

**Introduction**

This more detailed assessment was created for us to better understand your needs as a caregiver. Your responses will assist us in being able to serve you directly, as well as informing how we design and assess the effectiveness of our programs. We hope that this survey will also provide you with a comprehensive picture of your own caregiving journey. It will take 20-25 minutes to complete.

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**Caregiver Identity**

1. How long has it been since you began doing things for your loved one that they were no longer able to do for themselves?

0-1 years	1-2 years	2-3 years	3-5 years	5-10 years	10+ years

2. How fully do you identify with the term "caregiver"?

1. Not at all	2. A little bit	3. Moderately	4. Quite a bit	5. Extremely

3. Is there another term you relate to better?

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**Caregiver Visibility**

4. Do you feel acknowledged and seen as a caregiver by your...

	1. Not at all	2. A little bit	3. Moderately	4. Quite a bit	5. Extremely
Loved one					
Family Members					
Health Care System					
Support Services					
Friends					

**Caregiving Situation**

5. How many hours do you spend as a caregiver or partner caring for your loved one?

None	Occasional	1-5	5-10	10-20	20-30	30-40	Fulltime	40+	24hrs

6. I am related to the person I care for by Marriage or as their Significant Other

- Yes
- No

7. If not, I am...

Son	Daughter	Sister	Brother	Daughter- in-law	Son-in- law	Grandchild	Mother	Father	Friend

8. Do you live in the same house as the person you care for?

- Yes
- No

9. Questions regarding mobility:

- Is your loved on able to walk independently?
- Do they need some support?
- Can they only stand with support?
- Are they completely bed or wheelchair-bound?

10. Can you leave your home without requiring respite services?

- Yes
- No
- Sometimes

11. Is my loved one's illness progressive?

- Yes
- No
- Uncertain

12. If NO, can you estimate how much they have recovered since the onset of aphasia.

0-5 %	5-10%	10-20%	20-40%	50% or more

13. Has your loved one experienced significant...

- |   |  |
|---|--|
| <input type="checkbox"/> Changes in behavior<br><input type="checkbox"/> Depression<br><input type="checkbox"/> Confusion<br><input type="checkbox"/> Anger<br><input type="checkbox"/> Frustration | <input type="checkbox"/> Mood swings<br><input type="checkbox"/> Paranoia<br><input type="checkbox"/> Violent or aggressive tendencies<br><input type="checkbox"/> Cognitive loss (mental deterioration) |
|---|--|

14. Would you say their personality has changed?

- Yes
- No
- Uncertain

15. ADL / IADL Activity Does your loved one have difficulty with this activity?  
(Difficulty includes "needs some help" as well as  
"completely unable to do" )

	Yes	No
Eating (feeding)		
Dressing and undressing		
Personal Grooming		
Walking		
Getting out of bed		
Bathing or showering		
Toilet		
Using telephone		
Driving or public transit		
Shopping		
Preparing meals		
Housework		
Taking medication		
Handling money		

**Caregiver Health & Self-Care**

16. Do you have physical health problems that may be a result of caregiving?

1. Not at all      2. A little bit      3. Moderately      4. Quite a bit      5. Extremely

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17. Do you feel your mental health has suffered as a result of caregiving?

1. Not at all      2. A little bit      3. Moderately      4. Quite a bit      5. Extremely

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18. Do you feel stronger and more resilient as a result of caregiving?

1. Not at all      2. A little bit      3. Moderately      4. Quite a bit      5. Extremely

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19. Do you feel there is significant spiritual value for you in caregiving?

1. Not at all      2. A little bit      3. Moderately      4. Quite a bit      5. Extremely

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20. How would you rate your level of satisfaction in your role as caregiver? (10 being the highest)

1      2      3      4      5      6      7      8      9      10

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21. Do you feel the negative factors in caregiving outweigh the positive factors?

