



focus group guidelines

Organizing and conducting focus groups for people living with memory loss and for family caregivers

As a community works toward becoming dementia friendly, it's important that community members living with dementia and their family caregivers be involved in the work. Consider holding a focus group or community conversation to collect their views and insights.

Focus groups help us learn about opinions and needs. A focus group is typically 6 to 12 participants who usually don't know one another, but share a similar characteristic, experience or situation. A skilled facilitator guides the group by asking questions and stimulating discussion, and a note-taker records responses and general observations. Responses in a focus group are typically spoken, relatively broad, and qualitative in nature. Because focus groups are interactive, they can be effective in discovering what people really think and feel about a particular subject.

A focus group is not:

- A debate
- A support group or group therapy
- An educational session
- A conflict resolution session
- A problem-solving session
- An opportunity to collaborate
- A promotional opportunity

Guidelines and recommendations for holding a focus group or community conversation are described below. This is done during Phase 2 (Assess) of the ACT on Alzheimer's community engagement process to supplement the results of the sector interviews. You could also hold focus groups during Phase 4 (ACT Together) to gain new ideas for your community.

Focus Group Messaging: Stigma is a real barrier!

Most communities are likely to experience the stigma associated with the word Alzheimer's and even the word dementia. When assembling a focus group, know that individuals and families living with the disease may not be ready to be public about their situation. Some recommendations:

- Consider not using the ACT on Alzheimer's logo or the word Alzheimer's or dementia on materials to recruit people for a focus group. Phrases like "memory loss" or "memory changes" might yield greater participation.
- Instead of a traditional focus group format, hold a community education event called "Worried about Memory Loss - What to Know, What to Do" or something similar, followed by a community conversation. The community conversation becomes the focus group.

- Discourage having action team members present at focus groups because it may cause participants to be less open with their feedback.

Recruiting Participants

- A personal invitation will increase the likelihood of focus group participation. Most action team members will likely know people in the community impacted by memory loss and can reach out to them and encourage participation in the focus group.
- In some communities, flyers or displays may work well. Consider posting flyers in pharmacies, assisted living residences, coffee shops, government offices, churches and hair salons. Share with county public health, adult day programs, local police, and county commissioners. Post on Facebook and Twitter and promote in the local newspaper. It is important to place messages about the focus group in a place where community residents both frequent and trust.

A successful recruitment example:

“For 2 weeks, we used a large ‘sandwich’ board outside the library to promote the community conversation on memory loss. It was a successful tactic because libraries are a trusted community partner and used by residents for various reasons. When people see that the library is involved in an issue, it lends higher credibility.”

- Use the interest and trust developed in a community conversation about memory loss as an opportunity to recruit focus group participants. Find recruiting flyer language on page 9.

Focus Group Logistics

Size: 6-7 participants is ideal. If the format is a community education event followed by a discussion, the group size may be larger. When possible, divide the group into smaller conversation groups if you have enough facilitators.

Time duration: 45 to 60 minutes. Adjust according to the needs of your group. It’s best to have one focus group for family caregivers and a separate focus group for people impacted by memory loss, but a mixed group can also work. When the group is mixed, focus your attention and questions to one group at a time (family caregivers or persons with memory loss.)

Environment: The focus group should be held in a comfortable space that is quiet and free of distractions. A neutral public space such as a library, school, or a government or other office building is a good choice. Places such as memory care facilities, hospitals, nursing homes or even churches may be perceived negatively and could limit participation. Seat a focus group around a square or round table that is not too large. Being able to see and hear one another is critical and sitting around a table reinforces a casual, conversational atmosphere.

Name tents/tags: Create name tents that include the participant's first name and a number placed in the corner of the tent. The number is used to identify documented responses.

Confidentiality: Names of focus group participants should not be shared other than for organizing purposes (registration, reminder calls, etc.) All analysis documents will have an ID number, not the participant's name.

Focus Group Facilitation

The Facilitator: Deciding who should facilitate the focus group is important; the more skilled the facilitation, the better information you will receive and the more likely the participants will have an overall positive experience. Facilitating a focus group takes thoughtful preparation and specific skills, especially for a group with dementia.

A good facilitator:

- Has experience facilitating groups
- Can listen attentively with sensitivity and empathy
- Can appropriately manage challenging group dynamics
- Is knowledgeable about memory loss and dementia (for community conversations, it's important to have a memory loss expert present to answer questions about the disease)
- Uses "dementia friendly" language
- Relates well to persons living with dementia and to caregivers
- Understands and uses good communication techniques when talking with people who have memory loss or dementia, including:
 - Good eye contact
 - Repeating questions tactfully
 - Offering cues without leading anyone to answers
 - Matching the pace of the conversation to the needs of the individual/group
 - Allowing time for participants to reply
 - Making participants feel valued and respected
 - Ensuring people feel included even when they aren't verbalizing or don't fully understand
 - Making each person feel at ease and feel they are contributing

Focus Group Note-Taker – Documentation

You want to make sure participants' ideas don't get lost. Someone should write down what is said. Arrange for this in advance and be sure the note-taker is not the facilitator. Another option is to tape-record the session, with the groups permission. This option will take more time – transcribing the tape and synthesizing the information – but it provides an accurate record of the session.

