



Research on Cancer Survivors

A research study to help understand
life after cancer and what helps survivors
thrive!

Caregiver Follow-Up Survey

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Version: 3

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Thank you for being a part of our research study on survivorship. You were identified as the primary caregiver for a cancer patient who is also participating in this study. You completed a survey approximately one year ago about your role as a caregiver. We would like to find out how your caregiving role has changed over time. This survey should take approximately 30-45 minutes to complete.

Please answer every question to the best of your knowledge and as honestly as possible. There are no right or wrong answers.

SECTION 1: Caregiving Status

The first section is a few questions about you and whether you are still providing care to your Care Recipient.

1.1. What is your month and year of birth?

Month _____ Year _____

1.2. Which of these terms best describes your current marital status?

- Married
- Living as married
- Widowed
- Divorced
- Separated
- Never married

1.3. Which of the following phrases best describes your **current** employment status?

- Employed full time (including self-employed)
- Employed part time (including self-employed)
- Homemaker
- Unemployed
- Retired
- Disability
- Other (specify) _____

1.4. How many hours a week do you **currently** work for pay?

1.5. Are you **currently** caring for your Care Recipient?

Yes

→ **Go To Question 1.6**

No

→ **Go To Question 1.7**

1.6. Approximately how long ago did you begin providing care for your Care Recipient?

_____ years _____ months

→ **Go to Question 1.10**

1.7. Have/had you provided any care for your Care Recipient since the last survey?

Yes

No

1.8. Why are you no longer caring for your Care Recipient?

My Care Recipient is deceased

→ **Go to the blue section, Section 2**

My Care Recipient no longer needs care

My Care Recipient has someone else who is providing care

1.9. How long ago did you stop providing care for your Care Recipient?

_____ months ago

1.10. Does your Care Recipient live...

- In your household?
- Within a 20 minute drive of your home?
- Between 20 minutes and one hour from your home?
- One to two hours from your home?
- More than 2 hours from your home?

1.11. For approximately how long have you provided care for your Care Recipient?

_____ years _____ months

If you have provided any care for your Care Recipient since completing your last survey, please skip to the yellow section, Section 3.

If you have not provided any care for your Care Recipient since completing your last survey, please skip to the next white section, Section 7.

Only complete the following blue section, Section 2, if your Care Recipient is deceased.

SECTION 2: PATIENT IS DECEASED – HOSPICE AND GRIEF INVENTORY QUESTIONS

We would like to ask you a few questions about the passing of your loved one and about your own health since that event. Thank you for your time and please accept our condolences.

2.1 What is the month and year of your Care Recipient's passing?

Month _____ Year _____

2.2 Was your Care Recipient cared for by Hospice near the end of their life?

Yes →

Go to Question 2.3

No →

Go to Question 2.4

2.3 How long was your Care Recipient in hospice?

_____ months OR _____ days

2.4 For the following statements please answer based on your **current** feelings.

NEVER means less than once per month,

RARELY means more than once per month but less than weekly

SOMETIMES means more than weekly but less than daily

OFTEN means every day

ALWAYS means more than once every day

	Never	Rarely	Sometimes	Often	Always
I think about this person so much that it's hard for me to do the things I normally do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Memories of the person who died upset me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I cannot accept the death of the person who died	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel myself longing for the person who died	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel drawn to places and things associated with the person who died	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can't help feeling angry about their death	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel disbelief over what happened	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel stunned or dazed over what happened	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ever since s/he died it is hard for me to trust people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ever since s/he died I feel like I have lost the ability to care about other people or I feel distant from people I care about	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have pain in the same area of my body or I have some of the same symptoms as the person who died	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I go out of my way to avoid reminders of the person who died	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that life is empty without the person who died	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I hear the voice of the person who died speak to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I see the person who died stand before me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that it is unfair that I should live when this person died	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel bitter over this person's death	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel envious of others who have not lost someone else	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel lonely a great deal of the time ever since s/he died	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**If you provided any care for your Care Recipient since the last survey please continue to the yellow section, Section 3.
Otherwise, skip to the next white section, Section 7.**

SECTION 3: CARE TIME

Please answer the following questions based on the care you provided to your Care Recipient **since the last survey**.

3.1. Thinking about all of the care you provided to your Care Recipient due to their illness **since the last survey**, on how many **days per week** did you provide care, on average?

