



PATIENT CAREGIVER FORM

ALS PATIENT CARE DATABASE



This survey asks for your views about how caring for the patient has affected your life. Answer each question by shading the appropriate circle. This is not a test. There are no right or wrong answers. If you are unsure how to answer any question, please give the best answer you can.

Please use a blue or black pen to complete the survey.

Please print neatly within the boxes as shown:

1	2	3	4	5	6	7	8	9	0
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Please shade circles completely as shown:

Correct: ● Incorrect: ⊗ ⊕

These questions should be filled out by the doctor or clinic staff

1. Patient ID

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2. Clinic/Site ID

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3. Physician ID

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4. Is this the first time the caregiver has filled out this form?

Yes No

5. Today's date (month/day/year)

		/			/	2	0	0	
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These questions should be filled out by the primary caregiver.

6. Your date of birth (month/day/year)

		/			/				
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6a. Your initials

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7. What is your relationship to the patient?

Spouse Father/mother Other (specify)
 Son/daughter Other relative _____

8. Are you:

Male Female

9. Does the patient require assistance with activities of daily living?

Yes No

10. Who provides assistance with activities of daily living?

Myself Paid attendant Other (specify) _____

11. In general, would you say your health is:

Excellent Good Poor
 Very good Fair

12. Compared to 3 months ago, how would you rate your health now?

Much better About the same Much worse
 Somewhat better Somewhat worse

13. During the past 4 weeks, to what extent has your physical health or any emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

Not at all Moderately Extremely
 Slightly Quite a bit

14. Are you currently employed outside the home?

Work full time Work in the home only Retired
 Work part-time Do volunteer work

15. Do you live with the ALS patient?

Yes No

16. How many family members or friends (other than yourself) assist with care giving for the patient?

0 1 2 3-4 more than 4

17. Do you use government funded chore services to assist with care giving for the patient?

Yes No

18. Has care giving for the patient caused you to ... (check all that apply)

Cut back on hours at work
 Leave your job
 Hire caregivers that you pay for out of pocket
 Seek government funded chore services to assist with care giving
 Borrow money to meet expenses
 None of the above

19. What percentage of care do you provide the patient on a daily basis?

less than 10% 51% - 90%
 10% - 50% more than 90%

20. Do you get a break (respite) from your caregiver duties?

No (I do not want a break)
 No (no respite resources)
 No (patient opposes)
 Yes (however the time is inadequate)
 Yes (time is adequate)





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42636

21. Has assisting the patient...	Not at all	A little	Moderately	A lot	A great deal
a. Decreased the time you have to yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Increased the stress in your relationship with him/her?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Restricted personal privacy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Increased attempts by him/her to manipulate you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Decreased the time you have to spend in recreational activities?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Increased the number of unreasonable requests made of you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Added tension to your life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Restricted the vacation activities and trips you take?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. Increased the nervousness and depression you have concerning your relationship with him/her?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j. Added to your feelings that you are being taken advantage of?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k. Reduced the time you have to do your own work and daily chores?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
l. Increased demands made by him/her that are over and above what he/she needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
m. Increased your anxiety about things?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
n. Decreased the time you have for friends and other relatives?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
o. Decreased the money available to meet the rest of your expenses?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
p. Caused you to neglect other important relationships (e.g. children, parents)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
q. Affected your ability to attend to your personal medical needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

22. To what extent...

a. Is caring for the patient rewarding for you?

Not at all A little Moderately A lot A great deal

b. Does caring for the patient help you feel like you are doing something important?

Not at all A little Moderately A lot A great deal

