LTFU | Long-Term Follow-Up Study

Help us improve treatment and care of patients and long-term survivors

The LTFU Study has helped improve the lives of patients and long-term survivors around the world. Your help makes this possible. For more than 25 years, survivors have shared their experiences through the LTFU survey.

Survey responses have helped doctors and scientists:

- Know more health problems caused by treatments
- Make changes in treatments to prevent health problems later in life
- Increase awareness about screening and prevention

Your responses will help change lives. Please complete this LTFU survey.

Start here!

Today's date:

☐☐ / ☐☐ / ☐☐☐☐

m m d d y y y y

The questions in this survey relate to:

Person completing this survey is:

Your relationship:

☐ Self ☐ Parent ☐ Other: _____

If you are completing the survey on the participant's behalf, be aware that all survey questions are about

Please! Do not mark below this line

Edit ☐ Survey #332 Code ☐ H 1423622279

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HEALTH CONDITIONS

A. Please indicate whether or not you have any of the following health conditions and the severity of the condition. If you have more than one condition in a category, pick the one that is **most severe**. Name the specific condition you are rating.

	No problem	Mild problem but I do not need medication	Moderate problem, I need daily medication	Severe problem, uncontrolled with medication, or requiring multiple medications	Very severe problem requiring immediate treatment or medical care or significantly limits my daily function
a. **Heart problem** - Examples: chest pain or angina, heart attack or myocardial infarction, abnormal heartbeat or arrhythmia, valve problems. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
b. **Vascular problem** - Examples: circulatory problems like peripheral artery disease, hypertension (high blood pressure), high cholesterol, vascular surgery/repair for arteries in neck or legs, abdominal aortic aneurysm. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
c. **Blood problem** - Examples: anemia, hypercoagulability (easy clotting), or any other blood problem that affects the spleen or lymphatic system. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
d. **Respiratory problem** - Examples: asthma, emphysema, bronchitis, pulmonary embolism (clot in lungs), lung surgery. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
e. **Eye, ears, nose, throat, larynx** - Examples: glaucoma, cataract, loss of vision, hearing loss, vertigo, dizziness, loss of smell, throat problems. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
f. **Stomach/digestion** - Examples: heartburn/reflux, swallowing problems. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
g. **Intestinal problems** - Examples: intestinal hernia, constipation, anal problems, incontinence, colon problems/surgery. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
h. **Liver and pancreas** - Examples: includes gall bladder problems/removal, impaired liver function or infection. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
i. **Kidney** - Examples: kidney infection, poor kidney function, kidney surgery. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
j. **Urinary** - Examples: stones, infection, incontinence, surgery for kidney stones. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
k. **Musculoskeletal** - Examples: arthritis, other joint problems, osteoporosis, carpal tunnel, fibromyalgia, skin problems. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
l. **Neurologic** - Examples: stroke, peripheral neuropathy, headache, cognitive decline. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
m. **Endocrine/metabolic** - Ex.: thyroid problem, obesity, diabetes, hormonal problem. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
n. **Psychiatric/behavioral** - Ex.: depression, anxiety, alcohol or drug abuse, eating disorder. Name of Most Severe Condition: _____	☐	☐	☐	☐	☐

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MEDICAL CARE

B1. During the PAST 2 YEARS, how many times did you see or talk to the following healthcare providers for medical care?

	None	1-2 times	3-4 times	5-10 times	11-20 times	More than 20 times
a. Primary care doctor in the community (e.g., family physician, general internist, pediatrician, nurse practitioner, physician's assistant)	☐	☐	☐	☐	☐	☐
b. Clinician at a cancer center (e.g., oncologist, nurse practitioner or physician's assistant, other cancer specialist)	☐	☐	☐	☐	☐	☐
c. Other medical specialist (e.g., endocrinologist, cardiologist, surgeon)	☐	☐	☐	☐	☐	☐
d. Psychiatrist	☐	☐	☐	☐	☐	☐
e. Psychologist or counselor	☐	☐	☐	☐	☐	☐
f. Physical or occupational therapist	☐	☐	☐	☐	☐	☐
g. Alternative health practitioner (e.g., acupuncturist, herbalist, chiropractor)	☐	☐	☐	☐	☐	☐
h. Other specify: _____	☐	☐	☐	☐	☐	☐
i. Other specify: _____	☐	☐	☐	☐	☐	☐

If you had any visits, how many of these visits were related to health problems from your cancer or cancer treatments?