_____ days

3.2. Thinking about all of the care you provided to your Care Recipient **since the last survey**, on a typical day about how many **hours** did you provide care to your Care Recipient due to their illness?

_____ hours

3.3. Thinking about all of the care you provided to your Care Recipient **since the last survey**, about how many **hours** each week did you spend **driving or accompanying** them to an appointment or other location (destination)?

_____ hours → **If zero, Go to Question 3.5**

3.4. **Since the last survey**, when driving or accompanying your Care Recipient to an appointment, what mode of transportation did you use to get there?

- Personal vehicle
- Public transportation
- Taxi or shared ride service such as Uber or Lyft

3.5. How do you think your Care Recipient was feeling most days (**since the last survey**)?

- Excellent
- Very good
- Good
- Fair
- Poor

3.6. **Since the last survey**, have you needed to relocate or move in order to provide care?

- Yes
- No

3.7. **Since the last survey**, is there anyone else who provided unpaid care for your Care Recipient?

- Yes → **Answer Questions 3.7a and 3.7b**
- No → **Go to Question 3.8**

3.7a Who else helped care for your Care Recipient? [Select all that apply.]

- Their spouse or partner
- Their parent
- Their child
- Their grandparent
- Their grandchild
- Their sibling
- Their aunt or uncle
- Their friend
- Other (please specify _____)

3.7b In general, how satisfied were you with the care that others provided?

- Extremely satisfied
- Somewhat satisfied
- Neither satisfied nor dissatisfied
- Somewhat dissatisfied
- Extremely dissatisfied

3.8. **Since the last survey**, did you provide unpaid care to any other adults in addition to your Care Recipient?

- Yes No

3.9. **Since the last survey**, did you provide unpaid care for any children (yours or someone else's)?

- Yes → **Answer Question 3.9a** No → **Go to Question 3.10**

3.9a How many of these children were 5 years old or younger?

_____ children

3.10. Think about the time **since the last survey** while you were still caring for your Care Recipient. Which of the following phrases best describes your employment status during that time? (If more than one phrase describes your employment status, which describes your employment status for the longest duration during that time?)

- Employed full time (including self-employed) }
 Employed part time (including self-employed) } → **Go to Question 3.11**
 Homemaker }
 Unemployed }
 Retired } → **Go to Section 4**
 Disability }
 Other (specify) _____ }

3.11. Think about the time **since the last survey** while you were still caring for your Care Recipient. During that time, on average, how many **hours a week** did you work for pay?

_____ hours -OR- I did not work for pay while caring for my Care Recipient

3.12. Thinking about the job where you worked the longest while providing care for your Care Recipient **since the last survey**, did that employer offer paid time off while you provided care?

- Yes No

3.13. In order to provide care or assistance to your Care Recipient **since the last survey**, did you have to change your work schedule?

- Yes No

3.14. In order to provide care or assistance to your Care Recipient **since the last survey**, did you have to take extended **paid** time off from work?

- Yes → **Answer Questions 3.14a and 3.14b** No → **Go to question 3.15**

3.14a. **Since the last survey**, how much **paid** sick time did you use to care for your Care Recipient?

- None 1-3 months
 Less than 1 week 3-6 months
 1 week to 1 month 6 months or more

3.14b. **Since the last survey**, how much **paid** vacation time did you use to care for your Care Recipient?

- None 1-3 months
 Less than 1 week 3-6 months
 1 week to 1 month 6 months or more

3.15. In order to provide care or assistance to your Care Recipient **since the last survey**, did you have to take **unpaid** time off from work?

- Yes → **Answer Question 3.15a**
 No → **Go to Question 3.16**

3.15a. **Since the last survey**, how much **unpaid** time off work have you used to care for them?

- Less than 1 week
 3-6 months
 1 week to 1 month
 6 months or more
 1-3 months

3.16. In order to provide care or assistance to your Care Recipient **since the last survey**, did you have to change the number of hours you work each week?

- Yes
 No

3.17. In order to provide care or assistance to your Care Recipient **since the last survey**, did you have to change your job duties?

- Yes
 No

3.18. In order to provide care or assistance to your Care Recipient **since the last survey**, did you have to Change employment status (for example, leave your job, or get a new job)?

- Yes
 No

3.19. **Since the last survey**, in general, how difficult was it for you to balance work and caregiving demands?

