Research on Cancer Survivorship

A research study to help understand

life after cancer and what helps survivors thrive!

Caregiver Survey

Caregiver Survey
Version: 2
Revised: 2/8/2021

Thank you for being a part of our research study on survivorship. You have been identified as the primary caregiver for a cancer patient who is also participating in this study. We would like to find out more about your role as a caregiver.

Your **Care Recipient** is the person we named in the letter that came with this survey. We use the term **Care Recipient** because some people who are part of this study care for family members, while others are caring for friends or neighbors.

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

SECTION 1: Caregiver background

To begin, we would like to learn a little more about you. The first section is about your background and your relationship with your Care Recipient.

1.1. Are you:

- ❍ Male
- ❍ Female

1.2. Are you Hispanic or Latino?

- ❍ Yes
- ❍ No
- ❍ Don't know

1.3. Are you Arab American or Middle Eastern?

- ❍ Yes
- ❍ No
- ❍ Don't know

1.4. With which race(s) do you most closely identify (select all that apply)?

- ❍ Caucasian or White
- ❍ African American or Black
- ❍ Asian
- ❍ Native Hawaiian or Other Pacific Islander
- ❍ American Indian or Alaska Native
- ❍ Other (Please specify): _____

1.5. What is your month and year of birth?

Month _____ Year _____

1.6. What is the highest grade of school you have completed?

- ❍ Less than high school
- ❍ High school /GED
- ❍ Some College
- ❍ 2 year Degree
- ❍ 4 year Degree
- ❍ Graduate/ Professional Degree

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

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

1.8. What is your current relationship with your Care Recipient?

My Care Recipient is my:

- ❍ Husband or wife
- ❍ Girlfriend, boyfriend, or significant other
- ❍ Ex-husband or ex-wife
- ❍ Grandmother or grandfather
- ❍ Mother or father
- ❍ Brother or sister
- ❍ Son or daughter
- ❍ Grandson or granddaughter
- ❍ Friend
- ❍ Other family member (Please specify how you are related.) _____
- ❍ Other (Please specify): _____

1.9. How long have you known your Care Recipient?

- ❍ Less than 1 year
- ❍ 1-5 years
- ❍ 5-10 years
- ❍ 10-20 years
- ❍ More than 20 years

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. Has your Care Recipient begun cancer treatment?

❍ Yes → **Go to Question 1.12** ❍ No → **Go to Question 1.16**

1.12. What was the month and year that your Care Recipient began cancer treatment?

Month _____ Year_____

- ❍ Unknown

1.13. What was the month and year that you first started doing things to help your Care Recipient due to their cancer diagnosis (your best estimate is fine)?

Month _____ Year_____

1.14. Is your Care Recipient **currently** undergoing cancer treatment?

❍ Yes → **Go to Question 1.16** ❍ No → **Go to Question 1.15**

1.15. When did your Care Recipient complete cancer treatment (your best estimate is fine)?

Month_____ Year_____

1.16. Are you currently providing care to your Care Recipient due to their cancer diagnosis?

❍ Yes → **Go to Question 1.18** ❍ No → **Go to Question 1.17**

1.17. When did you stop providing care to your Care Recipient (your best estimate is fine)?

Month _____Year_____

1.18. Thinking about all of the care you provide/d to your Care Recipient due to their illness, on average, on how many **days per week** do/did you provide care?

_____ days

1.19. Thinking about all of the care you provide/d to your Care Recipient, on a typical day about how many **hours** do/did you provide care to your Care Recipient due to their illness?

_____ hours

1.20. Thinking about all of the care you provide/d to your Care Recipient, about how many **hours each week** do/did you spend ***driving or accompanying*** them to an appointment or other location (destination)?

_____ hours → **Go to Question 1.21**

❍ I did not spend time driving or accompanying them → **Go to Question 1.22**

1.21. When driving or accompanying your Care Recipient to an appointment, what mode of transportation do/did you use to get there?

