[Hello,] the Center for Senior Health at PeaceHealth has asked me to call you to conduct a follow-up survey about your experiences as a caregiver or someone who helps to provide care for someone else.

My name is ________, and I'm calling from the University of Oregon Survey Research Laboratory. Do you have any questions about the survey before we begin?

PROBE: This is a 10-minute survey about issues related to your role in providing care for
FIRST NAME:
LAST NAME:

PROBE: This is a follow-up survey to the one we completed six months ago. [Do you remember that one?] PROBE: You received a letter from the Center for Senior Health at PeaceHealth explaining this research study, and you signed a form saying that you would be willing to take part in it.
PROBE: I want to assure you that I am not selling a thing and
that this survey is completely confidential and voluntary.

1-->NO QUESTIONS OR QUESTIONS ANSWERED, OK TO BEGIN SURVEY
YES, HAS QUESTIONS ---> REFER TO INTERVIEWER INSTRUCTIONS
I:
show SHOWPFN 12 13 70 GRN
show SHOWPLN 13 13 70 GRN
key 1

Q: COOPERAT
T:
[Thank you.] We appreciate your cooperation.
[I'd like to begin the survey now.]

1-->OK
CTRL-END-->SCHEDULE CALLBACK
I:
key 1

Q: PATIENT
T:
I would like to start the interview by confirming our records
on your caregiving situation.

Our records show that you serve as a caregiver for:

FIRST NAME:
LAST NAME:

Is this correct?

NOTE: REMEMBER PATIENT'S NAME. WRITE IT DOWN IF NECESSARY

1 CORRECT --> SKIPTO RELAT1
2 INCORRECT --> SKIPTO PATIENT2
3 PARTIALLY CORRECT --> SPECIFY

7 REFUSED --> SKIPTO NOQAL
8 DON'T KNOW --> SKIPTO NOQAL
9 NO ANSWER --> SKIPTO NOQAL
I:
show SHOWPFN 7 13 70 GRN
show SHOWPLN 8 13 70 GRN
key 1-3,7-9
qal noqal
oth 3 15 35 24 75
if (ans = 1) skipto RELAT1
if (ans = 2) skipto PATIENT2
if (ans = 3) skipto RELAT1
if (ans > 3) skipto noqal

Q: PATIENT2
Do you currently serve as a caregiver for someone else?

NOTE: INFANTS AND CHILDREN DO NOT COUNT.

PROBE FOR "YES": What is that person's name?

NOTE IF "YES": WRITE DOWN OR REMEMBER NEW NAME FOR FUTURE QUESTIONS!

1 YES --> SPECIFY
2 NO --> SKIPTO NOQAL

7 REFUSED --> SKIPTO NOQAL
8 DON'T KNOW --> SKIPTO NOQAL
9 NO ANSWER --> SKIPTO NOQAL

Are you related to

FIRST NAME:
LAST NAME:

1 YES
2 NO-->SKIPTO RELAT3

7 REFUSED-->SKIPTO DIST1
8 DON'T KNOW-->SKIPTO DIST1
9 NO ANSWER-->SKIPTO DIST1

How are you related to

FIRST NAME:
LAST NAME:

PROBE FROM LIST

1 SPOUSE / SIGNIFICANT OTHER
2 Daughter / Son / Stepchild
3 Other Relative
4 Other --> Specify

7 Refused
8 Don't Know
9 No Answer

NOTE: All R's who answer this Q will skip to Dist1
I:
Show SHOWPFN 4 13 70 GRN
Show SHOWPLN 5 13 70 GRN
Key 1-4,7-9
Oth 4 20 5 24 65
Skip to Dist1

Q: RELAT3
T:

Are you a volunteer, paid employee, friend, or something else?