- Not at all difficult
 Very difficult
 A little difficult
 Extremely difficult
 Somewhat difficult

SECTION 4: Caregiver Confidence, Experience, and Burden

Some caregivers feel very confident while others do not. Please think about all of the care that you have provided for your Care Recipient as a result of their cancer **since the last survey**.

4.1 While providing care for your Care Recipient, how confident were you that you could...

	Not at all confident	A little confident	Somewhat confident	Very confident	Extremely confident
Take care of your Care Recipient's physical needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Take care of your Care Recipient's emotional needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Find out about services for your Care Recipient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cope with the stress of caregiving	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4.2 While providing care for your Care Recipient **since the last survey**, how confident did you feel that your caregiving was helping them?

- Not at all confident
 Somewhat confident
 Not very confident
 Very confident
 Neither confident nor not confident

- 4.3 How much longer do you feel that you can continue to provide adequate caregiving support to your Care Recipient?
- Not much longer
 - About 6 more months
 - Up to a year
 - 1-2 years
 - More than 2 years
 - Not applicable (I am not currently providing care)
- 4.4 If you were to stop caring for your Care Recipient, they will...
- Have no one to care for them
 - Have a caregiver that can provide at least the same or more care as they receive now
 - Have a caregiver to provide some care but not as much as they receive now
 - Not have a caregiver but will have services to support them
 - I do not know whether my Care Recipient will have a caregiver and/or any services to help them
 - Not applicable (I am not currently providing care)
- 4.5 Think about when you were caring for your Care Recipient **since the last survey**. When, during your caregiving responsibilities, would you say they needed the most help? (Please select all that apply)
- Following surgery
 - During chemotherapy treatment
 - During radiation therapy treatment
 - After they completed their treatment
 - Not applicable
- 4.6 Next, it is very important to us to get an idea of the specific things you did to help your Care Recipient. The questions in the next section ask you about the care you provided **since the last survey**, during the time when they needed the most help **due to their cancer**.

Since the last survey, during the time when your Care Recipient needed the most help as a result of their cancer, did you help them:	Yes	No	Not Needed
Get around inside (with walking, wheelchair, or other device)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get around outside (with walking, wheelchair, or other device)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Eat?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get in or out of bed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get in or out of a chair, or transfer between a chair and bed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Climb stairs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get dressed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bathe?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brush their teeth?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
With other grooming (for example, combing hair or shaving)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get on or off the toilet?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clean themselves after they used the toilet?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
With a bedpan?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
With a catheter?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
With a colostomy bag?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4.7 Next is a list of tasks that caregivers sometimes take over for patients as a result of their illness.

Since the last survey, during the time when your Care Recipient needed the most help as a result of their cancer, did you:	Yes	No	Not Needed
Manage their money (paid bills, managed cash)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Make telephone calls for them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do housework you wouldn't normally do (if they weren't sick)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wash laundry you wouldn't normally do?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Shop for their groceries?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cook meals for your Care Recipient that you would not have if they were not sick?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Drive them to a doctor's office, clinic, or hospital?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have to do other chores and tasks they would normally do if they were not ill?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4.8 The next set of questions ask about things caregivers might do either to provide home medical care, or because of the treatments the patient receives

Since the last survey, during the time when your Care Recipient needed the most help as a result of their cancer, did you:	Yes	No	Not Needed
Help administer medicine to them? ↳ If so, what kinds of medicine did you help administer? <input type="radio"/> Oral (pills, tablets or capsules) <input type="radio"/> Injection <input type="radio"/> Other (please specify)_____	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Make a decision about whether they needed medication?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Help keep track of, or watch for, side effects from their treatment?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Spend time helping them manage or control symptoms such as nausea/vomiting, fatigue, or pain?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Change their bandages?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do anything to treat their lungs, like give oxygen, give nebulizer treatment or perform chest percussions?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Decide whether to call a doctor?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Accompany them to treatments or doctor appointments?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4.9 Sometimes doctors, nurses, home health aides, social workers, or some other healthcare provider will train, teach, or show caregivers how to do the things their care recipients need.

