

THE PITTSBURGH REGIONAL CAREGIVERS SURVEY
BREAKOUTS BY CARE RECIPIENT DEMENTIA STATUS

Contents (click to jump to section)

Notes.....	1
Types of Caregiving.....	2
Caregiving Situation / Context.....	3
Care Activities.....	8
Aspects of Caregiving.....	23
Support Environment.....	27
Participation.....	31
Health.....	34
Health Literacy and Numeracy.....	39
Employment and Caregiving.....	41
Demographics.....	45
Information / Services / Policy.....	48
Health Insurance and Income.....	51

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; AD = Alzheimer’s disease or other type of dementia

Sample sizes:

AD n = 234

No AD n = 752

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?

	AD	No AD
Yes	65	46
No	35	54

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

	AD	No AD
Yes	97	98
No	3	2

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

	AD	No AD
Yes	73	60
No	27	40

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:

	AD	No AD
Your mother or mother-in-law	47	40
Your father or father-in-law	14	12
Your wife / partner	5	6
Your husband / partner	12	16
Your daughter or daughter-in-law	1	1
Your son or son-in-law	0	1
Some other relative	14	15
A non-relative	7	9

QCS2. Is the person you care for:

	AD	No AD
Male	33	37
Female	68	63

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

	AD	No AD
50 – 64	5	20
65 – 74	10	21
75 – 84	29	24
85 +	56	36

QCS5. Where does [he/she] live?

	AD	No AD
In your household → QCS9	42	44
Within 20 minutes of your home	42	43
Between 20 minutes and an hour from your home	12	11
One to two hours from your home	1	1
More than two hours away	3	2

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

	AD	No AD
His or her own home	62	74
Someone else's home → QCS9	7	9
An independent living or retirement community	10	12
In an assisted living facility where some care may be provided → QCS9	19	5
Somewhere else	1	1

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

QCS7. Does [he/she] live alone?

	AD	No AD
Yes	62	70
No	38	30

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

	AD	No AD
Short-term physical condition	4	15
Long-term physical condition	74	79
Emotional or mental health problem	27	16
Developmental or intellectual disorder or mental retardation	7	4
Behavioral issue	13	6
Memory problem	88	28
None of the above	0	6

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

QCS11. a heart attack or myocardial infarction?

	AD	No AD
Yes	20	24
No	80	76

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

	AD	No AD
Yes	30	34
No	70	66

QCS13. high blood pressure or hypertension?

	AD	No AD
Yes	61	67
No	39	33

QCS14. arthritis?

	AD	No AD
Yes	62	66
No	38	34

QCS15. osteoporosis or thinning of the bones?

	AD	No AD
Yes	39	34
No	61	66

QCS16. diabetes?

	AD	No AD
Yes	22	29
No	78	71

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

	AD	No AD
Yes	15	26
No	85	74

QCS18. cancer?

	AD	No AD
Yes	24	28
No	76	72

QCS18a. a stroke?

	AD	No AD
Yes	26	20
No	74	80

QCS19. serious difficulty seeing?

	AD	No AD
Yes	32	28
No	68	72

QCS20. serious difficulty hearing?

	AD	No AD
Yes	47	34
No	53	66

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

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

	AD	No AD
Yes	79	89
No	21	11

QCS22B. a hearing aid?

	AD	No AD
Yes	21	18
No	80	82

QCS22C. a cane?

	AD	No AD
Yes	34	45
No	67	55

QCS22D. a walker?

	AD	No AD
Yes	46	43
No	54	57

QCS22E. a wheelchair?

	AD	No AD
Yes	34	33
No	66	67

QCS22F. a scooter?

	AD	No AD
Yes	5	8
No	95	92

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

	AD	No AD
Yes	21	37
No	79	63

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

	AD	No AD
Yes	23	20
No	77	80

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.

	AD	No AD
Yes	5	5
No	95	95

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?

	AD	No AD
Yes	83	79
No → next section	17	21

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

	AD	No AD
A railing or ramp	61	64
Grab bars in the bathroom	84	75
A seat for the shower or tub	79	69
An emergency call system	47	42
Other	34	34

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?

	AD	No AD
Every day	72	43
Most days	10	17
Some days	12	22
Rarely	3	7
Never → QCA2	3	7
Does not do, but not because of poor health and functioning → QCA2	1	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]?

