

Caregiver Experience Questionnaire: For Case Managers

Background

The caregiver questionnaire was developed based on insights from the NPHI-led study, *Caregiver Experiences and Perceptions of Declining Health*. The questions are designed to help you identify the caregiver archetype of the individual you are working with, so that you can adapt your service offerings and communication style to each caregiver's unique perspective.

Scoring Instructions

- To score the questionnaire, compare the caregiver's responses to the acronyms identified in the "Scoring Rubric" below. Every answer is associated with a particular archetype – indicated by an acronym on the rubric (PPS, EC, BE, and DG).
- As you go through the results, mark a tally in the "Scoring Results" column that corresponds with the acronym associated with each answer given.
- Add up how many of each type of response the caregiver gave – e.g. PPS (7), EC (2), BE (2), DG (1). The top choice indicates the archetype most closely aligned with the caregiver, with the second most common choice providing added context.
- While not a definitive scientific assessment, respondents will likely skew towards one or two of the responses more than the others. In cases where answers are truly split evenly, you may need to probe further to clarify what would be most useful for them.

Scoring Rubric

1. Emotional Experience

When you think about caring for your loved one, which of the following statements resonates with you most?

- Pragmatism - I understand the situation for what it is, so I'm willing to take charge of my loved one's care. (EC)
- Determination - I know that, with perseverance, caring for my loved one is something I'm capable of doing. (PPS)
- Devotion - Even though it often feels overwhelming, I'm committed to doing everything I can to help. (DG)
- Acceptance - I understand that the end of life is a natural part of it. This perspective helps keep me going. (BE)

2. Approach to Care

Which of the following most accurately describes your personal approach to care?

- Sacrifice - I value giving. I'm willing to put myself at the service of my loved one no matter what. (DG)
- Ownership - Caring for my loved one is my decision. I take destiny into my own hands and view it as something we can solve. (PPS)
- Honor - It's an honor to take care of my loved one. I want to enjoy the time we have left together with no regrets. (BE)
- Control - Despite my loved one's loss of independence, I've found a way to manage the situation and have help and resources that I can rely on. (EC)

3. Strength

Which of the following words would you say is your biggest strength in caregiving?

- I'm devoted. (DG)
- I'm proactive. (PPS)
- I'm present. (BE)
- I'm organized. (EC)

4. Needs

Which of the following describes where you need the most support?

- Help honoring my loved one and enjoying the time we have left together. (BE)
- Help supporting my loved one without losing hope. (PPS)
- Help determining the right course of action. (EC)
- All around help. (DG)

5. Burden

What's the hardest part about being a caregiver?

- Feeling like I'm in over my head no matter how hard I try. (DG)
- All the responsibilities I have to manage. (EC)
- All the interferences that take me away from spending time with my loved one. (BE)
- Staying strong for my loved one when times get tough. (PPS)

6. Anticipatory Grief

When you think about your loved one dying, what comes to mind?

- I can't think about that right now. (DG)
- I just want to know that I did everything I could for them. (EC)
- I know it's inevitable, but for now I just take it one day at a time. (PPS)
- I know death is a part of life, but it'll be hard not having them here. (BE)

7. Support System

Which of the following statements best describes your access to support systems?

- I'm proactive about seeking support. I try my best to stay well informed and I'm open to asking for help. (PPS)
- I tend to delay seeking support until it's absolutely necessary. My financial resources are limited, which constrains my options and acts as a source of stress. (DG)
- I have reliable access to resources and support, which allows me to rely on professional help more frequently. (EC)
- I have a tight-knit and supportive community around me, which is a big source of emotional and organizational support. (BE)

8. Hypothetical

Say you get new test results back regarding your loved one's health. What's the first thing you would do?

- Contact family members to update them and get advice. (BE)
- Find the most qualified professional to help. (EC)
- Do some research to learn more. (PPS)
- I'm not sure. (DG)

9. Asking For Help

How comfortable are you asking for help?

- I often do things myself, but I'm comfortable seeking support. (PPS)
- It's usually hard for me to ask for help. (DG)
- I usually turn to family and community members for support. (BE)
- I frequently seek professional help. (EC)

10. Motivations

The biggest thing motivating me to care for my loved one is:

- I want to make sure my loved one gets the best treatments and services available. (EC)
- I want to be useful to my loved one. I choose to help and I'm proud to do so. (PPS)
- I do it because, if I don't, who will? Even though it's hard, I do it no matter the sacrifice. (DG)
- Love, respect, and tradition. I want to give back what my loved ones had given to me. (BE)

11. Drive

We know that caregiving can be hard work. What keeps you going when it gets tough?