Since the last survey, did any health care or other provider give you any training or show you how to:	Yes	No	Not Needed
Change your Care Recipient's bandages?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Administer medicine to them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Help them manage nausea?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Help them manage pain?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Help them manage fatigue?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Manage any other side effects or symptoms? ↳ If yes, please specify:_____	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provide any other treatments? ↳ If yes, please specify:_____	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4.10 The following questions reflect how people sometimes feel/felt when they are taking care of another person. After each question, indicate how often you feel that way: never, rarely, sometimes, frequently, or nearly always. There are no right or wrong answers.

Thinking of the time you spent caring for your Care Recipient since the last survey:	Never	Rarely	Some- times	Frequently	Nearly Always
Did you feel that they asked for more help than they needed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel that because of the time you spent with them, you did not have enough time for yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel stressed between caring for them and trying to meet other responsibilities for your family or work?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel embarrassed over their behavior?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel angry when you were around them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel that they affected your relationship with other family members or friends in a negative way?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Were you afraid about what the future holds for them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel that they were dependent on you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel strained when you were around them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel your health suffered because of your involvement with them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel that you did not have as much privacy as you would like, because of them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel that your social life had suffered because you were caring for them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel uncomfortable about having friends over, because of them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel that they seemed to expect you to take care of them, as if you were the only one they could depend on?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel that you did not have enough money to care for them, in addition to the rest of your expenses?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel that you would be unable to take care of them much longer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel you had lost control of your life since their illness?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you wish you could just leave the care of them to someone else?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel uncertain about what to do about them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel you should have done more for them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel you could have done a better job in caring for them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Overall, how often did you feel burdened in caring for your Care Recipient?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

5.3b. **Since the last survey**, did a **paid** home health aide assist your Care Recipient with personal care (bathing, feeding, healthcare tasks)?

Yes

No

5.3c. **Since the last survey**, did any nurses, doctors, therapists, or social workers come to your Care Recipient's home as a result of their cancer?

Yes

No

5.3d. **Since the last survey**, for about how many **weeks** (or months) did you use any **paid** helpers as a result of your Care Recipient's cancer?

_____ weeks **OR** _____ months

5.3e. **Since the last survey**, thinking about a typical week in which you used **paid** helpers, about how many **days per week** did they usually work?

_____ days

5.3f. **Since the last survey**, on a typical day in which you used **paid** helpers, for how many **hours per day** did they work?

_____ hours

5.3g. **Since the last survey**, about how much did you usually spend **per month** or in **total** on the following kinds of paid help? Best estimates are just fine.

<u>Since the last survey</u>, about how much did you spend on...	Amount per month, or	Amount in total
People paid to help with your Care Recipient's bathing, dressing, getting around the house, such as a nurse's aide, or home help aide?	_____	_____
People paid to help with your Care Recipient's household chores, errands, driving, cooking, or other tasks because of the illness?	_____	_____
In-home hospice services for your Care Recipient?	_____	_____
Nurses, doctors, therapists, or social workers who came to their home (other than hospice)?	_____	_____

SECTION 6: Interactions with your Care Recipient's Healthcare Providers

The next questions are about your Care Recipient's visits with their doctor(s) **since the last survey**.

- 6.1 How often did your Care Recipient see a cancer doctor?
- Less than once per month
 - Once per month
 - About once every 3 months
 - About once every 6 months
 - Less often than once every 6 months
 - Don't know
- 6.2 How often did your Care Recipient see their primary care doctor?
- Less than once per month
 - Once per month
 - About once every 3 months
 - About once every 6 months
 - Less often than once every 6 months
 - Don't know
- 6.3 How often did your Care Recipient see a doctor that is neither a cancer doctor nor primary care doctor?
- Less than once per month
 - Once per month
 - About once every 3 months
 - About once every 6 months
 - Less often than once every 6 months
 - Don't know

SECTION 7: Caregiver health

Now we would like to know more about your general health.

7.1 In general, how would you say that your health is now?

- Excellent
- Very good
- Good
- Fair
- Poor

7.2 What is your current weight (in pounds)?

_____ lbs

7.3 Has a doctor **ever** told you that you have any of the following medical conditions? [Please check all that apply, give your **approximate age at diagnosis**, and indicate if you are **currently being treated**.]