	AD	No AD
Every day	43	39
Most days	16	18
Some days	29	30
Rarely	5	9
Never	8	4

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)

	AD	No AD
Yes, another unpaid family member / friend	53	52
Yes, a paid helper	35	20
No	26	37

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?

	AD	No AD
Every day	62	34
Most days	12	24
Some days	15	27
Rarely	7	8
Never → QCA3	2	6
Does not do, but not because of poor health and functioning → QCA3	2	2

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]?

	AD	No AD
Every day	28	24
Most days	19	23
Some days	36	36
Rarely	7	11
Never	10	7

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

	AD	No AD
Yes, another unpaid family member / friend	52	53
Yes, a paid helper	12	6
No	42	44

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

	AD	No AD
Yes	84	49
No → QCA4	15	48
Does not do, but not because of poor health and functioning → QCA4	1	3

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

	AD	No AD
Yes	71	79
No	29	21

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

	AD	No AD
Yes, another unpaid family member / friend	40	31
Yes, a paid helper	18	6
No	45	63

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

	AD	No AD
Yes	93	59
No → QCA5	5	37
Does not do, but not because of poor health and functioning → QCA5	3	4

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

	AD	No AD
Yes	77	80
No	23	20

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

	AD	No AD
Yes, another unpaid family member / friend	46	38
Yes, a paid helper	1	2
No	54	61

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?

	AD	No AD
Every day	21	7
Most days	9	3
Some days	9	6
Rarely	11	10
Never → QCA6	50	75

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

	AD	No AD
Every day	30	22
Most days	12	13
Some days	29	24
Rarely	15	30
Never	15	12

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

	AD	No AD
Yes, another unpaid family member / friend	46	39
Yes, a paid helper	23	12
No	40	55

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

	AD	No AD
Every day	43	18
Most days	12	9
Some days	12	12
Rarely	10	11
Never → QCA7	24	51

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

	AD	No AD
Every day	23	20
Most days	16	11
Some days	19	23
Rarely	13	18
Never	29	27

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

	AD	No AD
Yes, another unpaid family member / friend	41	32
Yes, a paid helper	33	28
No	35	46

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

	AD	No AD
Every day	45	16
Most days	9	8
Some days	17	14
Rarely	9	15
Never → QCA8	21	47

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

	AD	No AD
Every day	27	19
Most days	16	14
Some days	34	29
Rarely	15	25
Never	9	13

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

	AD	No AD
Yes, another unpaid family member / friend	50	35
Yes, a paid helper	32	21
No	31	51

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

	AD	No AD
Every day	30	12
Most days	6	3
Some days	7	6
Rarely	13	9
Never → QCA9	44	70

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

	AD	No AD
Every day	33	27
Most days	15	9
Some days	18	23
Rarely	18	25
Never	15	16

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

	AD	No AD
Yes, another unpaid family member / friend	57	40
Yes, a paid helper	37	28
No	23	43

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

	AD	No AD
Every day	28	13
Most days	3	4
Some days	9	8
Rarely	14	13
Never → QCA10	46	63

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

	AD	No AD
Every day	22	20
Most days	12	8
Some days	27	23
Rarely	24	33
Never	15	16

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

	AD	No AD
Yes, another unpaid family member / friend	53	43
Yes, a paid helper	31	20
No	31	46

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

	AD	No AD
Every day	27	14
Most days	5	5
Some days	14	12
Rarely	17	17
Never → QCA11	37	53

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

	AD	No AD
Every day	25	18
Most days	12	11
Some days	37	31
Rarely	21	31
Never	5	9

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

	AD	No AD
Yes, another unpaid family member / friend	62	50
Yes, a paid helper	31	16
No	24	41

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

	AD	No AD
Every day	38	20
Most days	12	11
Some days	15	21
Rarely	11	14
Never → skip logic prior to QCA12A	25	34

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

	AD	No AD
Every day	25	19
Most days	21	15
Some days	39	37
Rarely	12	21
Never	4	9

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

	AD	No AD
Yes, another unpaid family member / friend	66	56
Yes, a paid helper	27	11
No	22	38

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?

	AD	No AD
Yes	48	32
No	52	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?

	AD	No AD
Yes	75	70
No	25	30

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?

	AD	No AD
Yes	77	70
No	23	30

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

	AD	No AD
Every day	17	10
Most days	12	17
Some days	37	37
Rarely	14	17
Never	21	18

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]?