1. Not at all      2. A little bit      3. Moderately      4. Quite a bit      5. Extremely

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22. How often to you feel the following:

	All the time	Much of the time	Some of the time	A little of the time	None of the time
Anger					
Frustration					
Resentment					
Disappointment					
Joy					
Connection					
Appreciation					
Gratitude					

Fulfillment					
Meaning					
Purpose					
Satisfaction					
Belonging					
Love					

23. How do you self-identify with the following terms?

1. Not at all    2. A little bit    3. Moderately    4. Quite a bit    5. Extremely

Crisis					
Coping					
Burnout					
Adapting					
Setbacks					
Empathy					
Learning					
Growing					
Thriving					
Advocating					
Emotional Care					

24. Are you concerned that you might die or become incapacitated while your loved one still needs you?

1. Not at all    2. A little bit    3. Moderately    4. Quite a bit    5. Extremely

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**Financial Costs of Caregiving**

25. Estimate your monthly out-of-pocket expenses in caring for your relative?

- N/A
- \$0-\$100
- \$100-\$500
- \$500-\$1000
- \$1000-\$5000

\$5000-\$10,000

\$10,000+

26. Is your family contributing to any out-of- pocket expenses?

1. Not at all      2. A little bit      3. Moderately      4. Quite a bit      5. Extremely

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27. Are you concerned about your financial future?

1. Not at all      2. A little bit      3. Moderately      4. Quite a bit      5. Extremely

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28. By what percentage has your work capacity been reduced by caregiving?

0-10%      10-20%      20-30%      30-40%      40-50%      50+%      N/A

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### Learning & Skill Development

29. In what areas do you feel you need more knowledge or skills?

- Aphasia communications techniques
- Self-Care
- Advocating for Yourself
- Advocating for your Loved one
- Financial Management
- Availability of support services and local resources
- Planned local outings and activities that are aphasia-friendly
- Conflict resolution
- Family Dynamics
- Meditation and Mindfulness
- Stress reduction
- Gratitude Exercises
- Process of Grieving

30. Do you feel supported to continue to grow your skills and abilities while being a caregiver or do you feel like you are losing those skills and abilities?

1. Not at all	2. A little bit	3. Moderately	4. Quite a bit	5. Extremely

31. What do you consider to be your main skills and abilities?

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1.

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2.

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3.

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4.

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5.

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32. How resilient do you consider yourself to be?

1. Not at all	2. A little bit	3. Moderately	4. Quite a bit	5. Extremely

33. Are you interested in becoming more resilient?

- Yes
- No
- Maybe

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### Support & Teamwork

34. **Do you** have a caregiving team to support you?

- Yes
- No

35. If yes, that team includes:

- Relatives
- Friends
- Faith Community
- PSW's (Gov Funded)
- PSW (Self-Funded)
- Companion Care

36. If yes to relatives, how supportive are they?

1. Not at all    2. A little bit    3. Moderately    4. Quite a bit    5. Extremely

Brother					
Sister					
Mother					
Father					
Daughter					
Son					
Sister-in-law					
Brother-in-law					
Other: _____					

37. Do you feel disappointed at the level of support you have received as a caregiver from your...

1. Not at all    2. A little bit    3. Moderately    4. Quite a bit    5. Extremely

Loved one					
Family Members					
Health Care System					
Support Services					
Friends					

38. How much do you agree with the following statements?

I would rather ask my family or friends for help than use community services.

1. Not at all    2. A little bit    3. Moderately    4. Quite a bit    5. Extremely

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39. I am proud of being able to care for my relative with little help from community services.

1. Not at all    2. A little bit    3. Moderately    4. Quite a bit    5. Extremely

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40. I believe in the idea that families should care for their own and not ask for outside help.