	0 visits	1 - 2 visits	3 - 4 visits	5 - 6 visits	7 - 10 visits	11 - 20 visits	More than 20 visits
a. Primary care doctor in the community (e.g., family physician, general internist, pediatrician, nurse practitioner, physician's assistant)	☐	☐	☐	☐	☐	☐	☐
b. Clinician at a cancer center (e.g., oncologist, nurse practitioner or physician's assistant, other cancer specialist)	☐	☐	☐	☐	☐	☐	☐
c. Other medical specialist (e.g., endocrinologist, cardiologist, surgeon)	☐	☐	☐	☐	☐	☐	☐
d. Psychiatrist	☐	☐	☐	☐	☐	☐	☐
e. Psychologist or counselor	☐	☐	☐	☐	☐	☐	☐
f. Physical or occupational therapist	☐	☐	☐	☐	☐	☐	☐
g. Alternative health practitioner (e.g., acupuncturist, herbalist, chiropractor)	☐	☐	☐	☐	☐	☐	☐
h. Other specify: _____	☐	☐	☐	☐	☐	☐	☐
i. Other specify: _____	☐	☐	☐	☐	☐	☐	☐

B2. When was the LAST TIME you saw a healthcare provider (e.g., doctor, nurse practitioner, physician's assistant) in each of the following locations where the provider asked you questions or examined you to see whether you had any health problems from your cancer or your cancer treatment?

	Less than 1 year ago	1-2 years ago	More than 2 but less than 5 years ago	5 or more years ago	Never
a. At a cancer survivor clinic	☐	☐	☐	☐	☐
b. At a cancer center, but not in a cancer survivor clinic	☐	☐	☐	☐	☐
c. At my primary care doctor's office	☐	☐	☐	☐	☐
d. Other specify: _____	☐	☐	☐	☐	☐
e. Other specify: _____	☐	☐	☐	☐	☐

B3. At your LAST check-up at each of the places in the previous question, did your healthcare provider give you advice about what to do to reduce your risks arising from your cancer or cancer therapy?

	Yes	No	Not sure	Never had a check-up there
a. At a cancer survivor clinic	☐	☐	☐	☐
b. At a cancer center, but not in a cancer survivor clinic	☐	☐	☐	☐
c. At my primary care doctor's office	☐	☐	☐	☐
d. Other specify: _____	☐	☐	☐	☐
e. Other specify: _____	☐	☐	☐	☐

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B4. Do you currently have a cancer survivorship care plan and/or a summary of treatment for your cancer (records from your cancer doctor that have details about your cancer treatment and medical tests you should have to check for future health problems)?

- ☐ No
- ☐ Yes
- ☐ Not sure

B5. Does your primary care doctor have a copy of your cancer survivorship care plan and/or a summary of your treatment for your cancer?

- ☐ I do not have a primary care doctor
- ☐ I have a primary care doctor but he/she does not have a copy of my cancer survivorship care plan and/or a summary of my treatment for my cancer
- ☐ Yes
- ☐ Not sure

B6. Have you been to an Emergency Room (ER) in the last 2 years?

- ☐ No → **Go to Question B8, below.**
- ☐ Yes

B7. How many times have you been to the ER in the last 2 years?

☐☐

B8. In the last 2 years, have you been hospitalized for physical or mental illness, procedures, or short stays of 24 hours or less? Do not include pregnancy or ER visits.

- ☐ No → **Go to Section C, below.**
- ☐ Yes

B9. How many times have you been admitted to a hospital in the last 2 years?

☐☐

MEDICAL TESTS

C. The following questions are about medical screening tests you may have received.

When was the last time you had . . .