1 Volunteer
2 Paid Employee
3 Friend
4 Other --> Specify
5 (If volunteered) Combination of the above --> Specify

7 Refused
8 Don't Know
9 No Answer
I:
Key 1-5,7-9
Oth 4 20 5 24 65
Oth 5 20 5 24 65

Q: DIST1
T:

Do you live in the same house as

First Name:
Last Name:

1 Yes --> Skip to Hours
2 No

7 Refused
8 Don't Know
9 No Answer
I:
Show SHOWPFN 4 13 70 GRN
Show SHOWPLN 5 13 70 GRN
Key 1,2,7-9
If (ans = 1) skip to Hours
Q: DIST2
T:
How many minutes does it take for you to get to where (she/he) lives?

PROBE: Using whatever mode of transportation you usually use--bicycling, walking, driving, etc.

PLEASE RECORD EXACT NUMBER OF MINUTES (0-120)

NOTE: 1 HOUR = 60 MINUTES
      1.5 HOURS = 90 MINUTES
      2 HOURS = 120 MINUTES

0 --> LESS THAN 1 MINUTE
120 --> TWO HOURS OR MORE

997 REFUSED
998 DON'T KNOW
999 NO ANSWER

I:
num 0 999 3 0 24 25
if (ans > 120)
  if (ans < 997) REASK
ENDIF

Q: HOURS
T:
How many hours per week do you spend providing care for

FIRST NAME:
LAST NAME:                    ?

PLEASE ENTER THE EXACT NUMBER OF HOURS BELOW

0 --> LESS THAN 1 HOUR

96 --> 96 OR MORE HOURS

97 REFUSED
98 DON'T KNOW
99 NO ANSWER

I:
show SHOWPFN 4 13 70 GRN
show SHOWPLN 5 13 70 GRN
num 0 99 2 0 15 25

Q: CARE1
T:
While providing care for
do you perform any of the following tasks: doing the shopping, housekeeping, doing the laundry, cooking, driving or helping with transportation, handling telephone calls, managing medication, paying bills, or managing other finances?

PROBE: If you help with any of these tasks, your answer is "yes".

1 YES
2 NO

7 REFUSED
8 DON'T KNOW
9 NO ANSWER
I:
show SHOWPFN 4 13 70 GRN
show SHOWPLN 5 13 70 GRN
key 1,2,7-9

Q:CARE2
T:

While providing care for

FIRST NAME:
LAST NAME:

do you help (him/her) with ANY of the following tasks: bathing, getting dressed, getting out of bed, getting out of chairs, walking around the house, eating, or using the toilet?

PROBE: If you help with any of these tasks, your answer is "yes".

1 YES
2 NO

7 REFUSED
8 DON'T KNOW
9 NO ANSWER
I:
show SHOWPFN 4 13 70 GRN
show SHOWPLN 5 13 70 GRN
key 1,2,7-9

Q:CARE3
T:

Do you also coordinate or manage others who are responsible for providing care for

FIRST NAME:
LAST NAME:

PROBE: Do you arrange for others
to provide care for (NAME / her / him)?

1 YES
2 NO

7 REFUSED
8 DON'T KNOW
9 NO ANSWER

I:
show SHOWPFN 5 13 70 GRN
show SHOWPLN 6 13 70 GRN
key 1,2,7-9

Q:CARE4
T:

Do you do any other [types of] activities while providing care for

FIRST NAME:
LAST NAME:

NOTE: THIS REFERS TO ACTIVITIES RELATED TO CAREGIVING

1 YES
2 NO-->SKIPTO CGB1

7 REFUSED-->SKIPTO CGB1
8 DON'T KNOW-->SKIPTO CGB1
9 NO ANSWER-->SKIPTO CGB1

I:
show SHOWPFN 4 13 70 GRN
show SHOWPLN 5 13 70 GRN
key 1,2,7-9
if (ans > 1) SKIPTO CGB1

Q:CARE4A
T:

What other tasks do you perform while providing care for

FIRST NAME:
LAST NAME:

OPEN-ENDED

PLEASE TYPE EXACT ANSWER BELOW

I:
show SHOWPFN 5 13 70 GRN
show SHOWPLN 6 13 70 GRN
opn 12 5 24 75

Q:CGB1
T:
Now I am going to read some questions about the amount of time it takes to provide care for

FIRST NAME:
LAST NAME:

Please tell me if you strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree with each statement.

