

Managing Your Loved One's Health (MYLOH)

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What is this questionnaire about?

This questionnaire will help you and your healthcare provider identify what you need to know and to do to help manage your loved one's health at home. Depending on how your loved one is doing, you may be required to help with some health management tasks, and you may need to take over some tasks completely. You may have already mastered some of the caregiving challenges, and you may need help with others. This survey will equip your healthcare team with the information necessary to help you develop required knowledge and skills and to support you in your caregiving journey.

There are no right or wrong answers. Please answer every question.

Definitions:

The terms “**He/She, Him/Her**” refer to your care recipient.

The term “**Health Care Providers**” refers to doctors, nurse practitioners, physician assistants, nurses, social workers, pharmacists, medical specialists (ex. cardiologist, psychiatrist), and other healthcare staff.

The term “**Care Partner**” refers to YOU.

Primary Care Partner: Live with or nearby the person who needs care. Regularly provide care and assist with daily and medical decisions and care tasks.

Helper Care Partner: Live with or nearby. Help a primary care partner when needed.

Long-distance Care Partner: Live further away. Visit when they can and assist with making decisions.

[myloh_cgtype]

What kind of Care Partner are you? Please answer questions below.

<input type="checkbox"/> I am a primary person responsible for care	<input type="checkbox"/> I am a helper person who assists with care	<input type="checkbox"/> I assist with care from long-distance
Your Age: [myloh_cgage]	Your Gender: <input type="checkbox"/> Male <input type="checkbox"/> Female [myloh_cggender]	Do you live with him/her? Y / N [myloh_reside]
Education: [myloh_educ]	Are you currently working? <input type="checkbox"/> No <input type="checkbox"/> Yes, full time <input type="checkbox"/> Yes, part-time [myloh_cgwork]	
Relationship to care recipient (ex. child, spouse): [myloh_relation]	How many years has she/he had a dementia diagnosis? [myloh_dementiayears]	How many years have you been his/her caregiver? [myloh_cgtime]
Your Ethnicity: <input type="checkbox"/> Hispanic/Latino <input type="checkbox"/> Not Hispanic/Latino Your Race: <input type="checkbox"/> Native Hawaiian or other Pacific Islander <input type="checkbox"/> African-American/Black <input type="checkbox"/> Asian [myloh_cgrace] <input type="checkbox"/> Caucasian/White <input type="checkbox"/> American Indian/Alaska Native		Where does he/she live? (ex. nursing home, assisted living) [myloh_ptliving]
How difficult is it for you to pay for all of the basic needs (ex. food, medical & other supplies, medications) for the person with dementia? (Please circle a number): [myloh_difficultypay]		
<div style="display: flex; justify-content: space-between;"> 1 2 3 4 5 </div> <p>NOT DIFFICULT —————→ EXTREMELY DIFFICULT</p>		
Would you consider your general health to be: <input type="checkbox"/> Very good <input type="checkbox"/> Good <input type="checkbox"/> Fair <input type="checkbox"/> Poor [myloh_cgheal]		
Do you have caregiving responsibilities for anyone else other than your care recipient? [myloh_othercaregiving] <input type="checkbox"/> No <input type="checkbox"/> Yes, for whom? [myloh_othercaregivingchild], [myloh_othercaregivingadult]		



How would you rate **your overall self-care from day-to-day when life is calm?**

(please place an "x" on the line)

Very poor

[values_calmselfcare]

Excellent

How would you rate **your overall self-care when your loved one is very ill?**

(please place an "x" on the line)

Very poor

[values_illselfcare]

Excellent

Brief Resilience Scale (BRS)

Please respond to each item by marking <u>one box per row</u>		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
BRS 1	[brs1_bounce] I tend to bounce back quickly after hard times.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
BRS 2	I have a hard time making it through stressful events. [brs2_makethrough]	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
BRS 3	It does not take me long to recover from a stressful event. [brs3_recover]	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
BRS 4	It is hard for me to snap back when something bad happens. [brs4_snapback]	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
BRS 5	I usually come through difficult times with little trouble. [brs5_comethrough]	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
BRS 6	I tend to take a long time to get over set-backs in my life. [brs6_getover]	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

Scoring: Add the responses varying from 1-5 for all six items giving a range from 6-30. Divide the total sum by the total number of questions answered.

My score: _____ item total / 6
[brs_total], [brs_average]

Smith, B. W., Dalen, J., Wiggins, K., Tooley, E., Christopher, P., & Bernard, J. (2008). The brief resilience scale: assessing the ability to bounce back. *International journal of behavioral medicine*, 15(3), 194-200.

Promoting Caregiver Resilience During Medical Crises of Persons Living with Dementia

NINR, R21. Investigators: Dr. Sadak, Dr. Borson

☐ Yes ☐ No ****If you had been a doctor that you could call to make a house-call, would you have used that service?** [int_housecall]

☐ Yes ☐ No ****Did you feel like you were involved with the process of making a decision about care plan or care options?** [int_decision]

☐ Yes ☐ No ****Did the doctor ask you questions on priorities of care for PWD?** [int_priorities]

☐ Yes ☐ No ****Did you feel that all of your questions were adequately answered?** [int_questions]

☐ Yes ☐ No ****Did the provider discuss the pros and cons of a hospitalization? Did you feel that you had a choice in what to do?** [int_procon], [int_choice]

☐ Yes ☐ No ****Were you referred to any Palliative or Geriatric specialty care?** [int_palliativereferral]

☐ ☐ Yes ☐ No ****Do you believe that this hospitalization could have been prevented?** [int_preventablehosp]

PROMPT to give FREE narrative

- If yes, why?
- If no, why not?
 - PROMPTS if needed
 - Did you need more knowledge about managing PWD symptoms?
 - Did you need more support from family and friends?
 - Did you need more support from health care providers?
 - Did you need easier access to health care?

☐ Yes ☐ No ****Did the provider/PCP follow up with you while PWD was in the hospital?** [int_fup]

☐ Yes ☐ No ****Did he/she (PCP) consult with the hospital doctors?** [int_consult]

☐ Yes ☐ No ****For patients still in hospital: Does the PCP know that he/she is in the** [int_pcpknow]

PCRC Palliative Question: (families need education regarding the progressive course of dementia and palliative care treatment options) **Did any provider explain what is the normal progression of dementia?** [int_dementiacgreport_progr]