	Never	Less than 1 year ago	1-2 years ago	More than 2 years but less than 5 years ago	5 or more years ago	I had one, but I don't recall when	I don't know if I ever had one
a. An echocardiogram (ultrasound of the heart to look at the heart muscle and heart valves) or a cardiac MRI?	☐	☐	☐	☐	☐	☐	☐
b. Sigmoidoscopy or colonoscopy to view the colon for signs of cancer or other problems?	☐	☐	☐	☐	☐	☐	☐
c. DNA stool testing for colon cancer (such as Cologuard)?	☐	☐	☐	☐	☐	☐	☐
d. A skin exam for skin cancer performed by a healthcare provider?	☐	☐	☐	☐	☐	☐	☐
For females							
e. A mammogram?	☐	☐	☐	☐	☐	☐	☐
f. A breast ultrasound?	☐	☐	☐	☐	☐	☐	☐
g. A breast MRI?	☐	☐	☐	☐	☐	☐	☐
h. A pap smear and/or cervical HPV test?	☐	☐	☐	☐	☐	☐	☐
For males							
i. A PSA or blood test to detect prostate cancer?	☐	☐	☐	☐	☐	☐	☐

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Needs Assessment for Childhood Cancer Survivors

To help better plan services for people who have survived childhood cancer, we are interested in whether or not your needs, which you may have faced as a result of being diagnosed with and treated for cancer, have been met. You will be presented with a list of possible needs, and there are two columns in this Needs Assessment. Please read the below instructions before starting.

In **Column 1**, indicate whether you have ever needed help with this issue as a result of having cancer. Mark the response that best describes whether or not you have needed help with this matter.

There are 5 possible choices:

NO UNMET NEED

No Need Existed - This was not a problem for me as a result of having cancer.
Need was Satisfied - I did need help with this, but I found resources to meet the need.
(Note: If "No need existed" or "Need was satisfied" is selected, leave Column 2 blank.)