- My emotional bond and connection with my loved one is what keeps me going, no matter how hard it is for me. (DG)
- Perspective keeps me going. I embrace the circle of life and know I'm doing the right thing by giving back. (BE)
- Despite all the emotions and responsibilities I juggle, I have to keep a level head in order to make sure everything goes according to plan. (EC)
- I remind myself that, with hard work, I can do it. I try to take care of my own health in order to remain strong for my loved one. (PPS)

12. Reward

Which of the following would you say is the most rewarding part of caring for your loved one?

- Knowing I gave it my all. (DG)
- Quality time with my loved one. (BE)
- Making sure my loved one has the best experience. (EC)
- Knowing I did the right thing. (PPS)

Scoring Results

Proactive Problem-Solvers (PPS)	Effective Coordinators (EC)	Balanced Embracers (BE)	Devoted Givers (DG)
Caregiver Archetype:			

Interpreting the Questionnaire: Four Caregiver Archetypes

Proactive Problem-Solvers (PPS)	
<p>These caregivers are determined and practical. Their commitment is “chosen” and they view caregiving as a problem that can be solved. Thus, they feel a sense of pride about their role as caregivers, and tend to be proactive and well-informed. Often motivated by individualism or a hard-working mindset, they can still be open to accepting outside help. While their practical attitude makes them more adept at navigating the healthcare system than others, this group may tend to prioritize logistical challenges over emotional or spiritual ones.</p>	
<i>Appropriate Services</i>	<i>Communication Style</i>
Educational resources specific to the loved one’s condition (e.g. NPHI Dementia or Cardiac Care guides).	Respectful and complimentary of their approach to caregiving. Acknowledge that they are well-informed and avoid “talking down” or oversimplifying when discussing medical issues.

Effective Coordinators (EC)	
<p>Often described as “level-headed” or “high-functioning,” these caregivers strongly believe in their ability to help their loved one through top-notch treatments and services. They tend to have solid access to financial resources, allowing for frequent use of professional help. Often in close supervision of their loved one, they may express a desire to feel in control. Because of their confidence in finding the best possible care, this group tends to be less collaborative with other family members and may describe the experience more in terms of burden than pride.</p>	
<i>Appropriate Services</i>	<i>Communication Style</i>
Information about programs offered by your hospice and/or local third party services to supplement and augment care provided by your team.	Detailed and thorough. This group wants to know everything they can and is more likely to do their own research, but may need to be reminded to take care of themselves, too.

Balanced Embracers (BE)

These caregivers are motivated by love, respect, and tradition. They accept that the end of life is natural, and find a sense of purpose and meaning by caring for their loved one during the final chapter. Knowing their time is finite, they want to enjoy it to the fullest with no regrets. Often caregivers in this category are part of more close-knit families, giving them practical and emotional support throughout the journey. As a result, they may be less willing to seek outside support.

Appropriate Services

Connection to a Death Doula or Chaplain who can assist with legacy projects and help make the most of time together.

Communication Style

Empathetic and optimistic. While they may be emotionally and spiritually resilient, they may need more help with practical considerations like medications, bathing, and administrative tasks.

Devoted Givers (DG)

These caregivers face the greatest burden, yet remain devoted to their loved one no matter how hard it gets. More likely to describe the experience in terms of desperation, uncertainty, and sacrifice, they tend to delay seeking professional help even though they would benefit from it. Caregivers in this category tend to have fewer financial resources. Even when they have family nearby, they may feel that other family members are not doing as much to help. These factors make for a challenging emotional and practical experience.

Appropriate Services

Respite care, connection to caregiver and grief support groups, and connection to potential social supports such as food programs or childcare.

Communication Style

Patient and compassionate. Recognize that this group may feel “in over their heads” but less willing to accept outside help. Remind them that it’s ok to take time for themselves, and that they’ll be a better caregiver for their loved one if they’re well cared for themselves.

Conclusion

This tool has been developed using insights from extensive caregiver interviews, but keep in mind that everyone is unique, and a caregiver’s attitude and experience may evolve over the course of their journey. The simple act of asking a caregiver to reflect on how they feel about their role has value in and of itself, so feel free to re-administer the questionnaire in the future if appropriate.