(NAME / The person for whom I provide care) needs my help to perform many daily tasks.

PROBE: Your care-receiver is the person(s) for whom you are providing care

1 STRONGLY DISAGREE
2 DISAGREE
3 NEITHER AGREE NOR DISAGREE
4 AGREE
5 STRONGLY AGREE
7 REFUSED
8 DON'T KNOW
9 NO ANSWER
I:
show SHOWPFN 5 13 70 GRN
show SHOWPLN 6 13 70 GRN
key 1-5,7-9

Q:CGB2
T:

(NAME / The person for whom I provide care) is dependent on me.

PROBE: Do you strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree?

1 STRONGLY DISAGREE
2 DISAGREE
3 NEITHER AGREE NOR DISAGREE
4 AGREE
5 STRONGLY AGREE
7 REFUSED
8 DON'T KNOW
9 NO ANSWER
I:
key 1-5,7-9

Q:CGB3
T:

I have to watch (NAME / The person for whom I provide care) constantly.

PROBE: Do you strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree?
I have to help (NAME / The person for whom I provide care) with many basic functions.

PROBE: Such as bathing, dressing, eating, walking, personal hygiene.

PROBE: Do you strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree?

1 STRONGLY DISAGREE
2 DISAGREE
3 NEITHER AGREE NOR DISAGREE
4 AGREE
5 STRONGLY AGREE

7 REFUSED
8 DON'T KNOW
9 NO ANSWER
I:
key 1-5,7-9

Q:CGB5
T:

I don't have a minute's break from my caregiving chores.

PROBE: Do you strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree?

1 STRONGLY DISAGREE
2 DISAGREE
3 NEITHER AGREE NOR DISAGREE
4 AGREE
5 STRONGLY AGREE

7 REFUSED
8 DON'T KNOW
9 NO ANSWER
I:
key 1-5,7-9

Q:CGB6
Next, I'm going to read some questions about how providing care may have affected your life.

[Please use the same answer categories.]

I feel that I am missing out on life.

PROBE: Do you strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree?

1 STRONGLY DISAGREE
2 DISAGREE
3 NEITHER AGREE NOR DISAGREE
4 AGREE
5 STRONGLY AGREE

7 REFUSED
8 DON'T KNOW
9 NO ANSWER
I:
key 1-5,7-9

Q:CGB7
T:

I wish I could escape from this situation.

PROBE: I wish that I could escape from my caregiving situation.
PROBE: Do you strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree?

1 STRONGLY DISAGREE
2 DISAGREE
3 NEITHER AGREE NOR DISAGREE
4 AGREE
5 STRONGLY AGREE

7 REFUSED
8 DON'T KNOW
9 NO ANSWER
I:
key 1-5,7-9

Q:CGB8
T:

My social life has suffered.

PROBE: As a result of caregiving, my social life has suffered.
PROBE: Do you strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree?

1 STRONGLY DISAGREE
2 DISAGREE
I feel emotionally drained due to caring for

FIRST NAME: 
LAST NAME: 

PROBE: Do you strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree?

1 STRONGLY DISAGREE
2 DISAGREE
3 NEITHER AGREE NOR DISAGREE
4 AGREE
5 STRONGLY AGREE

7 REFUSED
8 DON'T KNOW
9 NO ANSWER
I:
key 1-5,7-9

I'm not getting enough sleep.

PROBE: As a result of my caregiving duties, I am not getting enough sleep. PROBE: Do you strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree?

1 STRONGLY DISAGREE
2 DISAGREE
3 NEITHER AGREE NOR DISAGREE
4 AGREE
5 STRONGLY AGREE

7 REFUSED
8 DON'T KNOW
9 NO ANSWER
I:
key 1-5,7-9
Q:CGB11
T:

My health has suffered.

PROBE: As a result of my caregiving duties, my own health has suffered.
PROBE: Do you strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree?