The note-taker should not use participant names in the notes, but instead identify each speaker with an ID number (such as the number written on the name tent). Similarly, if the focus group is recorded, identify people by a number on the transcript document. It is not necessary to document every word or every conversation. The goal is to capture the intent, not necessarily every word.

Both the note-taker and the facilitator need to identify common themes and key messages that emerge. This listening” is critical to synthesizing the results of the focus group.

A good note-taker:

- Makes each participant a name tent
- Takes notes throughout the focus group
- Runs a tape recorder during the session (optional)
- Notes/records body language or other subtle but relevant clues
- Allows the facilitator to do all the talking
- Provides a legible document at the end of the focus group

Focus Group Meeting – The Three Phases

Phase 1: Setting the Stage (5-10 minutes)

- Welcome and introduce yourself.
- Invite the participants to introduce themselves.
- Share a bit about the work that your community is engaged in (optional).
- Define what dementia friendly communities are and give some examples (optional).
- State that the purpose of the focus group/community discussion is to gather insights about memory loss and the role of community. Share that what you learn will influence the efforts of the community action team.
- Assure the participants that there is no right or wrong answer to the questions and that they do not have to answer every question.
- Inform the group that someone else will be taking notes (introduce the note-taker) or that the group will be audio-recorded for the purpose of summarizing key messages.
- Discuss confidentiality: You can modify these points to suit your needs or situation.
 - “What is said in this room is for the purpose of informing the action team on common themes that come out of the conversation.”
 - “We will not identify anyone by name in our report or when we share key findings. You will remain anonymous.”

Phase 2: The Conversation (45 minutes)

- Ask one question at a time (sample questions are found on pages 6-7), in any order, that makes sense to the flow of the conversation. You don't need to get to all your questions, but you may want to prioritize them based on what your action team is most interested in knowing.
- If no one responds to a question, first wait for 15 to 20 seconds and then repeat the question. If still no response, move on to another question.
- Ask good follow-up questions. This is a way to understand more deeply what the person is saying and often provides valuable information. Good follow-up questions may organically start to address other key questions and will feel more like a conversation than a question-and-answer session.
 - "Can you talk about that more?"
 - "Help me understand what you mean."
 - "Can you give an example?"
 - "Have others had a similar (or different) experience?"
- Before moving on to the next question, consider asking if anyone else has a comment on the question you are discussing (repeat the question). Look around the table and make brief eye contact with individuals who have not spoken. This may prompt a response.
- Ask your next question and proceed with other questions in the same general manner. The ordering and phrasing of the questions, the follow-ups, and how much time to spend on each one are decisions of the facilitator.
- When your key questions have been addressed, and before moving into the "Wrap up," ask if anyone has any other comments to make. This can be an effective way of gathering other opinions that have not yet been voiced.

Phase 3: Wrap Up (5-10 minutes)

- Summarize the common themes that emerged during the conversation.
- Reinforce that the key messages will be brought back to the action team and will influence actions that the community may take.
- Consider having a way for participants to privately share thoughts they did not bring up in the group. Provide a form and invite everyone to jot down any additional thoughts before they leave.
- If appropriate, invite members of the focus group to participate in the Community Action Team—share meeting dates.
- Thank each person for participating.

Focus Group Meeting Follow-up

- If you have contact information for participants, send each one either a handwritten or an email thank you.
- Invite participants to attend the Community Meeting in Phase 4 (ACT Together) to learn results of your community assessment and to help determine action items.

Sample Focus Group Questions for Community Members with Memory Loss

- Are there ways in which you feel your community is dementia friendly? In what ways?
OR
- Do you feel your community does a good job in supporting people who are living with memory loss?

Ask for specific examples they have experienced in a bank, grocery store, beauty/barber shop, restaurant, health club, church, public transportation, home improvement stores (e.g., Menards), or in accessing good information, using support groups, or other activities.

- Have you ever had a bad experience in your community where perhaps you felt lost or confused and no one seemed to help?

What happened, what could have made the situation better?

- Do you think your community treats you differently, or would treat you differently, if they knew you have memory loss?
- What do you want your community to know about people living with memory loss?
- Do you think there are enough opportunities for people living with memory loss to stay involved in community life?
AND/OR
- What do you see as the biggest obstacles to staying involved in your community?
- If I could wave a magic wand and make (your community name) a great place to live for those with memory loss, what would it look like?
AND/OR
- What is the most important thing your community could do over the next year to better meet your needs?