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

1.22. How do you think your Care Recipient is feeling most days?

❍ Excellent
❍ Very good
❍ Good
❍ Fair
❍ Poor

1.23. Did you relocate or move in order to provide care?

- ❍ Yes
- ❍ No

1.24. Do you feel you had a choice in taking on this responsibility for providing care to your Care Recipient?

- ❍ Yes
- ❍ No

1.25. Is there anyone else who provides unpaid care for your Care Recipient?

❍ Yes → **Go to Question 1.26** ❍ No → **Go to Question 1.28**

1.26. Who else helps 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) _____

1.27. In general, how satisfied are you with the care that others provide?

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

1.28. Do you provide unpaid care to any *other* adults in addition to your Care Recipient?

- ❍ Yes
- ❍ No

1.29. Do you provide unpaid care for any children (yours or someone else's)?

❍ Yes → **Go to Question 1.30** ❍ No → **Go to Question 1.31**

1.30. How many of these children are 5 years old or younger? _____children

1.31. Which of the following phrases best describes your employment status at the time of your Care Recipient's cancer diagnosis?

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

1.32. On average, how many hours a week do you work for pay?

_____ hours → **Go to Question 1.33**

❍ I do not spend any hours working for pay → **Go to Section 2**

1.33. In order to provide care or assistance to your Care Recipient since their cancer diagnosis, have you had to do any the following? (Please answer yes or no for each option):

	Yes	No
Change your work schedule	❍	❍
Take extended paid time off from work	❍	❍
Take unpaid time off from work	❍	❍
Change the number of hours you work each week	❍	❍
Change your job duties	❍	❍
Change employment status (for example, leave your job, or get a new job)	❍	❍

1.34. Since your Care Recipient was diagnosed with cancer, how much paid sick time have you used to care for them?

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

1.35. Since your Care Recipient was diagnosed with cancer, how much paid vacation time have you used to care for them?

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

1.36. Since your Care Recipient was diagnosed with cancer, how much unpaid time off work have you used to care for them?

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

1.37. In general, how difficult was/is it for you to balance work and caregiving demands?

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

SECTION 2: Caregiver Confidence, Experience, and Burden

Some caregivers feel very confident while others do not. Please think about all that you provide for your Care Recipient as a result of their cancer.

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

- ❍ Extremely
- ❍ Quite a bit
- ❍ Somewhat
- ❍ A little bit
- ❍ Not at all

2.2. How confident are you that you can…

	Not at all confident	A little confident	Somewhat confident	Very confident	Extremely confident
Take care of your Care Recipient's physical needs	❍	❍	❍	❍	❍
Take care of your Care Recipient's emotional needs	❍	❍	❍	❍	❍
Find out about services for your Care Recipient	❍	❍	❍	❍	❍
Cope with the stress of caregiving	❍	❍	❍	❍	❍

2.3. How confident do you feel that your caregiving is helping your Care Recipient?

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

2.4. How much longer do you feel 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

2.5. If you are no longer your Care Recipient's caregiver, 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

2.6. Next, it is very important to us to get an idea of the specific things you do to help your Care Recipient. Think about when you were caring for them. When, during your caregiving responsibilities, would you say your Care Recipient needed the most help?

- ❍ Currently
- ❍ At the time of their diagnosis
- ❍ During their treatment
- ❍ After they completed their treatment

2.7. The questions in the next section ask you about the care you provided to your Care Recipient **during the time when they needed the most help** due to their cancer.

During the time when your Care Recipient needed the most help, have you helped them:	**Yes**	**No**	**Not Needed**
Get around inside (with walking, wheelchair, or other device)?	❍	❍	❍
Get around outside (with walking, wheelchair, or other device)?	❍	❍	❍
Eat?	❍	❍	❍
Get in or out of bed?	❍	❍	❍
Get in or out of a chair, or transfer between a chair and bed?	❍	❍	❍
Climb stairs?	❍	❍	❍
Get dressed?	❍	❍	❍
Bathe?	❍	❍	❍
Brush their teeth?	❍	❍	❍
With other grooming (for example, combing hair or shaving)?	❍	❍	❍
Get on or off the toilet?	❍	❍	❍
Clean themselves after they used the toilet?	❍	❍	❍
With a bedpan?	❍	❍	❍
With a catheter?	❍	❍	❍
With a colostomy bag?	❍	❍	❍