1. Not at all      2. A little bit      3. Moderately      4. Quite a bit      5. Extremely

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41. I wish there were someone who could tell me more about community services for my relative

- Yes
- No

42. I do not have time or energy to look for community services for my relative

- Yes
- No

43. Do you have a Caregiving Plan that you update and operate from?

- Yes
- No
- Uncertain

44. Do you have a designated back up person to support you?

- Yes
- No

45. Do you have a community that supports your journey as a caregiver?

- Yes

Please name that community\_\_\_\_\_

- No

46. Do you feel supported by a faith or spiritual community?

- Yes
- No
- Not Applicable

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### Communication, Story Sharing & Advocacy

47. How well do you feel you know your story as a caregiver?

1. Not at all      2. A little bit      3. Moderately      4. Quite a bit      5. Extremely

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48. Do you relate to caregiving as a journey?

1. Not at all

2. A little bit

3. Moderately

4. Quite a bit

5. Extremely

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49. Do you share your story as a caregiver with others?

Yes

No

50. If yes, how?

Social Media

Support Circles

Family Gatherings

To Friends

In a faith community

In another setting \_\_\_\_\_?

51. Do you gain satisfaction, insight, or inspiration from sharing your story?

Yes

No

Uncertain

52. Do you gain satisfaction, insight, or inspiration from hearing other's caregiving stories?

Yes

No

Uncertain

53. Do you experience a sense of connection by sharing and listening to caregiving stories?

Yes

No

Uncertain

54. How do you prefer to express yourself?

- |   |   |
|---|---|
| <input type="checkbox"/> Through the written word | <input type="checkbox"/> Images and Photographs   |
| <input type="checkbox"/> Through the spoken word  | <input type="checkbox"/> Through Movement         |
| <input type="checkbox"/> Poetry                   | <input type="checkbox"/> Through Acts of Kindness |
| <input type="checkbox"/> Painting or Drawing      | <input type="checkbox"/> All of the above         |

55. Has your relationship suffered due to communication loss?

Very significantly	Significantly	Moderately	Somewhat	Not at all	n/a

56. Has your communication become more superficial?

Very significantly	Significantly	Moderately	Somewhat	Not at all	n/a

57. Do you consider yourself to be a caregiver advocate?

1. Not at all	2. A little bit	3. Moderately	4. Quite a bit	5. Extremely

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### Love & Belonging

58. To what extent do you believe your loved one considers themselves to be a burden?

1. Not at all	2. A little bit	3. Moderately	4. Quite a bit	5. Extremely

59. Do you communicate at the emotional level?

Very significantly	Significantly	Moderately	Somewhat	Not at all	n/a

60. Do you feel connected and communicate at a spiritual level?

Very significantly	Significantly	Moderately	Somewhat	Not at all	n/a

61. Do you resolve problems together?

Very significantly	Significantly	Moderately	Somewhat	Not at all	n/a

62. Do you share personal opinions and beliefs?

Very significantly	Significantly	Moderately	Somewhat	Not at all	n/a

63. Do you share feelings and experiences?

Very significantly	Significantly	Moderately	Somewhat	Not at all	n/a

64. Do you share emotional needs and desires?

Very significantly	Significantly	Moderately	Somewhat	Not at all	n/a

65. Do you share hopes and dreams?

Very significantly	Significantly	Moderately	Somewhat	Not at all	n/a

66. Are you able to share your fears and uncertainties?

Very significantly	Significantly	Moderately	Somewhat	Not at all	n/a

67. Are you both willing to be vulnerable together?

Very significantly	Significantly	Moderately	Somewhat	Not at all	n/a

68. Do you consider yourself to be a caregiver advocate?

1. Not at all	2. A little bit	3. Moderately	4. Quite a bit	5. Extremely

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### Post Caregiving Transition

69. Do you have a Post-Caregiving or Transitional Plan?

- Yes
- No
- Partially

70. Will you be reentering the workforce?

I need to	Very Likely	Possibly	Unlikely	No	N/ A

71. Post-Caregiving, do you fear being socially isolated?

1. Not at all	2. A little bit	3. Moderately	4. Quite a bit	5. Extremely

72. Do you feel optimistic about your future?

1. Not at all	2. A little bit	3. Moderately	4. Quite a bit	5. Extremely