Sample Focus Group Questions for Family Member, Relative or Friend Caring for Someone with Memory Loss

- Are there ways in which you feel your community is dementia friendly? In what ways?
OR
- Do you feel your community does a good job in supporting people who are living with memory loss?

Ask for specific examples they have experienced in a bank, grocery store, beauty/barber shop, restaurant, health club, church, public transportation, home improvement stores (e.g., Menards), or in accessing good information, using support groups, or other activities.

- Do you feel the community is well informed about memory loss and dementia?

Why do you feel this way?

- Do you feel YOU are well informed?
AND/OR
- Do you feel prepared for this role?

- Do you feel your community understands your role as a care partner?
AND/OR
- What do you want your community to understand about caring for a relative (spouse, loved one) with memory loss or dementia?

- What is something the community could do, or offer, that would help you in your role as a care partner?
AND/OR
- What caregiver resources would you like to see in your community?

- Are you concerned about your own health and well-being?
AND/OR
- In what ways could the community play a positive role in your health and well-being?

- Are there adequate opportunities for people living with memory loss and their family caregivers to stay involved and enjoy community life?

- If I could wave a magic wand and make (your community name) a great place to live for those caring for someone with memory loss, what would it look like?
AND/OR
- What is the most important thing your community could do over the next year to better meet your needs?

Real focus group comments of people with memory loss:

Give me more time, the community is impatient.

I am a person with feelings, emotions, and sensitivities.

I want to feel needed in my community.

Make it ok for me to ask for help.

If it looks like I need help, please ask me; the community needs to be educated on what a person looks like who might need help.

Please show kindness.

The most important thing I need from my community is to be needed.

Real focus group comments of care partners:

Information comes too late.

Community lacks the knowledge they need.

I want a community that offers empathy and understanding.

The community needs to understand that caregivers can't just walk away.

This role limits my ability to have the life I want.

I am not sure I am up for the job; this is so lonely.

I will be angry and irritable; please understand.

It is hard to ask for help but if I do, I hope my community is up for the job.

Synthesize and Analyze Focus Group Results

For all participant comments to be understood and useful, they must be narrowed down to essential information. If the focus group was recorded, you need to produce a written transcript. Eliminate any unnecessary words or comments. If the focus group was documented by a note-taker, he/she should clean up/organize the notes and create a legible, written summary of the session. To capture the most relevant information for your action team:

- Make one copy of the Synthesis Worksheet (found on page 10) for each question asked that received a response.
- Write each question on a separate Synthesis Worksheet.
- With your transcript and/or notes in hand, write the responses to each question in column B.
- Identify the person (ID number) giving the response in column A. Responses can be summarized or paraphrased as long as the point is not lost.
- After recording the responses on the Synthesis Worksheets, ask these questions of the facilitator, note-taker, and at least one person from the action team to gain consensus:
 - What are the common themes/responses?
 - What conclusions seem accurate?
 - Is there a key finding to take forward?
- The Key Findings are recorded in column C.
- Complete the Key Findings Summary (found on page 10).
- Share Key Findings with your action team.

Details to Include in Focus Group Recruitment Flyer

Some examples of information to use in recruiting focus group participants:

- What should a community that supports people with memory loss look and feel like?
- What should a community that takes care of family caregivers look and feel like?
- Be part of the discussion for our community. What matters to you? We welcome your participation in one of the following focus group discussions.

<p>Focus Group: Community Members Living with Memory Loss</p> <p>We're seeking people with mild or moderate memory loss who can verbally express thoughts and ideas.</p> <p>[Day and date] [Time]</p>	<p>Focus Group: Community Members in a Supporting or Caregiving Role</p> <p>We're seeking spouses, partners, or other family members living with a person who is experiencing mild or moderate memory loss.</p> <p>[Day and date] [Time]</p>
<p>The group discussions will be facilitated by [Name of person and/or organization]. Interested persons are asked to leave contact information (phone number and/or e-mail) with [Name]. [Name] will contact you to answer your questions, confirm your participation and share the location for the discussion.</p>	

Focus Group Synthesis Worksheet

Date of focus group: _____

Question #: _____

Type of group (circle one): Support partner Persons with memory loss Mixed group

Column A	Column B	Column C
Participant ID	Response	Is there a key finding to take forward?

Key Findings Summary

Review Column C from each Synthesis Worksheet. Identify up to 5 of the most common themes, ideas, needs, and/or recommendations that emerged from the focus group. Share with your action team.

Persons with Memory Loss

- 1.
- 2.
- 3.
- 4.
- 5.

Family Caregivers

- 1.
- 2.
- 3.
- 4.
- 5.