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

During the time when your Care Recipient needed the most help, as a result of their cancer have you:	**Yes**	**No**	**Not Needed**
Managed their money (paid bills, managed cash)?	❍	❍	❍
Made telephone calls for them?	❍	❍	❍
Done housework you wouldn't normally do (if they weren't sick)?	❍	❍	❍
Washed laundry you wouldn't normally do?	❍	❍	❍
Shopped for their groceries?	❍	❍	❍
Cooked meals for your Care Recipient that you would not have if they were not sick?	❍	❍	❍
Driven them to a doctor's office, clinic, or hospital?	❍	❍	❍
Had to do other chores and tasks they would normally do if they were not ill?	❍	❍	❍

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

During the time when your Care Recipient needed the most help, have you:	**Yes**	**No**	**Not Needed**
Helped administer medicine to them? ↳ If so, what kinds of medicine did you help administer? ❍ Oral (pills, tablets or capsules) ❍ Injection ❍ Other (please specify)_____	❍	❍	❍
Made a decision about whether they needed medication?	❍	❍	❍
Helped keep track of, or watch for, side effects from their treatment?	❍	❍	❍
Spent time helping them manage or control symptoms such as nausea/vomiting, fatigue, or pain?	❍	❍	❍
Changed their bandages?	❍	❍	❍
Done anything to treat their lungs, like give oxygen, give nebulizer treatment or perform chest percussions?	❍	❍	❍
Decided whether to call a doctor?	❍	❍	❍
Accompanied them to treatments or doctor appointments?	❍	❍	❍

2.10. 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.

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?	❍	❍	❍
Administer medicine to them?	❍	❍	❍
Help them manage nausea?	❍	❍	❍
Help them manage pain?	❍	❍	❍
Help them manage fatigue?	❍	❍	❍
Manage any other side effects or symptoms? ↳ If yes, please specify:_____	❍	❍	❍
Provide any other treatments? ↳ If yes, please specify:_____	❍	❍	❍

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

SECTION 3: Costs of Caregiving

3.1. Some caregivers have said that they have had to buy a lot of things using their own money as a result of their Care Recipient's illness, while others report that they have not had to buy anything themselves.

Have you had to spend money on any of the following out of your own pocket because of your Care Recipient's cancer?	**Yes**	**No, or not needed**	**Estimated money spent**	**Unknown**
Prescription medicine for them	❍	❍	_____	❍
Over the counter medication for them	❍	❍	_____	❍
Modifications on the home, such as handrails, ramps, lifts, etc.	❍	❍	_____	❍
Wigs or hats or scarves	❍	❍	_____	❍
Equipment for the home, such as hospital beds, special chairs, wheelchairs, etc.	❍	❍	_____	❍
Special food or drinks for them	❍	❍	_____	❍
Driving them to and from appointments for treatments	❍	❍	_____	❍
Payments for their doctor's visits	❍	❍	_____	❍
Payments for their hospital bills	❍	❍	_____	❍
Payments for their outpatient clinic bills	❍	❍	_____	❍
Other expenses of caregiving ↳ Please describe:_____	❍	❍	_____	❍
Their medical supplies, such as ostomy supplies, bandages, catheters, IV supplies?	❍	❍	_____	❍

3.2. How much do you agree or disagree with the following statements?

	Disagree a lot	**Disagree a little**	**Neither agree nor disagree**	**Agree a little**	**Agree a lot**
My financial resources are adequate to pay for things that are required for caregiving.	❍	❍	❍	❍	❍
It is difficult to pay for things my Care Recipient needs.	❍	❍	❍	❍	❍
Caring for my Care Recipient puts a financial strain on me.	❍	❍	❍	❍	❍

3.3. Have you used / hired any ***paid*** helpers to assist you or your Care Recipient as a result of their cancer?

❍ Yes → **Go to Question 3.4**

❍ No → **Go to Section 4**

3.4. Have you used the services of a person who was paid to help with shopping, cleaning, laundry, or preparing meals as a result of your Care Recipient's cancer?