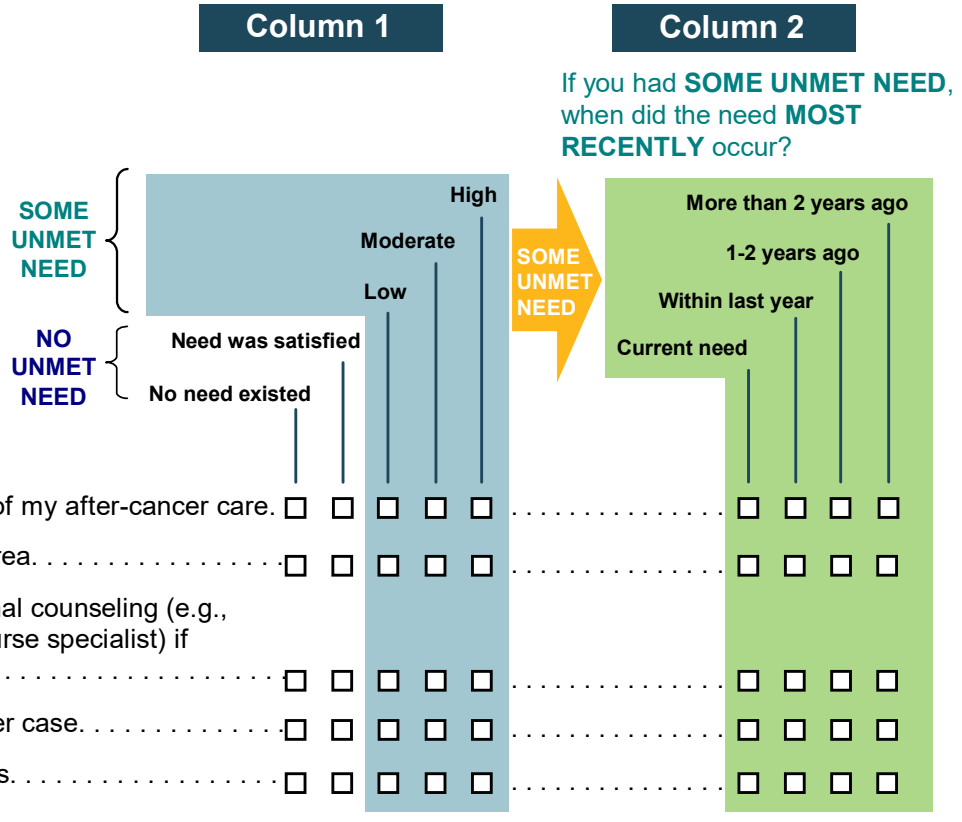
SOME UNMET NEED

Low need for help - This item caused me little concern or discomfort. I had little need for additional help.
Moderate need for help - This item caused me some concern or discomfort. I had some need for help.
High need for help - This item caused me a lot of concern or discomfort. I had a strong need for additional help.
(Note: If "Low need for help", "Moderate need for help", or "High need for help" is selected, check one of the boxes in Column 2.

In **Column 2**, if you had **SOME UNMET NEED**, mark the response to indicate when you MOST RECENTLY experienced this need.

There are 4 possible choices:
Current need
Within last year
1-2 years ago
More than 2 years ago

D. Mark the response that best describes whether or not you needed help with this matter.



I needed:

Health Care Concerns

1. Information about the important aspects of my after-cancer care. . . . . ☐ ☐ ☐ ☐ ☐ . . . . . ☐ ☐ ☐ ☐
2. Information about support groups in my area. . . . . ☐ ☐ ☐ ☐ ☐ . . . . . ☐ ☐ ☐ ☐
3. Help finding out how to access professional counseling (e.g., psychologist, social worker, counselor, nurse specialist) if I/family/friends need it. . . . . ☐ ☐ ☐ ☐ ☐ . . . . . ☐ ☐ ☐ ☐
4. To be treated like a person not just another case. . . . . ☐ ☐ ☐ ☐ ☐ . . . . . ☐ ☐ ☐ ☐
5. Choices about when to go in for check-ups. . . . . ☐ ☐ ☐ ☐ ☐ . . . . . ☐ ☐ ☐ ☐

Please! Do not mark below this line

Mark the response that best describes whether or not you needed help with this matter.

Column 1

Column 2

If you had **SOME UNMET NEED**, when did the need **MOST RECENTLY** occur?

SOME UNMET NEED

NO UNMET NEED

I needed:

	Column 1: NO UNMET NEED		Column 1: SOME UNMET NEED			Column 2: SOME UNMET NEED			
	No need existed	Need was satisfied	Low	Moderate	High	Current need	Within last year	1-2 years ago	More than 2 years ago
6. One health care provider with whom I could talk about my health.	☐	☐	☐	☐	☐	☐	☐	☐	☐
7. My doctors to talk to each other to coordinate my care.	☐	☐	☐	☐	☐	☐	☐	☐	☐
8. Help to know how to give input to my medical team in order to manage my health.	☐	☐	☐	☐	☐	☐	☐	☐	☐
9. My complaints about my care heard and addressed.	☐	☐	☐	☐	☐	☐	☐	☐	☐
10. Information about who to call for help.	☐	☐	☐	☐	☐	☐	☐	☐	☐
Cancer-related Health Information									
11. Information about cancer recurrence.	☐	☐	☐	☐	☐	☐	☐	☐	☐
12. Information about how cancer affected my body.	☐	☐	☐	☐	☐	☐	☐	☐	☐
13. Information about what causes cancer.	☐	☐	☐	☐	☐	☐	☐	☐	☐
14. Information about the late effects of my cancer therapy.	☐	☐	☐	☐	☐	☐	☐	☐	☐
15. Information about what symptoms to report to the doctor or nurse.	☐	☐	☐	☐	☐	☐	☐	☐	☐
16. Information about specific diseases that can result from cancer therapy.	☐	☐	☐	☐	☐	☐	☐	☐	☐
17. Information about what I can do to reduce my chances of developing late effects.	☐	☐	☐	☐	☐	☐	☐	☐	☐
18. Information about my treatments or medications.	☐	☐	☐	☐	☐	☐	☐	☐	☐
19. Information about my test results as soon as possible.	☐	☐	☐	☐	☐	☐	☐	☐	☐
20. Information about which organ systems may have been affected by my cancer treatment.	☐	☐	☐	☐	☐	☐	☐	☐	☐
21. Information about how cancer will affect my life.	☐	☐	☐	☐	☐	☐	☐	☐	☐
Survivor Care and Support									
22. Reassurance by medical staff that the way I feel is normal.	☐	☐	☐	☐	☐	☐	☐	☐	☐
23. Health care providers to acknowledge and show sensitivity to my feelings and emotional needs.	☐	☐	☐	☐	☐	☐	☐	☐	☐
24. To be able to see the specialists I need/want to see.	☐	☐	☐	☐	☐	☐	☐	☐	☐
25. To secure more timely clinic appointments.	☐	☐	☐	☐	☐	☐	☐	☐	☐
26. Someone to respond to my requests for medical help.	☐	☐	☐	☐	☐	☐	☐	☐	☐
27. More say in decisions about my medical treatment.	☐	☐	☐	☐	☐	☐	☐	☐	☐

