

Penn State ALS Clinic Caregiver Assessment - Initial V.8.19.2010

1. Welcome

Welcome to the Hershey ALS Clinic Caregiver Assessment. We want to get to know you so that we can provide you with the support that you need. Please take some time to complete the caregiver assessment. This will be reviewed with you in confidence at your upcoming ALS clinic appointment. We will ask you to complete this assessment approximately every 3 months.

Thank you very much!

The ALS Clinic Team

Date

Date of your
upcoming ALS Clinic
appointment:

MM DD YYYY

/ /

Please provide us with your contact information.

Your Name:

Name of ALS Patient:

Email Address:

Phone Number:

Please tell us your age in years.

Age

Gender

Male

Female

Ethnicity

Caucasian - Not Hispanic

African American

Hispanic

Asian

Prefer not to answer

Other (please specify)

What is your relationship to the patient with ALS?

- Spouse
- Significant other
- Sibling
- Parent
- Child
- Friend

Other (please specify)

What is your living arrangement in relation to the patient with ALS?

- I live with them
- I live somewhere else

Other (please specify)

What is your employment status?

- Full-time employment
- Part-time employment
- Retired
- On Disability

Other (please specify)

Quality of Life

Very bad

Excellent

Considering all parts of my life - physical, emotional, social, spiritual, and financial - over the past week, the quality of my life has been:

2. Caregiving Tasks

Please tell us about your level of concern (e.g., worry, anxiety, unease) with providing the care activities listed below.

If you do not provide the care activity, please record this by marking "I do not provide this activity" on the far right of the response options.

	1 Low Concern	2	3	4	5 High Concern	I do not provide this activity
Feeding	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bathing/Grooming	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dressing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Help with communicating	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Help with toileting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mobility (help with transfers, walking, steps, body positioning, etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Exercises to improve strength, maintain range of motion, including stretching	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assistance with medication (administrating medications and/or management of medications)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Help with equipment and devices	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Offer emotional support and/or spiritual support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Encourage loved one to participate in different activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Encourage prevention of injuries or accidents	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Coordinating care with other family members/friends/professional caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Work with health insurance and available programs (i.e., OVR, VA)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Meal preparation/Housekeeping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Shopping/community involvement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Financial management	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please describe other activities that you do.

Caregiving Hours

How many hours per day are you the actual caregiver to the person with ALS?

Help in the home

	Yes	No
Would additional help in the home be useful for you?	<input type="radio"/>	<input type="radio"/>

3. Caregiver Supports

What activities do you engage in that are supportive to you? Please check all that apply.

- Exercise
- Prayer ,meditation, or connecting with a community of faith
- Socializing with friends and family
- Art/music
- Spending time with animals
- Journaling
- Reading
- Hobby
- Working
- Volunteering
- Attending educational sessions about ALS
- Counseling
- Support Group
- None
- I do not know what support I need.

Other, please specify.

What activities are you no longer doing that you enjoyed previously?

What is preventing you from participating in supportive activities?



4. Caregiver Health and Well-Being

Are you being followed by a family doctor?

Yes

No

Does your family doctor know that you are a primary caregiver?

Yes

No

Health Assessment

	1 Very healthy	2	3	4	5	6	7	8	9	10 Very ill
On a scale of 1 to 10 with 1 being "very healthy" to 10 being "very ill", please rate your current health compared to what it was this time last year.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Stress Assessment

	1 Not Stressful	2	3	4	5	6	7	8	9	10 Extremely Stressful
On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful", please rate how stressful your life is.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Over the past two weeks, I have felt down, depressed, or hopeless

True

False

If true, have you felt this way for:

several days

more than 1/2 the days

nearly every day

Over the past two weeks, I have felt little interest or pleasure in doing things

True

False

If true, have you felt this way for

several days

more than 1/2 the days

nearly every day

5. Caregiver Confidence

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1 Very Low 2 3 Moderate 4 5 Very High

What is your perception of your ability to do what needs to be done?	jñ	jñ	jñ	jñ	jñ
What is your level of comfort with your problem solving ability?	jñ	jñ	jñ	jñ	jñ

What qualities and personal strengths do you bring to your caring role?

5

6

What is the most rewarding thing for you about caring for your loved one?

5

6

What are your primary concerns about caregiving?

5

6

Is there anything else that you would like to share with us?

5

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