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.

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

☐ I am a **primary** person responsible for care	☐ I am a **helper** person who assists with care	☐ I assist with care from **long-distance**
Your Age: ________________	**Your Gender:** ☐ **Male** ☐ **Female**	**Do you live with him/her? Y / N**
Education: _______________	**Are you currently working?** ☐ **No** ☐ **Yes, full time** ☐ **Yes, part-time**	
Relationship to care recipient (ex. child, spouse): ___________________________	**How many years has she/he had a dementia diagnosis?** ___________________________	**How many years have you been his/her caregiver?** ___________________________
Your Ethnicity: ☐ **Hispanic/Latino** ☐ **Not Hispanic/Latino**		**Where does he/she live? (ex. home, nursing home, assisted living)** ___________________________
Your Race: ☐ **Native Hawaiian or other Pacific Islander** ☐ **African-American/Black** ☐ **Asian** ☐ **Caucasian/White** ☐ **American Indian/Alaska Native**		

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):

1 — 2 — 3 — 4 — 5

NOT DIFFICULT ⟶ **EXTREMELY DIFFICULT**

Would you consider your general health to be: ☐ **Very good** ☐ **Good** ☐ **Fair** ☐ **Poor**

Do you have caregiving responsibilities for anyone else other than your care recipient?
☐ **No** ☐ **Yes, for whom?** _________________________

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	Agree Completely	Agree	Disagree	Disagree Completely	Not My Job
1. I understand WHAT his/her problems are:					
A. With **Memory** (ex. remembering, planning, making decisions)					
B. With **Mood/Behaviors** (ex. anger, sadness, irritation, poor sleep)					
C. With **Medical Issues** (ex. illnesses, pain, headaches)					
D. With **Self-Care** (ex. eating, dressing, showering, using the toilet)					
2. Right now, I can deal with DAY-TO-DAY problems he/she has:					
A. With **Memory** (ex. remembering, planning, making decisions)					
B. With **Mood/Behaviors** (ex. anger, sadness, irritation, poor sleep)					
C. With **Medical Issues** (ex. illnesses, pain, headaches)					
D. With **Self-Care** (ex. eating, dressing, showering, using the toilet)					
3. I know, or can get information about:					
A. What medications his/her health care provider recommends (prescription and non-prescription)					
B. What dose, **when and how** these medications should be taken (ex.10 mg tablet twice a day)					
C. What conditions these medications are used for (ex. blood pressure, blood sugar, dementia)					
4. I watch to be sure that he/she takes medications correctly and **provide help when needed**					
5. If I have concerns about his/her medications (ex. I worry about the safety or value of what is prescribed) I tell the clinician about them					

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	Agree Completely	Agree	Disagree	Disagree Completely	Not My Job
6. I can tell when there are NEW or RAPIDLY WORSENING changes in his/her:					
A. Memory (ex. remembering, planning, making decisions)					
B. Mood/Behaviors (ex. anger, sadness, irritation, poor sleep)					
C. Medical Issues (ex. illnesses, pain, headaches)					
D. Self-Care (ex. eating, dressing, showering, using the toilet)					
7. When NEW or RAPIDLY WORSENING changes happen, I know:					
A. What to **watch for** and what to **report** to his/her healthcare provider					
B. What I can **deal with on my own**					
C. When to **contact** his/her **health care provider**					
D. Which health care provider I should contact (ex. doctor, nurse, pharmacist)					
E. When I **need immediate assistance** and I should call 911 or other emergency medical help					
8. In helping with HEALTH CARE DECISIONS (ex. start new medication, go to a hospital, have surgery), **I understand:**					
A. What would be important to the person I care for					
B. How to speak up on his/her behalf					
C. The responsibilities of a person who has a Power of Attorney for Medical Decision Making					
9. In regards to CAREGIVING RIGHT NOW:					
A. I **can do everything needed** to ensure that his/her care needs are met					
B. I am **taking care of myself** so that I can **continue to care** for him/her (ex. I take a break when needed)					
C. When I **need help** with caregiving, I know how to **get it**					
D. I know **what to do** if I have a personal crisis and **cannot provide care** or help with care as I usually do.					

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Please take another look at all the questions you just answered.

Choose the **3 most important questions** to talk about with a *healthcare provider* **now** (ex. 7A, 1B):

The question you would like to discuss **first:**	Question #________________
The question you would like to discuss **second:**	Question #________________
The question you would like to discuss **third:**	Question #________________

Is there **anything else** we did not ask about that a healthcare provider **could help you with** in caring for your loved one?

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THANK YOU!

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