Please! Do not mark below this line

Mark the response that best describes whether or not you needed help with this matter.

Column 1

Column 2

If you had **SOME UNMET NEED**, when did the need **MOST RECENTLY** occur?

SOME UNMET NEED

NO UNMET NEED

I needed:

	Need was satisfied	No need existed	Column 1: Low	Column 1: Moderate	Column 1: High	Column 2: Current need	Column 2: Within last year	Column 2: 1-2 years ago	Column 2: More than 2 years ago
28. To know that the medical staff is being honest.	☐	☐	☐	☐	☐	☐	☐	☐	☐
29. To know who to call if I have questions.	☐	☐	☐	☐	☐	☐	☐	☐	☐
30. To know how to ask my physician to provide me with choices/options.	☐	☐	☐	☐	☐	☐	☐	☐	☐
31. To have my physician understand my points of view.	☐	☐	☐	☐	☐	☐	☐	☐	☐
32. My physician to have more confidence in my ability to make changes that are good for my health.	☐	☐	☐	☐	☐	☐	☐	☐	☐
33. My physician to be more accepting of me.	☐	☐	☐	☐	☐	☐	☐	☐	☐
34. My physician to help me understand how to reduce my late effects risks.	☐	☐	☐	☐	☐	☐	☐	☐	☐
35. My physician to encourage me to ask questions.	☐	☐	☐	☐	☐	☐	☐	☐	☐
36. To have more trust in my physician.	☐	☐	☐	☐	☐	☐	☐	☐	☐
37. My physician to answer my questions fully and carefully.	☐	☐	☐	☐	☐	☐	☐	☐	☐
38. My physician to listen to how I would like to do things.	☐	☐	☐	☐	☐	☐	☐	☐	☐
39. My physician to care about me as a person.	☐	☐	☐	☐	☐	☐	☐	☐	☐
40. My physician to understand how I see things before suggesting a new way to do things.	☐	☐	☐	☐	☐	☐	☐	☐	☐
41. To share my feelings with my physician.	☐	☐	☐	☐	☐	☐	☐	☐	☐
Surveillance									
42. Information about what screening tests I need based on my treatment history.	☐	☐	☐	☐	☐	☐	☐	☐	☐
43. Information about how I will feel during screening tests (e.g., bone scans, echo).	☐	☐	☐	☐	☐	☐	☐	☐	☐
44. Information on how to prepare for screening tests.	☐	☐	☐	☐	☐	☐	☐	☐	☐
45. Information about how I will feel after screening tests.	☐	☐	☐	☐	☐	☐	☐	☐	☐
46. Information about how screening tests are performed.	☐	☐	☐	☐	☐	☐	☐	☐	☐
47. Information about why screening tests need to be performed.	☐	☐	☐	☐	☐	☐	☐	☐	☐
48. Information about which tests will help detect late effects of treatment.	☐	☐	☐	☐	☐	☐	☐	☐	☐
49. Help with responsibilities so that I can participate in the recommended health screenings.	☐	☐	☐	☐	☐	☐	☐	☐	☐
50. Realistic information about how much time screening tests will take.	☐	☐	☐	☐	☐	☐	☐	☐	☐