	AD	No AD
Every day	2	2
Most days	3	2
Some days	4	4
Rarely	6	5
Never	56	61
Do not use	30	27

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?

	AD	No AD
Yes	79	56
No	21	44

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

	AD	No AD
Yes	70	40
No	30	61

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

	AD	No AD
Orally (by mouth as pills, capsules, liquid)	100	98
Insulin injection	9	14
Other injection	3	7
Infusion pump	0	1
Inhaler	8	15
Suppository	3	3
Medication patch	6	5
Spray	4	4
Eye/Ear drops	23	15
Other	3	9

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

	AD	No AD
Yes	8	6
No	92	94

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

	AD	No AD
Yes	11	9
No	89	91

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

	AD	No AD
Yes	34	26
No	66	74

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

	AD	No AD
Yes	27	28
No	73	72

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

	AD	No AD
Yes	33	16
No	67	85

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

	AD	No AD
Yes	34	28
No	66	73

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

	AD	No AD
Yes	34	26
No	66	74

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

	AD	No AD
Yes	52	46
No	48	54

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?

	AD	No AD
Yes	53	34
No	47	66

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

	AD	No AD
Yes	45	52
No	55	48

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

	AD	No AD
Yes	5	4
No	95	97

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)

	AD	No AD
Yes	47	47
No	53	53

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

	AD	No AD
Yes	11	20
No	90	80

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)

	AD	No AD
Yes	9	8
No	91	92

(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.

	AD	No AD
1. Not at all difficult	51	56
2.	21	20
3.	17	14
4.	8	7
5. Very difficult	5	4

QCA17. Did anyone prepare you to do these tasks?

	AD	No AD
Yes	22	26
No → QCA21	78	74

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

	AD	No AD
Hospital nurse	14	24
Hospital doctor	2	7
Primary care doctor	7	17
Nurse in doctor's office or outpatient setting	14	11
Home care nurse	16	27
Social worker/geriatric care manager	2	3
Physical or occupational therapist	14	20
Pharmacist	7	6
Medical supply technician	11	7
Friend or neighbor	9	7
You learned on your own	30	26
Other	64	38

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

	AD	No AD
Very well	81	79
Somewhat well	19	19
Not well	0	3

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

	AD	No AD
None → QCA24PRE	52	42
One time	20	21
2 times	14	16
3 or more times	14	21

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...

	AD	No AD
Yes, all the time	67	55
Only some of the time	17	26
No, and you should have been	5	5
No, but you did not need to be	11	14

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]?

	AD	No AD
Yes	78	71
No	16	22
Not applicable	6	7

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

	AD	No AD
Very well	57	54
Somewhat well	34	35
Not well	9	11

QCA24PRE. Now think about the last YEAR.

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

	AD	No AD
Yes	74	63
No	26	37

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

	AD	No AD
Yes	73	64
No	27	36

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

	AD	No AD
Yes	82	86
No	18	14

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.]

	AD	No AD
Yes	29	26
No	71	74

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.]

	AD	No AD
Yes	47	36
No	53	64

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?

	AD	No AD
8 hours or less per week	32	44
9 to 19 hours per week	22	26
20 to 39 hours per week	21	14
40 or more hours per week	25	15

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.

	AD	No AD
Regular schedule	56	51
Varied	44	49

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

	AD	No AD
3 months or less	1	7
4 to 12 months	8	11
1 - 2 years	23	18
3 - 5 years	34	27
More than 5 years	34	36

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

	AD	No AD
Increased in the past month	52	31
Been about the same in the past month	44	59
Decreased in the past month	4	11

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?

	AD	No AD
Will increase	44	29
Will be about the same	53	61
Will decrease	3	10

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

	AD	No AD
Yes	44	46
No	56	54

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

	AD	No AD
Very worried	6	5
Somewhat worried	12	12
Only a little	35	27
Not at all	47	57

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".)

	AD	No AD
1 CR has not been suffering physically	17	12
2	14	8
3	15	14
4	9	9
5	14	15
6	13	7
7	7	13
8	5	11
9	3	5
10 CR has been suffering terribly	3	6

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".)

	AD	No AD
1 CR has not been suffering physically	9	14
2	7	10
3	9	12
4	6	8
5	17	15
6	12	9
7	8	10
8	17	11
9	7	5
10 CR has been suffering terribly	8	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]?