1 STRONGLY DISAGREE
2 DISAGREE
3 NEITHER AGREE NOR DISAGREE
4 AGREE
5 STRONGLY AGREE

7 REFUSED
8 DON'T KNOW
9 NO ANSWER
I:
key 1,5,7-9

Q:CGB12
T:

Caregiving has made me physically sick.

PROBE: As a result of my caregiving duties, I have become ill more frequently.
PROBE: Do you strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree?

1 STRONGLY DISAGREE
2 DISAGREE
3 NEITHER AGREE NOR DISAGREE
4 AGREE
5 STRONGLY AGREE

7 REFUSED
8 DON'T KNOW
9 NO ANSWER
I:
key 1,5,7-9

Q:CGB13
T:

I am physically tired.

PROBE: As a result of my caregiving duties, I am physically tired.
PROBE: Do you strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree?

1 STRONGLY DISAGREE
2 DISAGREE
3 NEITHER AGREE NOR DISAGREE
4 AGREE
5 STRONGLY AGREE

7 REFUSED
8 DON'T KNOW
9 NO ANSWER
I:
key 1-5,7-9

Q:CGB14
T:

I don't get along with other family members as well as I used to.

PROBE: As a result of my caregiving duties, I don't get along with other family members as well as I used to.
PROBE: Do you strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree?

1 STRONGLY DISAGREE
2 DISAGREE
3 NEITHER AGREE NOR DISAGREE
4 AGREE
5 STRONGLY AGREE

7 REFUSED
8 DON'T KNOW
9 NO ANSWER
I:
key 1-5,7-9

Q:CGB15
T:

My caregiving efforts aren't appreciated by others in my family.

PROBE: Do you strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree?

1 STRONGLY DISAGREE
2 DISAGREE
3 NEITHER AGREE NOR DISAGREE
4 AGREE
5 STRONGLY AGREE

7 REFUSED
8 DON'T KNOW
9 NO ANSWER
I:
key 1-5,7-9

Q:CGB16
T:

I've had problems with my marriage or with my partner.

PROBE: As a result of my caregiving responsibilities.
Q:CGB17
T:

I don't do as good a job at work as I used to.

NOTE: REFERS TO EMPLOYMENT/WORK OTHER THAN CAREGIVING.

PROBE: By "work," I mean your job or any other duties or responsibilities you may have.
PROBE: Do you strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree?

Q:CGB18
T:

I feel resentful of other relatives who could, but do not help.

PROBE: Do you strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree?
I feel embarrassed by the behaviors of the person for whom I provide care.

PROBE: Do you strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree?

1 STRONGLY DISAGREE
2 DISAGREE
3 NEITHER AGREE NOR DISAGREE
4 AGREE
5 STRONGLY AGREE

7 REFUSED
8 DON'T KNOW
9 NO ANSWER
I:
key 1-5,7-9

I feel ashamed of (NAME / the person for whom I provide care).

PROBE: Do you strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree?

1 STRONGLY DISAGREE
2 DISAGREE
3 NEITHER AGREE NOR DISAGREE
4 AGREE
5 STRONGLY AGREE

7 REFUSED
8 DON'T KNOW
9 NO ANSWER
I:
key 1-5,7-9

I resent (NAME / the person for whom I provide care).

PROBE: Do you strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree?
Q: CGB22
T:
I feel uncomfortable when I have friends over.

PROBE: Do you strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree?

1 STRONGLY DISAGREE
2 DISAGREE
3 NEITHER AGREE NOR DISAGREE
4 AGREE
5 STRONGLY AGREE

6 (IF VOLUNTEERED) NOT APPLICABLE: R DOES NOT LIVE WITH CARE-RECEIVER.

7 REFUSED
8 DON'T KNOW
9 NO ANSWER
I:
key 1-6,7-9

Q: CGB23
T:
I feel angry about my interactions with (NAME / the person for whom I provide care).

PROBE: Do you strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree?