❍ Yes
❍ No

3.5. Has a ***paid*** home health aide assisted your Care Recipient with personal care (bathing, feeding, healthcare tasks)?

❍ Yes
❍ No

3.6. Have any nurses, doctors, therapists, or social workers come to your Care Recipient's home as a result of their cancer?

❍ Yes
❍ No

3.7. For about how many **weeks** (or months) have you used any ***paid*** helpers as a result of your Care Recipient's cancer?

_____weeks **OR** _____months

3.8. Thinking about a typical week in which you used ***paid*** helpers, about how many **days per week** did they usually work?

_____ days

3.9. On a typical day in which you used ***paid*** helpers, for how many **hours per day** did they work?

_____ hours

3.10. About how much have you usually spent **per month** or in **total** on the following kinds of paid help since your Care Recipient's cancer diagnosis? Best estimates are just fine.

About how much have you spent 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 come to their home (other than hospice)?	_____	_____

SECTION 4: Interactions with your Care Recipient's Healthcare Providers

The next questions are about your experiences talking with your Care Recipient's cancer doctor (oncologist) since the cancer diagnosis.

4.1. How often does your Care Recipient see a cancer doctor?

- ❍ More often 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

4.2. How often are you with your Care Recipient when they see a cancer doctor?

- ❍ Never
- ❍ Rarely

→ **Go to Section 5**

- ❍ Sometimes
- ❍ Usually
- ❍ Always

→ **Go to Question 4.3**

4.3. Thinking about the times you were with your Care Recipient when they saw a cancer doctor:

	Never	Rarely	Some-times	Usually	Always
How often did the doctor speak too fast?	❍	❍	❍	❍	❍
How often did the doctor use words that were hard to understand?	❍	❍	❍	❍	❍
How often did the doctor find out what your concerns were?	❍	❍	❍	❍	❍
How often did the doctor let you say what you thought was important?	❍	❍	❍	❍	❍
How often did the doctor take your concerns about your Care Recipient's health seriously?	❍	❍	❍	❍	❍
How often did the doctor explain your Care Recipient's test results such as blood tests or CT scans?	❍	❍	❍	❍	❍
How often did the doctor clearly explain the result of your Care Recipient's physical exam?	❍	❍	❍	❍	❍
How often did you, your Care Recipient, and the doctor work out a treatment plan together?	❍	❍	❍	❍	❍
If there were treatment choices, how often did the doctor ask if you would like to help decide on the treatment?	❍	❍	❍	❍	❍
How often was the doctor concerned about your Care Recipient's feelings?	❍	❍	❍	❍	❍
How often did the doctor really respect you and your Care Recipient as people?	❍	❍	❍	❍	❍
How often did the doctor treat you and your Care Recipient as equals?	❍	❍	❍	❍	❍
How often did the doctor pay less attention to you and/or your Care Recipient because of your race or ethnicity?	❍	❍	❍	❍	❍

SECTION 5: Caregiver health

Now we want to talk about you. The next items will ask about your personal health history.

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

- ❍ Excellent
- ❍ Very good
- ❍ Good
- ❍ Fair
- ❍ Poor

5.2 What is your current height? Feet _____ Inches _____

5.3 What is your current weight?_____ pounds

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

SECTION 6: Caregiver Health Behaviors – Physical Activity

The next section asks about your physical activity.

6.1. 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 6.2**

❍ No → **Go to Question 6.8**

6.2. ***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 6.5**

6.3. 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

6.4. 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

6.5. ***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 6.8**

6.6. 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

6.7. 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

6.8. Has your average level of physical activity increased, decreased, or remained the same over the **past year**?

❍ Increased ❍ Decreased ❍ Remained the same

6.9. On average, **in the past year**, 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

6.10. On average, **in the past year**, 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 or more

SECTION 7: 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.