Medical Condition	Ever Diagnosed?			Age at Diagnosis	Currently Being Treated?	
	Yes	No	Unsure		Yes	No
1. Arthritis ↳ What kind? <input type="radio"/> Rheumatoid <input type="radio"/> Osteoarthritis <input type="radio"/> Unspecified/unknown	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	_____	<input type="radio"/>	<input type="radio"/>
2. Cancer (other than non-melanoma skin cancer, and in situ (CIN) cervical cancer) ↳ Which type of cancer(s) have you been diagnosed with? _____	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	_____	<input type="radio"/>	<input type="radio"/>
3. Emphysema	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	_____	<input type="radio"/>	<input type="radio"/>
4. COPD (chronic obstructive pulmonary disease)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	_____	<input type="radio"/>	<input type="radio"/>
5. Depression	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	_____	<input type="radio"/>	<input type="radio"/>
6. Diabetes ↳ What kind? <input type="radio"/> Type I <input type="radio"/> Type II <input type="radio"/> Gestational <input type="radio"/> Unknown	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	_____	<input type="radio"/>	<input type="radio"/>
7. Fracture (broken bone), over age 50 ↳ Part of body? _____	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	_____	<input type="radio"/>	<input type="radio"/>
8. Heart Problems ↳ What kind? <input type="radio"/> Heart Attack <input type="radio"/> Congestive Heart Failure <input type="radio"/> Afib (Atrial fibrillation) <input type="radio"/> Coronary artery disease <input type="radio"/> Other <input type="radio"/> Unsure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	_____	<input type="radio"/>	<input type="radio"/>
9. Hepatitis (any type) ↳ What kind? <input type="radio"/> A <input type="radio"/> B <input type="radio"/> C <input type="radio"/> Unknown	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	_____	<input type="radio"/>	<input type="radio"/>
10. High cholesterol	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	_____	<input type="radio"/>	<input type="radio"/>
11. Hypertension (high blood pressure)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	_____	<input type="radio"/>	<input type="radio"/>
12. Stroke	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	_____	<input type="radio"/>	<input type="radio"/>
13. Thyroid problem ↳ What type? <input type="radio"/> Hypothyroidism <input type="radio"/> Hyperthyroidism <input type="radio"/> Other <input type="radio"/> Unknown	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	_____	<input type="radio"/>	<input type="radio"/>
14. Any other medical condition not previously listed ↳ How many? _____ Please Specify which condition(s): _____	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	_____	<input type="radio"/>	<input type="radio"/>

SECTION 8: Caregiver Health Behaviors – Physical Activity

The next section asks about your physical activity

- 8.1. Physical activity can include any activity that increases your heart rate, such as walking, jogging, yard work, shoveling snow, etc. In the **past 4 weeks**, did you participate in any physical activity to improve or maintain your physical fitness?

Yes →

Go to Question 8.2

No →

Go to Question 8.8

- 8.2. ***Vigorous*** activities are those that cause large increases in breathing or heart rate, during which you can only say a few words without stopping to catch your breath (such as aerobic or fast dancing, jumping rope, race walking, jogging, or running, swimming laps, tennis, or heavy yard work). In the **past 4 weeks**, did you participate in regular vigorous exercise, at least once a week?

Yes

No →

Go to Question 8.5

- 8.3. In the **past 4 weeks**, how many times each week did you participate in ***vigorous*** activities on average?

Once

2-4 times

5-6 times

7 times or more

- 8.4. When you did ***vigorous*** activities in **the past 4 weeks**, for how many minutes on average did you do them each time?

Less than 10 minutes

20-29 minutes

45-59 minutes

10-19 minutes

30-44 minutes

60 minutes or more

- 8.5. ***Moderate*** activities are those that cause small increases in breathing or heart rate (such as walking briskly, biking on level ground or with few hills, playing golf, ballroom or line dancing, general gardening, or using a manual wheelchair). In the **past 4 weeks** did you participate in any moderate activities at least once a week?

Yes

No →

Go to Question 8.8

- 8.6. In the **past 4 weeks**, how many times each week did you participate in ***moderate*** activities on average?

Once

2-4 times

5-6 times

7 times or more

- 8.7. When you did ***moderate*** activities in **the past 4 weeks**, for how many minutes on average did you do them each time?

Less than 10 minutes

20-29 minutes

45-59 minutes

10-19 minutes

30-44 minutes

60 minutes or more

- 8.8. Has your average level of physical activity increased, decreased, or remained the same **since the last survey**?

Increased

Decreased

Remained the same

- 8.9. On average, **since the last survey**, how many hours each day did you spend watching TV, videos, or using a home computer?