1 STRONGLY DISAGREE
2 DISAGREE
3 NEITHER AGREE NOR DISAGREE
4 AGREE
5 STRONGLY AGREE

7 REFUSED
8 DON'T KNOW
9 NO ANSWER
I:
key 1-5,7-9
In what other ways has caregiving affected your life?

PROBE: Other than the ways discussed in the previous set of questions. PROBE: Please feel free to include both positive and negative effects.

OPEN-ENDED

PLEASE TYPE EXACT RESPONSE BELOW
I:

The next questions are about your experiences with

FIRST NAME:
LAST NAME:

(NAME's) doctors and at the doctor's office.

Have you ever visited the doctor's office with (NAME)?

PROBE: Their (regular/primary) doctor's office, not the emergency room or urgent care facility.

1 YES --> SKIPTO CGS1A
2 NO
7 REFUSED
8 DON'T KNOW
9 NO ANSWER
I:
show SHOWPFN 4 13 70 GRN
show SHOWPLN 5 13 70 GRN
key 1,2,7-9
if (ans = 1) skipto CGS1A

Have you had any contact at all with

FIRST NAME:
LAST NAME:

primary doctor or doctors?

PROBE: (His/Her) (regular/primary) doctor's office, not the emergency room or urgent care facility.

1 YES
Q:CGS1A
T:

Please think about how you feel, in general, about your experiences with

FIRST NAME:
LAST NAME:

(NAME’s) doctor's office. For each statement I read, please tell me if you disagree, agree, strongly agree, or very strongly agree.

The first one is: The physical environment is inviting, comfortable and pleasant.

PROBE: [Do you disagree, agree, strongly agree, or very strongly agree with that statement] [when you think about your care-receiver's doctor's office, in general]?

1 DISAGREE
2 AGREE
3 STRONGLY AGREE
4 VERY STRONGLY AGREE

Q:CGS2A
T:

The staff at the doctor's office truly care about me as a person.

PROBE: [Do you disagree, agree, strongly agree, or very strongly agree with that statement] [when you think about your care-receiver's doctor's office, in general]?

1 DISAGREE
2 AGREE
3 STRONGLY AGREE
4 VERY STRONGLY AGREE
The staff at the doctor's office are caring and compassionate.

PROBE: [Do you disagree, agree, strongly agree, or very strongly agree with that statement] [when you think about your care-receiver's doctor's office, in general]?

1 DISAGREE
2 AGREE
3 STRONGLY AGREE
4 VERY STRONGLY AGREE

I have confidence and trust in the staff at the doctor's office.

PROBE: [Do you disagree, agree, strongly agree, or very strongly agree with that statement] [when you think about your care-receiver's doctor's office, in general]?

1 DISAGREE
2 AGREE
3 STRONGLY AGREE
4 VERY STRONGLY AGREE

I feel free to discuss with the staff at the doctor's office any concerns or anxieties I have.

PROBE: [Do you disagree, agree, strongly agree, or very strongly agree with that statement] [when you think about your care-receiver's doctor's office, in general]?
The staff at the doctor's office answer my questions completely and in a way I can understand.

PROBE: [Do you disagree, agree, strongly agree, or very strongly agree with that statement] [when you think about your care-receiver's doctor's office, in general]?

The different staff at the doctor's office are well coordinated - they know what each other are doing and work as a team.

PROBE: [Do you disagree, agree, strongly agree, or very strongly agree with that statement] [when you think about your care-receiver's doctor's office, in general]?
The doctors and nurses include me as a full partner in discussing

FIRST NAME:
LAST NAME:

(NAME's) condition and making decisions about (her/his) care.

PROBE: [Do you disagree, agree, strongly agree, or very strongly agree with that statement] [when you think about your care-receiver's doctor's office, in general]?

1 DISAGREE
2 AGREE
3 STRONGLY AGREE
4 VERY STRONGLY AGREE

7 REFUSED
8 DON'T KNOW
9 NO ANSWER

I:
show SHOWPFN 4 13 70 GRN
show SHOWPLN 5 13 70 GRN
key 1-4,7-9

Q:CGS9A
T:

The staff at the doctor's office make sure that I am kept informed about

FIRST NAME:
LAST NAME:

(NAME's) condition and care as much as (NAME / she / he) and I want.