7.1. 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

7.2. 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**
7.3. eat processed meat, such as ham, bologna, salami, hot dogs, bacon or sausage?	❍	❍	❍	❍	❍
7.4. eat other red meat, such as steak, hamburger, pork or lamb, alone or in other dishes such as sandwiches, pasta or pizza?	❍	❍	❍	❍	❍
7.5 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**.	❍	❍	❍	❍	❍
7.6 eat fast food such as McDonald's, KFC or Taco Bell?	❍	❍	❍	❍	❍
7.7 eat sweets or desserts such a cookies, cake, pie or ice cream?	❍	❍	❍	❍	❍

In the past 4 weeks…	**None, or less than 1**	**1-3**	**4-6**	**7-9**	**10 or more**
7.8 how many glasses of water did you drink each day? (A glass is equal to 8 ounces)	❍	❍	❍	❍	❍

SECTION 8: 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.

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

❍ Yes → **Go to Question 8.2** ❍ No → **Go to Question 8.9**

8.2. 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** → **Go to Question 8.9**

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

❍ Yes → **Go to Question 8.4** ❍ No → **Go to Question 8.5**

8.4. Do you currently smoke inside your home?

❍ Yes →
❍ No → **Go to Question 8.6**

8.5. 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: _____

8.6. **Over the entire time** you smoked, how many cigarettes do *I* 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

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

❍ Yes → **Go to Question 8.8** ❍ No → **Go to Question 8.9**

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

_____ Years

8.9. 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

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

❍ Yes ❍ No → **Go to Section 9**

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

❍ Yes ❍ No

SECTION 9: Caregiver Health Behaviors – Alcohol Use

These next items will ask about your recent alcohol consumption **over the past 4 weeks**.

9.1. In the **past 4 weeks**, have you consumed alcoholic beverages such as beer, wine, or liquor?

❍ Yes → **Go to Question 9.2**

❍ No → **Go to Section 10**

9.2. In the **past 4 weeks**, how many of each type of alcoholic beverage did you consume per week, on average? If less than 1 per week, enter 0 (zero).

Number per week

_____ Glasses of wine (5 oz)

_____ Cans or bottles of beer (12 oz)

_____ Shots of liquor (such as whiskey, gin, vodka; straight or mixed – 1.5 oz)

_____ Malt liquor (8 oz)

9.3. Is this more than, less than, or typical of your average alcohol consumption?

❍ More than usual
❍ Less than usual
❍ Typical alcohol consumption

SECTION S: SLEEP SUPPLEMENT

Next, you will be asked a series of questions related to your usual sleep habits during **the past two weeks**. Your answers should indicate the most accurate reply for the majority of days and nights.

S1. During the past two weeks,	**No**	**Yes**	**If Yes:**	**Mild**	**Moderate**	**Severe**	**Very Severe**
a. Have you had difficulty falling asleep?	❍	❍	How severe is this problem?	❍	❍	❍	❍
b. Have you had difficulty staying asleep?	❍	❍	How severe is this problem?	❍	❍	❍	❍
c. Have you had a problem waking up too early?	❍	❍	How severe is this problem?	❍	❍	❍	❍

S2. If Yes to Sleep Health a, b or c above; Did these problems occur at least 3 times per week?

❍ Yes ❍ No

S3. During the past two weeks,	**Not at all**	**A little**	**Some -what**	**Much**	**Very much**
a. To what extent have you considered your sleep problem to interfere with your daily functioning (such as daytime fatigue, your mood or your memory)?	❍	❍	❍	❍	❍
b. How noticeable to others do you think your sleeping problem is in terms of impairing the quality of your life?	❍	❍	❍	❍	❍
c. How worried or distressed are you about your current sleep problem?	❍	❍	❍	❍	❍

S4. How satisfied or dissatisfied have you been with your sleep patterns?