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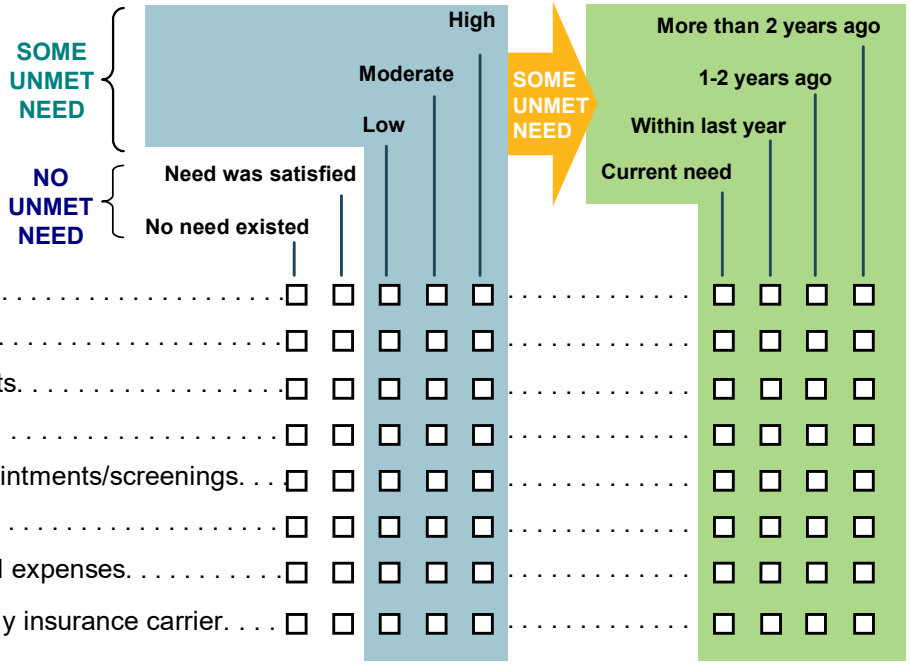
Mark the response that best describes whether or not you needed help with this matter.

I needed:



Financial Concerns

51. Help paying for prescription medications. . . . . ☐ ☐ ☐ ☐ ☐ . . . . . ☐ ☐ ☐ ☐
52. Help paying for medical treatments. . . . . ☐ ☐ ☐ ☐ ☐ . . . . . ☐ ☐ ☐ ☐
53. Help paying for physician or hospital costs. . . . . ☐ ☐ ☐ ☐ ☐ . . . . . ☐ ☐ ☐ ☐
54. Help paying for medical screenings. . . . . ☐ ☐ ☐ ☐ ☐ . . . . . ☐ ☐ ☐ ☐
55. Transportation to and from medical appointments/screenings. . . ☐ ☐ ☐ ☐ ☐ . . . . . ☐ ☐ ☐ ☐
56. Insurance coverage for my medications. . . . . ☐ ☐ ☐ ☐ ☐ . . . . . ☐ ☐ ☐ ☐
57. Insurance coverage for my other medical expenses. . . . . ☐ ☐ ☐ ☐ ☐ . . . . . ☐ ☐ ☐ ☐
58. Help with payments for care denied by my insurance carrier. . . . ☐ ☐ ☐ ☐ ☐ . . . . . ☐ ☐ ☐ ☐

In the future, we would like to send a questionnaire to one of your close family members or friends who could answer some basic questions about any problems you may be having. Sometimes, our family sees some of our struggles before we do. The questions would be very brief, asking about sleep, social activities, physical function, and emotional stress in your life. This person could be a family member, roommate, or anyone else who is familiar with your daily life.

1. Is there someone who could answer these questions about you?

☐ Yes

☐ No → **Continue on next page.**

2. What is this person's relationship to you?

☐ Spouse or Partner ☐ Sibling (brother/sister)

☐ Parent ☐ Friend

☐ In-Law ☐ Other

☐ Child

Specify

3. Please list their name, address, phone number, and preferred email address:

Name: _____

Address: _____

_____

_____

Phone number: _____

Email address: _____

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