Less than 1

1 – 2

3 – 4

5 or more

- 8.10. On average, **since the last survey**, how many hours each day did you spend sitting during the day (at work or at home)?

Less than 1

1 – 2

3 – 4

5-6

7 or more

SECTION 9: Caregiver Health Behaviors – Diet

Now you will be asked a few questions about your diet in the past month. Please think about the foods you ate including both meals and snacks.

- 9.1 In the **past 4 weeks**, how many servings of fruit (such as a medium apple or banana or 1 cup of grapes or berries) did you eat per day? **Do not count juices.**
- None, or less than 1 per day
 - 1 per day
 - 2 per day
 - 3 per day
 - 4 per day
 - 5 or more per day
- 9.2 In the **past 4 weeks**, how many servings of vegetables (like green salad, green beans, tomatoes, carrots, onions, or broccoli) did you eat per day? **Do not count fried potatoes.** (A serving is one cup of vegetables such as broccoli or carrots or cooked greens, or 2 cups of raw leafy greens such as lettuce or spinach.)
- None, or less than 1 per day
 - 1 per day
 - 2 per day
 - 3 per day
 - 4 per day
 - 5 or more per day

In the past 4 weeks, how often did you...	Never, or less than once per week	1-3 times per week	4-6 times per week	Once per day	More than once per day
9.3. eat processed meat, such as ham, bologna, salami, hot dogs, bacon or sausage?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9.4. eat other red meat, such as steak, hamburger, pork or lamb, alone or in other dishes such as sandwiches, pasta or pizza?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9.5 have a serving of regular soda or pop that contains sugar? (A serving is the same as a 12-oz can of soda). Do not include diet soda.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9.6 eat fast food such as McDonald's, KFC or Taco Bell?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9.7 eat sweets or desserts such as cookies, cake, pie or ice cream?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In the past 4 weeks...	None, or less than 1	1-3	4-6	7-9	10 or more
9.8 how many glasses of water did you drink each day ? (A glass is equal to 8 ounces)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SECTION 10: Caregiver Health Behaviors – Tobacco Use

The next items ask about cigarette smoking. Please think about cigarette smoke only, and do not include the smoke from a pipe or cigars.

10.1. Have you smoked at least 100 cigarettes in your life?

Yes →

Go to Question 10.2

No →

Go to Question 10.9

10.2. How old were you when you first started smoking cigarettes **on a regular basis**?
(Regular is defined as at least one cigarette a day for 1 month or more)

Age in years _____ **OR** I never smoked **on a regular basis**

10.3. Do you **currently** smoke cigarettes on a regular basis (at least one cigarette a day for the past month)?

Yes →

Go to Question 10.4

No →

Go to Question 10.5

10.4. Do you currently smoke inside your home?

Yes →

Go to Question 10.6

No →

10.5. How old were you when you last smoked cigarettes on a regular basis (at least one cigarette a day for 1 month or more)?

Age in years: _____ **OR** Year Quit: _____

10.6. **Over the entire time** you smoked, how many cigarettes do / did you smoke, on average, per day **or** per week? (Note: There are 20 cigarettes in a pack. If you smoke 1 pack per day you would enter 20)

_____ Cigarettes per day **OR** _____ Cigarettes per week

10.7. During the **entire time** you / you've smoked, was there any time where you quit **for 1 year or more**?

Yes →

Go to Question 10.8

No →

Go to Question 10.9



10.8. During the **entire time** you/ you've smoked, for how many **total** years did you quit smoking?

_____ Years

10.9. Do you live in the same household with someone who smokes cigarettes regularly (at least one cigarette a day for a month or more) while in your presence?

Yes

No

10.10. Have you **ever** vaped or smoked electronic cigarettes (e-cigarettes)?

Yes

No →

Go to Section 11

10.11. Do you **currently** vape or smoke e-cigarettes?

Yes

No

The next set of questions will ask about your sleep over **the past week only**. Your answers should indicate the most accurate reply for the majority of days and nights in the past week.

S5. During the past week, what time did you usually go to bed at night? (that is, turn off the lights and try to go to sleep for the night)?

Time: _____ am/ pm

S6. During the past week, how long (in minutes) did it usually take you to fall asleep each night?

Minutes to fall asleep: _____

S7. During the past week, when have you usually gotten up (out of bed) in the morning? (That is, get out of bed for the day?)