	AD	No AD
A lot	64	72
Some	30	22
A little	5	5
Not at all	1	1

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

	AD	No AD
A lot	16	19
Some	30	24
A little	30	29
Not at all	24	28

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

	AD	No AD
A lot	75	82
Some	16	11
A little	7	6
Not at all	2	3

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

	AD	No AD
A lot	19	20
Some	36	29
A little	30	33
Not at all	14	18

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...

	AD	No AD
Gotten much better	17	17
Gotten somewhat better	18	21
Stayed about the same	47	48
Gotten somewhat worse	17	11
Gotten much worse	1	3

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.

	AD	No AD
Very much	39	38
Somewhat	43	35
Not so much	18	27

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

	AD	No AD
Very much	52	46
Somewhat	37	37
Not so much	11	17

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

	AD	No AD
Very much	47	48
Somewhat	37	35
Not so much	16	17

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

	AD	No AD
Very much	82	77
Somewhat	16	19
Not so much	2	3

QAC6A. Is helping CR financially difficult for you?

	AD	No AD
Yes	28	21
No	72	79

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

	AD	No AD
Yes	76	56
No	25	44

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

	AD	No AD
Yes	31	28
No	69	72

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*)

	AD	No AD
1. A little difficult	12	10
2.	11	10
3.	30	32
4.	26	24
5. Very difficult	21	24

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

	AD	No AD
1. A little difficult	10	13
2.	11	19
3.	33	27
4.	23	23
5. Very difficult	23	18

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

	AD	No AD
1. A little difficult	6	10
2.	18	18
3.	33	37
4.	27	22
5. Very difficult	16	13

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

	AD	No AD
Very much	9	8
Somewhat	34	18
Not so much	57	74

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.

	AD	No AD
Very much	40	29
Somewhat	33	29
Not so much	28	42

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

	AD	No AD
Very much	27	22
Somewhat	38	33
Not so much	36	45

QAC9C. You don't have time for yourself.

	AD	No AD
Very much	29	25
Somewhat	38	32
Not so much	33	43

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

	AD	No AD
Very much	12	11
Somewhat	36	25
Not so much	52	64

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?

	AD	No AD
Yes	94	88
No	6	12

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?

	AD	No AD
Yes	53	52
No	47	48

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

	AD	No AD
Yes	72	66
No	28	34

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

	AD	No AD
Yes	11	4
No	89	96

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?

	AD	No AD
Yes	33	16
No	68	84

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

	AD	No AD
Yes	10	9
No	90	91

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

	AD	No AD
Yes	21	16
No	79	84

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)*

	AD	No AD
Yes	25	17
No	75	84

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?

	AD	No AD
Yes	47	41
No	53	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?

	AD	No AD
Yes	50	41
No	50	59

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

	AD	No AD
Yes	35	17
No	65	83

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?

	AD	No AD
One	16	25
Two	33	26
Three or more	51	50

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

	AD	No AD
Caregiver's Brother(s)	31	25
CG's Sister(s)	39	39
CG's husband	19	20
CG's wife	7	8
CG's other relative(s) / in-law(s)	57	53
CG's friend(s)	18	11
Other	22	25

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

	AD	No AD
Live(s) with you	39	39
Within twenty minutes of your home	66	64
Between twenty minutes and an hour from your home	27	25
One to two hours from your home	5	6
Two to four hours away	4	4
More than four hours away	14	10

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

	AD	No AD
We complement each other – we each help CR with different tasks.	27	30
We help with the same things but we divide the help over time.	18	17
We share some tasks, and others we do separately	55	53

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?

	AD	No AD
Respondent is the primary caregiver	49	58
Someone else is the primary caregiver	36	28
Care is equally shared	15	14

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

	AD	No AD
To a great extent	4	1
To a moderate extent	13	7
Only a little	32	28
Not at all	52	64

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

	AD	No AD
Very satisfied	62	70
Moderately satisfied	29	24
Moderately dissatisfied	6	5
Very dissatisfied	3	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?

	AD	No AD
Yes	85	85
No	16	15

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]?

