Child	Spouse	Other
1. Not at all difficult	26	27	31
2	8	5	9
3	14	12	11
4	11	6	11
5. Very difficult	16	14	12
Not applicable	24	36	26

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)*

	Adult Child	Spouse	Other
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	89	85	71
Requiring hospitals to keep you informed about major decisions, like transferring or discharging CR	91	89	73
Requiring hospitals or facilities to instruct or demonstrate any medical or nursing tasks you might need to do	91	87	78
Having respite services available, where someone would take care of CR to give you a break	75	71	62
Requiring a doctor, nurse, or social worker ask you about what you need to help care for CR	84	77	70
Requiring a doctor, nurse, or social worker ask you about what you need to take care of yourself	67	69	53
None of the above	4	4	11

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.

	Adult Child	Spouse	Other
An income tax credit to caregivers, to help offset the cost of care	33	45	29
A partially paid leave of absence from work for caregivers who are employed	22	13	14
A program where caregivers could be paid for at least some of the hours they provide care	45	43	57

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?

	Adult Child	Spouse	Other
Yes	28	75	41
No → QHI3	72	25	59

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

	Adult Child	Spouse	Other
Yes	68	67	69
No	32	33	31

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

	Adult Child	Spouse	Other
Yes	11	8	18
No	89	92	82

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.

	Adult Child	Spouse	Other
Yes	80	72	70
No	20	28	30

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?

	Adult Child	Spouse	Other
Yes	2	5	3
No	98	95	97

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

	Adult Child	Spouse	Other
Medicare	81	74	67
Medicaid	19	9	23
Private Health Insurance	56	70	42
Tricare/CHAMPVA	3	5	4

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

	Adult Child	Spouse	Other
Yes	78	82	67
No	22	18	33

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

	Adult Child	Spouse	Other
Yes	96	97	95
No	4	3	5

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

	Adult Child	Spouse	Other
Yes	78	74	69
No	22	26	32

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

	Adult Child	Spouse	Other
Yes	18	19	20
No	82	81	80

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

	Adult Child	Spouse	Other
Yes	77	68	63
No	24	32	37

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

	Adult Child	Spouse	Other
Yes	39	33	29
No	61	68	71

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?

	Adult Child	Spouse	Other
0 – less than \$10,000	8	2	9
\$10,000 to less than \$20,000	9	6	16
\$20,000 to less than \$30,000	8	12	12
\$30,000 to less than \$40,000	9	21	15
\$40,000 to less than \$50,000	10	13	8
\$50,000 to less than \$60,000	10	11	9
\$60,000 to less than \$70,000	8	8	9
\$70,000 to less than \$80,000	6	8	4
\$80,000 to less than \$90,000	6	6	3
\$90,000 to less than \$100,000	5	6	4
\$100,000 to less than \$110,000	6	2	3
\$110,000 to less than \$120,000	2	1	2
\$120,000 to less than \$130,000	2	1	2
\$130,000 to less than \$140,000	0	1	0
\$140,000 to less than \$150,000	3	1	1
More than \$150,000	10	3	3

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?

	Adult Child	Spouse	Other
Yes	34	75	23
No	66	25	77

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?

	Adult Child	Spouse	Other
Yes	9	70	9
No	91	30	91

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

	Adult Child	Spouse	Other
Yes	10	33	5
No	90	67	95

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?

	Adult Child	Spouse	Other
Yes	28	42	15
No	72	59	85

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.

	Adult Child	Spouse	Other
Yes	19	32	13
No	81	68	87

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

	Adult Child	Spouse	Other
Yes	10	15	5
No	90	85	95

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,]

	Adult Child	Spouse	Other
More than \$1,000 → QHI6	27	75	31
Less than \$1,000 → QHI7	73	25	69

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

	Adult Child	Spouse	Other
Yes	56	70	50
No	44	30	50

(skip to next section)

QHI17. Was it less than \$500?

	Adult Child	Spouse	Other
Yes	73	57	83
No	27	43	17