Time: _____ am/ pm

S8. During the past week, how many hours of actual sleep did you get at night? (This may be different than the number of hours you spend in bed).

Hours of sleep each night: _____

S9. During the past week, how often did you have trouble sleeping because you...	Not at all	Once a week	Twice a week	3 times or more a week	Don't know
a. Could not get to sleep within 30 minutes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Woke up in the middle of the night or early morning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Had to use the bathroom	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Could not breathe comfortably	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Coughed or snored loudly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Felt too cold	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Felt too hot	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Had bad dreams	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. Heard noises	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j. Had pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k. Have pets	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
l. Other reason(s); Please describe: _____	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
m. During the past week , how often did you take medicine (prescribed or "over the counter") to help you sleep?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
n. During the past week , how often did you have trouble staying awake while eating meals, or engaging in social activity?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SECTION 12: PROMIS (Patient-Reported Outcomes Measurement Information System) Measures

12.1. The next several questions ask about your mental and emotional health. For each item, please select the one response [per row] that best reflects your experience in the **past 7 days**.

Over the past 7 days:	Never	Rarely	Some- times	Often	Always
I felt fearful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found it hard to focus on anything other than my anxiety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My worries overwhelmed me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt uneasy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt worthless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt helpless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt depressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt hopeless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

12.2. How often do you attend meetings of programs or groups, clubs, or organizations that you belong to?

- More than once a day
- Once a day
- 2 or 3 times a week
- About once a week
- Less than once a week
- Never

12.3. How close do you feel your relationship is between you and your Care Recipient **right now**?

- Not at all close
- A little close
- Somewhat close
- Very close

12.4. How close do you feel your relationship was between you and your Care Recipient **before their cancer diagnosis**?

- Not at all close
- A little close
- Somewhat close
- Very close

SECTION 13: Social Needs

The next several questions ask about **your** social needs. (Please answer yes or no to each statement.)

- 13.1 Was there a time **since the last survey** when you needed to see a doctor but could not because of cost?
- Yes No
- 13.2 **Since the last survey**, did you ever eat less than you felt you should because there wasn't enough money for food?
- Yes No
- 13.3 **Since the last survey**, has your utility company shut off your service for not paying your bills?
- Yes No
- 13.4 Are you worried that in the **next 2 months** you may not have stable housing?
- Yes No
- 13.5 **Since the last survey**, have you ever had to go without health care because you didn't have a way to get there?
- Yes No
- 13.6 Generally, do you feel safe in your neighborhood?
- Yes No

SECTION 14: Use of electronic and mobile technology

The next two items ask about **your** use of the Internet, smartphones, and other technology in relation to health and healthcare for your Care Recipient.

- 14.1 Do you own and/or have regular access to a desktop computer, laptop computer, tablet or smartphone?
- Yes No
- 14.2. Have you ever gone online to find health-related information related to your Care Recipient's illness or treatment? (This could include searching for information about a health condition or disease, specific symptoms, or about medical treatments or procedures?)
- Yes No

SECTION 15: Household Information

The next few items ask about **your** household and where you live.

15.1 What was your household income last year, before taxes?

- Less than \$10,000
- \$10,000-\$19,999
- \$20,000-\$39,999
- \$40,000- \$59,999
- \$60,000-\$79,999
- \$80,000 or more

15.2 How many people live in your household (please include yourself)?

- 1
- 2
- 3
- 4
- 5
- 6 or more

15.3 How long have you lived at your current address?

_____Years _____Months

**PLEASE COMPLETE THE REQUESTED INFORMATION ON THE
INSIDE OF THE BACK COVER TO CHOOSE YOUR GIFT CARD AND
COMPLETE THE REQUESTED INFORMATION**

END SURVEY

Caregiver Follow Up Survey

Version: 3

Revised: 9/30/2021

STUDY ID#:

Thank you for completing the survey! You will receive one \$25 gift card for completing the survey. Please select which card you would like to receive as a thank you for your time.

- Meijer
- Target
- CVS

Please provide your preferred contact information:

Mailing address:

Phone number(s)

	Type				Okay to text?	
	Home	Cell	Work	Other	Yes	No
1. _____	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. _____	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Email Address:

Please share any feedback or additional information you feel is important [in the box below].

**Thank you very much for filling out this survey - your answers are very important to us.
We will invite you to complete another survey in approximately 1 year.**

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