

Pre-Focus Group Orientation (to be sent via email with post-screening confirmation and again the morning of the session)

My name is Helen Zee and I'm going to facilitate the online discussion in which you will participate on June [INSERT 23, 24, 25 and 30] from 7:00 pm to 8:00 pm (Eastern Standard Time). My role will just be to ask some questions and guide the discussion. I'm not selling anything and I have no vested interest in any outcome.

The purpose of the session is to discuss your thoughts, opinions, and experiences finding care for an aging family member.

About the Session

- First of all, thank you for participating. What you have to say is important and the goal of this discussion is to hear your views.
- The purpose of the chat is to learn about the experiences families have when they look for and use services to help their aging relatives.
- Here are some easy "ground rules":
 - Everyone needs to participate – it's important to hear all viewpoints. I'm going to do my best to get answers from everyone so I may call on you. If you need time to think of your answer or want to hear from others first, just pass and we'll come back to you.
 - There are no wrong answers – just say whatever you are thinking. Each of us has different situations, experiences and attitudes - our goal is to understand these.
 - The session will last 60 minutes, once everyone is logged in and ready to go. We have a few topics to cover so we may have to move ahead to new subjects in the interest of time.
 - We realize that some people type faster than others but we hope to give everyone equal "air time."
 - All the information you share is confidential. Your comments will only be identified by your first name and last initial. Plus you'll also have an option to send me a "private" message if you have any issues or concerns during the session.

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- [GfK: Insert explanation regarding how session will be viewed by the sponsors of the research and how session is “recorded”]
- [GfK: Insert explanation of on-line chat functions]

Understanding How Families Access and Use Long-Term Care Services: Discussion Guide

INTRODUCTIONS (0 minutes: posted before session begins)

Welcome to tonight’s chat. My name is Helen Zee and I am moderating tonight’s discussion. I’d like to start tonight’s discussion by giving you a little background as to what we’re doing.

I have been asked to help find out what Americans experience when they have an older relative who needs long-term care. As part of this project, we will be conducting web-based focus groups with people like you over the next few days.

Tonight’s focus group will take no more than 60 minutes. You are not required to participate in this chat and you may refuse to answer any questions that may make you feel uncomfortable. However, for those that you do choose to answer, we would appreciate your answers to be as detailed as possible, depending on your memory and recollections.

You have been selected to be part of this panel because you recently took a GfK survey on planning for your future long-term care needs and because you indicated that you had a family member who needed long-term care. We are very interested in hearing about the unique experience you had and how well it worked for family. Please note that we may want to follow-up with some of you individually, based on the answers you give tonight. You do not have to participate further after tonight’s discussion.

You will receive an incentive directly from GfK for your participation in this focus group. The overall benefits are that the information we collect may help make Americans better

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prepared for their futures. Only the project team will see this information in its entirety, and some members of the team will be viewing our discussion as it progresses.

Is everybody ready to begin?

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Looking for Long-Term Care

I want to start off by introducing a very important topic that you all are very familiar with: long-term care. We're going to be talking a lot tonight about that topic tonight and it probably means many different things to all of us. So to make sure we're all on the same page, here is a brief definition of "long-term care" (LTC) to guide us:

[Insert Slide 1]

Long-term care is not traditional medical care. It represents the array of services and supports that help older adults and people with disabilities accomplish everyday tasks such as bathing, dressing, preparing a meal, or managing money. This care may be provided in a number of settings, including at-home, in adult day support centers, residential care communities or assisted living, or nursing homes.

Does anyone have any questions about that definition?

[Pause for respondents' questions]

Ok, great. Let's move along. As I mentioned before, you're all familiar with long-term care, because all of you have something in common: you all have had a personal experience with LTC. In one way or another you all indicated that someone close to you – whether a family member or a friend - needed the type of care described above.

Some of you may have known many people who needed this type of care. For purposes of this discussion tonight, however, I would like for you to pick the one family member (or close friend) who most recently needed long-term care. We'll focus on that family member throughout this chat.

Let's take a quick moment so you can tell me a little bit more about this person – can you tell me:

- o their relationship to you (mother, father, sibling, etc),
- o age when they started to have some trouble with everyday activities,
- o type of care they needed, and
- o any other relevant information

For example, you can say something like: My father, 85, fell in the shower, we have an aide visit him every day to help with feeding, bathing and dressing; he's also starting to develop dementia

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Does anyone have any questions? *** And please note, these responses will be private and none of the other participants will be able to see them, but they will help give me some context for our discussion. ***

[Insert Slide 2]

Which family member will you be discussing today?

What is your relationship to them?

At what age did they start having trouble with everyday activities?

What type of care do/did they need?

Great, thanks! I now have all the responses.

Now I would like to open the conversation up to the whole group. Let's start by thinking about when you and your family decided that your loved one needed some additional services or supports. What made your family's decide to look for services? Was it a specific event like a hospitalization? Did things gradually deteriorate over time? I'd like for you to explain what helped you make the decision to look for additional services in the home, in your community, or in a residential community such as an assisted living facility or nursing home. You don't have to mention who it was that needed the care or assistance as you already did earlier. But if you would like, feel free to do so.

[Pause for respondents' answers]

Wow, some tough circumstances. Every family is different, so I'd like to know more about how this worked for your family. Did any of your family members take part in the decision to seek help? If so, did everyone agree it was time to get support? Were there debates among family members? How did the family member who had been providing most of this support to your loved one feel?

[Pause for respondents' answers]

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Sources of Information

With that in mind, I would like to know a little about who you or your family got information about these services from first. Did you talk to friends? Did you look online? Where did you start?

[Pause for respondents' answers]

So there are lots of different sources of information out there. Did you get everything you needed from the first source, or did you have to look other places or talk to other people? Who? To the extent you remember, please list all of the sources of information you used when looking for this information.

[Pause for respondents' answers]

How useful or relevant was most of the information that you received? Did you hit to a lot of dead ends? Which were the most useful sources and which were not as useful? For those of you who got information from government resources- how relevant and useful was the information you received from those sources?

[Pause for respondents' answers]

Decision-Making Process

Ok, great. So now your family has gathered information. Tell me more about the process of making a decision about what type of care to get and where to get it from. Did your research help you decide what kind of care your family member needed? Did it help you decide between providers? What factors were important in your decision?

[Pause for respondents' answers]

Often, finding care for an older relative is an iterative process, either because their health deteriorates or because the first care provider is not a good fit. Did this happen to any of you? What did you and your family have to do?

[Pause for respondents' answers]

What helped during this process? What made it more difficult?

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[Pause for respondents' answers]

In retrospect, is there anything you wish you had known when you started looking into care that would have made this process easier?

[Pause for respondents' answers]

What information was either not available or not readily accessible to you when you were looking at options for care?

[Pause for respondents' answers]

How could the process of looking for this care be improved? What would you tell other families in a similar position to do?

[Pause for respondents' answers]

CLOSING

(10 minutes)

Before we end, I'd like to ask for some closing thoughts on your experience. For starters, do you have ideas on how we can help you find valuable information and make it understandable?

[Pause for respondents' answers]

I'd like to thank everyone for their thoughtful insights and opinions and for sharing your own personal stories with us.

TIMING BREAKDOWN

Introduction	0 (on screen beforehand)
Looking for Long-Term Care	15
Sources of Information	15
Decision Making Process	20
Closing	10
Total	60

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