**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.

**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 |
|  |  |  |  |  |  |

1. 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 |
|  |  |  |  |  |

1. Is there another term you relate to better?

**\_ \_ \_ \_ \_ \_ \_ \_ \_ \_ \_ \_ \_ \_ \_ \_ \_ \_ \_ \_ \_ \_ \_ \_ \_ \_**

**Caregiver Visibility**

1. 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**

1. 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 |
|  |  |  |  |  |  |  |  |  |  |

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

* Yes
* No

1. If not, I am…

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

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

* Yes
* No

1. 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?

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

* Yes
* No
* Sometimes

1. Is my loved one’s illness progressive?

* Yes
* No
* Uncertain

1. 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 |
|  |  |  |  |  |

1. Has your loved one experienced significant…

* Changes in behavior
* Depression
* Confusion
* Anger
* Frustration
* Mood swings
* Paranoia
* Violent or aggressive tendencies
* Cognitive loss (mental deterioration)

1. Would you say their personality has changed?

* Yes
* No
* Uncertain

|  |  |  |
| --- | --- | --- |
| 1. 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**

1. 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 |
|  |  |  |  |  |

1. 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 |
|  |  |  |  |  |

1. 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 |
|  |  |  |  |  |

1. 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 |
|  |  |  |  |  |

1. 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 |
|  |  |  |  |  |  |  |  |  |  |

1. 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 |
|  |  |  |  |  |

1. 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 |  |  |  |  |  |

1. 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 |  |  |  |  |  |

1. 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 |
|  |  |  |  |  |

**Financial Costs of Caregiving**

1. 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+

1. 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 |
|  |  |  |  |  |

1. Are you concerned about your financial future?

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

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

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

**Learning & Skill Development**

1. 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

1. 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 |
|  |  |  |  |  |

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

1.

2.

3.

4.

5.

1. How resilient do you consider yourself to be?

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

1. Are you interested in becoming more resilient?

* Yes
* No
* Maybe

**Support & Teamwork**

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

* Yes
* No

1. If yes, that team includes:

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

1. 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:  \_\_\_\_\_\_\_\_\_\_\_\_ |  |  |  |  |  |

1. 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 |  |  |  | |  |  |

1. 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 |
|  |  |  |  |  |

1. 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 |
|  |  |  |  |  |

1. 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 |
|  |  |  |  |  |

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

* Yes
* No

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

* Yes
* No

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

* Yes
* No
* Uncertain

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

* Yes
* No

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

* Yes

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

* No

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

* Yes
* No
* Not Applicable

**Communication, Story Sharing & Advocacy**

1. 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 |
|  |  |  |  |  |

1. Do you relate to caregiving as a journey?

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

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

* Yes
* No

1. If yes, how?

* Social Media
* Support Circles
* Family Gatherings
* To Friends
* In a faith community
* In another setting\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_?

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

* Yes
* No
* Uncertain

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

* Yes
* No
* Uncertain

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

* Yes
* No
* Uncertain

1. How do you prefer to express yourself?

* Through the written word
* Through the spoken word
* Poetry
* Painting or Drawing
* Images and Photographs
* Through Movement
* Through Acts of Kindness
* All of the above

1. Has your relationship suffered due to communication loss?

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Very significantly | Significantly | Moderately | Somewhat | Not at all | n/a |
|  |  |  |  |  |  |

1. Has your communication become more superficial?

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Very significantly | Significantly | Moderately | Somewhat | Not at all | n/a |
|  |  |  |  |  |  |

1. 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 |
|  |  |  |  |  |

**Love & Belonging**

1. 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 |
|  |  |  |  |  |

1. Do you communicate at the emotional level?

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Very significantly | Significantly | Moderately | Somewhat | Not at all | n/a |
|  |  |  |  |  |  |

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

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Very significantly | Significantly | Moderately | Somewhat | Not at all | n/a |
|  |  |  |  |  |  |

1. Do you resolve problems together?

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Very significantly | Significantly | Moderately | Somewhat | Not at all | n/a |
|  |  |  |  |  |  |

1. Do you share personal opinions and beliefs?

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Very significantly | Significantly | Moderately | Somewhat | Not at all | n/a |
|  |  |  |  |  |  |

1. Do you share feelings and experiences?

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Very significantly | Significantly | Moderately | Somewhat | Not at all | n/a |
|  |  |  |  |  |  |

1. Do you share emotional needs and desires?

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Very significantly | Significantly | Moderately | Somewhat | Not at all | n/a |
|  |  |  |  |  |  |

1. Do you share hopes and dreams?

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Very significantly | Significantly | Moderately | Somewhat | Not at all | n/a |
|  |  |  |  |  |  |

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

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Very significantly | Significantly | Moderately | Somewhat | Not at all | n/a |
|  |  |  |  |  |  |

1. Are you both willing to be vulnerable together?

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Very significantly | Significantly | Moderately | Somewhat | Not at all | n/a |
|  |  |  |  |  |  |

1. 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 |
|  |  |  |  |  |

**Post Caregiving Transition**

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

* Yes
* No
* Partially

1. Will you be reentering the workforce?

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| I need to | Very Likely | Possibly | Unlikely | No | N/ A |
|  |  |  |  |  |  |

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

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

1. Do you feel optimistic about your future?

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