PROBE: [Do you disagree, agree, strongly agree, or very strongly agree with that statement] [when you think about your care-receiver's doctor's office, in general]?

1 DISAGREE
2 AGREE
3 STRONGLY AGREE
4 VERY STRONGLY AGREE

7 REFUSED
8 DON'T KNOW
9 NO ANSWER

I:
show SHOWPFN 4 13 70 GRN
show SHOWPLN 5 13 70 GRN
key 1-4,7-9

Q:CGS10A
T:

The staff at the doctor's office involve me in
(NAME’s) care as much as (NAME / she / he) and I want.

PROBE: [Do you disagree, agree, strongly agree, or very strongly agree with that statement] [when you think about your care-receiver's doctor's office, in general]?

1 DISAGREE
2 AGREE
3 STRONGLY AGREE
4 VERY STRONGLY AGREE

7 REFUSED
8 DON'T KNOW
9 NO ANSWER
I:
key 1-4,7-9

Q:CGS11A
T:

Overall, the quality of care at the doctor's office is excellent.

PROBE: [Do you disagree, agree, strongly agree, or very strongly agree with that statement] [when you think about your care-receiver's doctor's office, in general]?

1 DISAGREE
2 AGREE
3 STRONGLY AGREE
4 VERY STRONGLY AGREE

7 REFUSED
8 DON'T KNOW
9 NO ANSWER
I:
key 1-4,7-9

Q:SEX
T:

I need to end the survey by asking you some questions about yourself.

[I know this may sound silly (but I am required to ask)]
Are you male or female?

1 MALE
2 FEMALE

7 REFUSED
Q: AGE
T:

How old are you?

PLEASE ENTER EXACT NUMBER OF YEARS

96 --> 96 OR OLDER

97 REFUSED
98 DON'T KNOW
99 NO ANSWER
I:
num 18 99 2 0 15 30

Q: EMPLOY
T:

Are you currently employed outside of your caregiving situation?

PROBE FOR YES: Are you employed full-time or part-time?

1 YES, FULL-TIME
2 YES, PART-TIME
3 NO

7 REFUSED
8 DON'T KNOW
9 NO ANSWER
I:
key 1-3,7-9

Q: STUDENT
T:

Are you currently enrolled in any classes at any school?

PROBE FOR YES: Do you take classes full-time or part-time?

1 YES, FULL-TIME
2 YES, PART-TIME
3 NO

7 REFUSED
8 DON'T KNOW
9 NO ANSWER
I:
key 1-3,7-9

Q: CUTBACK
T:

Have you cut back your (work/school) schedule because of your caregiving responsibilities?

1 YES
2 NO

7 REFUSED
8 DON'T KNOW
9 NO ANSWER
I:
key 1,2,7-9

Q:ENDING
T:

That is the end of the interview! Is there anything else you would like to add?

OPEN-ENDED

PLEASE TYPE THE EXACT RESPONSE
I:
opn 10 5 24 75

Q:ENDING2
T:

On behalf of the Center for Senior Health at PeaceHealth and your care-receiver's doctor, I would like to thank you sincerely for your time and effort on these questions.

I will be calling you for another interview in 12 months.

Good-bye.

PRESS "1" TO CONTINUE
I:
key 1

Q:INTCOMM
T:

INTERVIEWER - PLEASE RECORD ANY OBSERVATIONS RELEVANT TO THE INTERVIEW BELOW.
I:
opn 10 10 25 60

Q:INTID
T:

PLEASE ENTER YOUR INTERVIEWER ID NUMBER.
I:
num 1 800 3 0 25 25
ALL RESPONDENTS ARE PRE-QUALIFIED-->CONTACT COORDINATOR IMMEDIATELY

RECORD NUMBER:

PRESS "1" TO DISQUALIFY
I:
show RecNum 4 16 31 GRN
key 1
DISPOS = 22
ENDQUEST