	AD	No AD
Yes	42	27
No	58	73

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

	AD	No AD
Very important	58	51
Somewhat important	32	34
Not so important	10	15

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

	AD	No AD
Yes	58	61
No	42	39

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

	AD	No AD
Yes	15	12
No	85	88

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

	AD	No AD
Very important	45	47
Somewhat important	25	23
Not so important	30	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.]

	AD	No AD
Yes	46	48
No	54	52

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.]

	AD	No AD
Yes	26	19
No	74	81

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.]

	AD	No AD
Very important	29	31
Somewhat important	37	29
Not so important	34	40

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.

	AD	No AD
Yes	85	83
No	15	17

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.]

	AD	No AD
Yes	34	22
No	66	78

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.]

	AD	No AD
Very important	49	48
Somewhat important	43	36
Not so important	9	16

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

	AD	No AD
Yes	36	37
No	65	63

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

	AD	No AD
Yes	22	14
No	78	86

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.

	AD	No AD
Yes	41	41
No	59	59

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

	AD	No AD
Yes	7	8
No	93	92

HEALTH

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

	AD	No AD
Excellent	13	16
Very good	33	31
Good	37	30
Fair	15	19
Poor	3	4

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

	AD	No AD
Yes	8	7
No	92	93

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

	AD	No AD
Yes	12	8
No	88	92

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

	AD	No AD
Yes	41	41
No	59	59

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

	AD	No AD
Yes	45	49
No	55	51

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

	AD	No AD
Yes	21	20
No	79	80

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

	AD	No AD
Yes	17	14
No	83	86

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

	AD	No AD
Yes	15	16
No	85	84

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

	AD	No AD
Yes	13	14
No	87	86

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

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

	AD	No AD
Yes	64	61
No	37	39

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

	AD	No AD
Yes	19	16
No	81	84

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

	AD	No AD
Yes	29	31
No	71	69

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

	AD	No AD
Yes	40	39
No	60	61

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

	AD	No AD
Yes	57	50
No	43	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?

	AD	No AD
Every night	11	9
Most nights	18	14
Some nights	35	32
Rarely	22	28
Never	16	18

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

	AD	No AD
Every night	4	2
Most nights	6	4
Some nights	25	17
Rarely	23	23
Never	42	53

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:

	AD	No AD
< 18.5 (underweight)	0	1
18.5 – 24.9 (normal)	28	27
25.0 – 29.9 (overweight)	39	35
30.0 – 34.9 (moderately obese)	21	23
35.0 – 39.9 (severely obese)	6	8
40.0 + (very severely obese)	6	6

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

	AD	No AD
Yes	32	29
No → QHE25A	68	71

QHE24a. Were you trying to lose weight?

	AD	No AD
Yes	71	67
No	29	33

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

	AD	No AD
Every day	10	16
Most days	47	46
Some days	31	29
Rarely	10	8
Never	1	1

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

	AD	No AD
Every day	8	14
Most days	38	39
Some days	35	32
Rarely	16	13
Never	3	2

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

	AD	No AD
Every day	11	17
Most days	33	32
Some days	35	31
Rarely	17	16
Never	4	4

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

	AD	No AD
Every day	2	2
Most days	5	6
Some days	23	22
Rarely	35	31
Never	35	40

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

	AD	No AD
Every day	4	2
Most days	10	6
Some days	25	19
Rarely	29	28
Never	32	44

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

	AD	No AD
Every day	5	3
Most days	6	9
Some days	58	44
Rarely	29	36
Never	3	7

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

	AD	No AD
Not at all	52	57
Several days	35	31
More than half the days	10	7
Nearly every day	3	5

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

	AD	No AD
Not at all	50	59
Several days	38	31
More than half the days	8	7
Nearly every day	4	4

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

	AD	No AD
Not at all	40	42
Several days	43	44
More than half the days	13	7
Nearly every day	5	7

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

	AD	No AD
Not at all	45	53
Several days	33	31
More than half the days	14	7
Nearly every day	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?

	AD	No AD
Not at all	1	4
A little bit	4	4
Somewhat	10	8
Quite a bit	27	29
Extremely	58	55

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?

	AD	No AD
Never	67	68
Rarely	22	24
Sometimes	9	8
Often	1	0
Always	0	0

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

	AD	No AD
Never	63	65
Rarely	25	25
Sometimes	11	9
Often	1	1
Always	0	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)?

	AD	No AD
Correct	64	67
Incorrect	36	33

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*)

	AD	No AD
Correct	85	81
Incorrect	15	19

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*)

	AD	No AD
Correct	78	76
Incorrect	22	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.