❍ Very Satisfied ❍ Mildly Satisfied ❍ Very Dissatisfied
❍ Satisfied ❍ Dissatisfied

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	❍	❍	❍	❍	❍
b. Woke up in the middle of the night or early morning	❍	❍	❍	❍	❍
c. Had to use the bathroom	❍	❍	❍	❍	❍
d. Could not breathe comfortably	❍	❍	❍	❍	❍
e. Coughed or sneezed loudly	❍	❍	❍	❍	❍
f. Felt too cold	❍	❍	❍	❍	❍
g. Felt too hot	❍	❍	❍	❍	❍
h. Had bad dreams	❍	❍	❍	❍	❍
i. Heard noises	❍	❍	❍	❍	❍
j. Have pets	❍	❍	❍	❍	❍
k. Other reason(s); Please describe: _____	❍	❍	❍	❍	❍
l. **During the past week**, how often did you take medicine (prescribed or "over the counter") to help you sleep?	❍	❍	❍	❍	❍
m. **During the past week,** how often did you have trouble staying awake while eating meals, or engaging in social activity?	❍	❍	❍	❍	❍

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.

S10. During the past week, how much of a problem has it been for you to keep up enough enthusiasm to

get things done?

❍ No Problem ❍ Somewhat ❍ Don't know
❍ Very slight ❍ Very big

S11. During the past week, how would you rate your sleep quality overall?

❍ Very good ❍ Fairly bad
❍ Fairly good ❍ Very bad

S12. Does anyone sleep in the same room as you?

❍ Yes ❍ No

S13. Does anyone sleep in the same bed as you?

❍ Yes ❍ No

Next, we would like to know how likely you are to doze off or fall asleep if you were in the following situations. This is in contrast to feeling just tired. Even if you did not do some of these things recently, try to think how they would have affected you.

S14. During the past week, how likely were you to have dozed off while you were…	**Would never doze**	**Slight chance of dozing**	**Moderate chance of dozing**	**High chance of dozing**
a. Sitting and reading	❍	❍	❍	❍
b. Watching TV	❍	❍	❍	❍
c. Sitting, inactive in a public place (e.g., a theater or a meeting)	❍	❍	❍	❍
d. As a passenger in a car for an hour without a break	❍	❍	❍	❍
e. Lying down to rest in the afternoon when circumstances permit	❍	❍	❍	❍
f. Sitting and talking to someone	❍	❍	❍	❍
g. Sitting quietly after a lunch without alcohol	❍	❍	❍	❍
h. In a car driving, while stopped for a few minutes in traffic	❍	❍	❍	❍

SECTION 10: Emotional Health

10.1. 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	❍	❍	❍	❍	❍
I found it hard to focus on anything other than my anxiety	❍	❍	❍	❍	❍
My worries overwhelmed me	❍	❍	❍	❍	❍
I felt uneasy	❍	❍	❍	❍	❍
I felt worthless	❍	❍	❍	❍	❍
I felt helpless	❍	❍	❍	❍	❍
I felt depressed	❍	❍	❍	❍	❍
I felt hopeless	❍	❍	❍	❍	❍

10.2. 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

10.3. 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

10.4. 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 11: Social Needs

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

11.1. Was there a time in the **past 12 months** when you needed to see a doctor but could not because of cost?

❍ Yes ❍ No

11.2. In the **past 12 months** did you ever eat less than you felt you should because there wasn't enough money for food?

❍ Yes ❍ No

11.3. In the **past 12 months**, has your utility company shut off your service for not paying your bills?

❍ Yes ❍ No

11.4. Are you worried that in the **next 2 months** you may not have stable housing?

❍ Yes ❍ No

11.5. In the **past 12 months**, have you ever had to go without health care because you didn't have a way to get there?

❍ Yes ❍ No

11.6. Generally, do you feel safe in your neighborhood?

❍ Yes ❍ No

SECTION 12: Use of electronic and mobile technology

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

12.1. Do you own and/or have regular access to a desktop computer, laptop computer, tablet or smartphone?

❍ Yes ❍ No

12.2. 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 13: Household Information

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

13.1. 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

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

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

13.3. How long have you lived at your current address?

_____Years _____Months

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

SECTION 14: Wrap-up

14.1 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

14.2. Please provide your preferred contact information:

14.2.a Mailing address:

_____

14.2.b Phone number(s)

	Type				Okay to text?	
	Home	Cell	Work	Other	Yes	No
1._____	❍	❍	❍	❍	❍	❍
2._____	❍	❍	❍	❍	❍	❍

14.2.c Email Address:

_____

14.3. 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.

END SURVEY

WAYNE STATE
School of Medicine