	AD	No AD
Yes → QEC4	50	46
No	20	23
Retired / don't work anymore → QEC16	31	31

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

	AD	No AD
Yes → QEC4	2	8
No	70	68
Retired / don't work anymore → QEC16	28	24

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

	AD	No AD
Yes, looking for a job → QEC16	16	15
Yes, on layoff → QEC16	6	5
No → QEC16	69	74
Retired / don't work anymore → QEC16	9	6

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

	AD	No AD
Yes	22	22
No	78	78

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

	AD	No AD
20 or fewer	22	22
21 – 39	21	19
40 or more	57	59

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?

	AD	No AD
Yes	65	58
No	35	42

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

	AD	No AD
Daytime	88	80
Some other schedule	12	21

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?

	AD	No AD
Yes	43	44
No → QEC12	57	56

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.

	AD	No AD
Yes	35	30
No	65	70

QEC9B. You were sick.

	AD	No AD
Yes	49	38
No	51	62

QEC9C. You took time off to help CR.

	AD	No AD
Yes	41	46
No	59	54

QEC9D. Other family members were sick.

	AD	No AD
Yes	18	21
No	82	79

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

	AD	No AD
Yes	41	35
No	59	65

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?

	AD	No AD
One	50	53
Two	25	20
Three or more	25	28

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?

	AD	No AD
Yes	33	23
No →QEC14	68	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.

	AD	No AD
1 A little harder	5	18
2	11	10
3	18	19
4	21	11
5	16	16
6	13	6
7	11	5
8	3	12
10 A lot harder	3	4

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

	AD	No AD
Yes	83	76
No	17	24

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

	AD	No AD
Telecommuting or working from home	31	31
Programs like information, referrals, counseling, or an employee assistance program, to help caregivers like yourself	34	36
Paid leave, where you could take paid time off from work for several weeks to care for a family member	35	33
Paid sick days	54	53
None of the above	28	28

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

	AD	No AD
Went in late, left early, or took time off during the day to provide care	46	41
Took a leave of absence	14	12
Went from working full-time to part-time, or cut back your hours	16	14
Turned down a promotion	5	3
Lost any of your job benefits	7	4
Gave up working entirely	16	12
Retired early	14	12
Received a warning about your performance or attendance at work	5	4
None of the above	41	44

DEMOGRAPHICS

QDE1. INTERVIEWER: RECORD PERSON'S SEX

	AD	No AD
Male	21	27
Female	80	73

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

	AD	No AD
44 or under	8	13
45 – 54	16	20
55 – 64	48	36
65 or older	29	32

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

	AD	No AD
Married	58	59
Living with a partner in a marital-like relationship	4	5
Divorced or separated	16	12
Widowed	5	5
Single/never married	18	18

QDE4. Are you of Hispanic or Latino descent?

	AD	No AD
Yes	1	2
No	99	98

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

	AD	No AD
Caucasian/White	83	82
Asian/Pacific Islander	1	1
American Indian or Alaskan Native	1	1
Black or African-American	16	16
None of the above	0	1

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

	AD	No AD
Eighth grade or less	0	0
Some high school	0	1
High school graduate or GED	21	19
Some college, no degree	17	22
Associate's degree, occupational	6	7
Associate's degree, academic	6	6
Bachelor's degree	31	25
Master's degree	15	15
Professional degree	3	2
Doctoral degree	2	2

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

	AD	No AD
Live alone → QDE11PRE	16	14
Live in a household with family or others	84	85
Have some other living arrangements	0	1

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

	AD	No AD
One	4	5
Two	61	66
Three	23	22
Four	9	7
Five	3	1
Six	0	0

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

	AD	No AD
Zero	83	80
One	11	10
Two	4	7
Three	2	2
Four	1	1
Five	0	1
Six	0	0

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

	AD	No AD
Your spouse / partner	74	77
Your child(ren)	35	32
Your grandchild(ren)	4	5
Your parent(s)	23	17
Other relatives of yours	8	11
Non-relatives	4	3

QDE11PRE. And now just a couple questions about CR.

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

	AD	No AD
Eighth grade or less	3	6
Some high school	6	7
High school graduate or GED	52	45
Some college, no degree	8	8
Associate's degree, occupational	4	7
Associate's degree, academic	2	4
Bachelor's degree	15	13
Master's degree	5	6
Professional degree	3	1
Doctoral degree	4	2

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

	AD	No AD
Yes	0	1
No	100	100

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

	AD	No AD
Caucasian/White	84	82
Asian/Pacific Islander	0	1
American Indian or Alaskan Native	1	1
Black or African-American	16	17
None of the above	0	1

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?

	AD	No AD
Yes	46	35
No	55	65

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?

	AD	No AD
Yes	27	15
No	73	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.

	AD	No AD
1. Not at all difficult	75	74
2	11	13
3	7	8
4	2	3
5. Very difficult	6	3

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.

	AD	No AD
1. Not at all difficult	66	71
2	14	12
3	14	7
4	3	5
5. Very difficult	4	5

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.

	AD	No AD
1. Not at all difficult	38	40
2	12	8
3	12	11
4	9	6
5. Very difficult	9	8
Not applicable	19	26

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.

	AD	No AD
1. Not at all difficult	33	33
2	12	9
3	13	10
4	10	4
5. Very difficult	16	13
Not applicable	17	31

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.

	AD	No AD
1. Not at all difficult	21	29
2	10	7
3	18	12
4	13	9
5. Very difficult	17	14
Not applicable	20	29

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*)

	AD	No AD
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	86	83
Requiring hospitals to keep you informed about major decisions, like transferring or discharging CR	89	85
Requiring hospitals or facilities to instruct or demonstrate any medical or nursing tasks you might need to do	87	87
Having respite services available, where someone would take care of CR to give you a break	81	68
Requiring a doctor, nurse, or social worker ask you about what you need to help care for CR	84	77
Requiring a doctor, nurse, or social worker ask you about what you need to take care of yourself	71	62
None of the above	4	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.

	AD	No AD
An income tax credit to caregivers, to help offset the cost of care	30	36
A partially paid leave of absence from work for caregivers who are employed	20	18
A program where caregivers could be paid for at least some of the hours they provide care	50	46

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?

	AD	No AD
Yes	38	42
No → QHI3	62	58

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

	AD	No AD
Yes	51	72
No	49	28

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

	AD	No AD
Yes	12	12
No	88	88

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.

	AD	No AD
Yes	78	75
No	23	25

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?

	AD	No AD
Yes	3	3
No	97	97

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

	AD	No AD
Medicare	80	75
Medicaid	19	18
Private Health Insurance	55	56
Tricare/CHAMPVA	4	3

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

	AD	No AD
Yes	75	77
No	25	24

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

	AD	No AD
Yes	94	97
No	7	3

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

	AD	No AD
Yes	76	75
No	24	25

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

	AD	No AD
Yes	22	18
No	78	82

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

	AD	No AD
Yes	73	71
No	28	29

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

	AD	No AD
Yes	38	34
No	62	66

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?

	AD	No AD
0 – less than \$10,000	8	7
\$10,000 to less than \$20,000	9	10
\$20,000 to less than \$30,000	11	10
\$30,000 to less than \$40,000	15	12
\$40,000 to less than \$50,000	9	11
\$50,000 to less than \$60,000	10	10
\$60,000 to less than \$70,000	10	8
\$70,000 to less than \$80,000	5	6
\$80,000 to less than \$90,000	4	6
\$90,000 to less than \$100,000	3	6
\$100,000 to less than \$110,000	5	4
\$110,000 to less than \$120,000	2	1
\$120,000 to less than \$130,000	3	2
\$130,000 to less than \$140,000	0	0
\$140,000 to less than \$150,000	2	2
More than \$150,000	9	6

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?

	AD	No AD
Yes	43	39
No	57	61

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?

	AD	No AD
Yes	18	23
No	82	77

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

	AD	No AD
Yes	11	14
No	89	86

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?

	AD	No AD
Yes	29	28
No	71	72

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.

	AD	No AD
Yes	19	21
No	82	79

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

	AD	No AD
Yes	17	8
No	83	92

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 [SP]'s [medications or medical care,]

	AD	No AD
More than \$1,000 → QHI6	45	43
Less than \$1,000 → QHI7	55	57

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

	AD	No AD
Yes	71	60
No	30	40

(skip to next section)

QHI17. Was it less than \$500?

	AD	No AD
Yes	58	77
No	42	23