

2023

# Focus Groups: Best Practices for Seniors with Cognitive Decline



Prepared by

**Rhianna R. Benson, BSW**

ThreeCubed

Three<sup>3</sup>

520 W. Summit Hill Drive, Suite 1101  
Knoxville, TN 37902  
865.963.3255

## Acknowledgements

These best practices were developed as part of a larger research project designed to assess the needs of elders with cognitive decline and their caregivers in Knoxville, Tennessee. Thanks to the Knox County Health Department and Mikaela Gass for their partnership and support throughout the project's development and implementation. Thanks also to the members of Three<sup>3</sup> that supported me as I developed this guide, including Erin Rose, Andrea Young, and Jha'Niyah Holland. This work was conducted under the employment of Three<sup>3</sup>, a 501(c)(3) research and evaluation nonprofit located in Knoxville, TN with a mission to *foster equitable and sustainable futures*.

*\*The Healthy Brain Initiative Road Map Strategists Program is supported by the Centers for Disease Control and Prevention and the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award. All views represented are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by the Alzheimer's Association, the CDC/HHS or the U.S. Government.*

## Focus Groups, Best Practices for Elders with Cognitive Decline

Prepared by Rhianna R. Benson, BSW

*There are numerous resources detailing best practices for focus groups. However, there is more limited information available on how to appropriately organize and lead focus groups for elders with cognitive decline. Compiled in this guide is current information for best practices from across the web. The author strongly suggests that further research be conducted to fill existing gaps in research regarding this topic.*

- **Timing: no more than 2 hours** (Alzheimer’s Society, n.d.a)
  - Time of day:
    1. To avoid Sundowning, **start and end before the late afternoon** (Graff-Radford, 2022).
    2. If a **“get to know me” sheet** is distributed for group candidates prior to meeting, elders can indicate times that they prefer.
    3. Where appropriate, discuss best timing with caretakers, since participants will likely have routines that might be disrupted by a lack of informed planning.
- **Prior to Starting Day:**
  - Have each participant (or their caregiver, if the participant is unable) fill out an “information about me” form several days before the meeting, including questions on the form regarding **any dietary needs and incontinence and accessibility accommodations** (Alzheimer’s Society, n.d.a) *Templates, signage, forms, & tips on pg. 8.*
  - **Provide an agenda** for participants. *Example on pg. 8.*
  - *Checklist for preparing supportive systems for people with dementia provided on page 9.*
- **Setting: hearing and sight will be more limited, as well as memory and mobility**
  - *Hearing*
    1. Participants might not hear as well, so accommodations should be made:
      - Using a **microphone** or
      - Conducting in a **smaller room** where people are close to the speaker.
  - *Imagery/facilitation tools*
    1. Handouts should have **large font, contrasting colors, and clear times.**
    2. It might help to have a larger **sign near the front** that gives presenters’ names, reason for conducting the focus group, and a short list of rules for the meeting.
    3. “Use **PowerPoint and presentations sparingly**, with only a few words, large font, and visuals to support” (Alzheimer’s Society, n.d.d).
  - *Memory*
    1. Provide Dementia-Friendly Signage. *Templates, signage, forms, & tips on pg. 8.*
    2. “Ensure **the way to the toilets - and out again - is clearly signposted**” (Alzheimer’s Society, n.d.a; emphasis added).
    3. Assign a staff member to meet participants at the entrance and direct them to where they need to go throughout the day.

4. Ask:
  - Is the layout simple, or should there be accommodations for a more complicated building layout that might be forgotten?
  - Will participants be comfortable going to a place they are new to? If not, provide directions and a map of the meeting areas ahead of time to increase comfortability.
- *Mobility and comfort*
  1. Ask: What level of accessibility do the selected buildings have?
  2. “Convenience and comfort... [for] parking and public transportation [should be considered]” (Ataie & Morgan, 2015).
  3. **Ask participants prior to the meeting day if they experience incontinence and explain what accommodations will be made.**
  4. Provide/ensure:
    - Wheelchair accommodations, sufficient space, handrails, light-weight doors, higher seats, etc.
    - **Unisex pads for incontinence and clinical/sanitary waste disposal bins** in both male and female bathrooms. Provide 5 pads per event. (Alzheimer’s Society, n.d.c)
- *Other Setting considerations:*
  1. **Keep floors plain.** Matts or rugs can look like holes to certain individuals with dementia (MacIntyre Dementia Project, 2018).
  2. If necessary, use colored tape on stairs to make steps more visible.
  3. “Previous studies with people with disabilities have shown that the **physical setting in which focus groups take place can have a significant impact on research outcomes.** In particular, participants in focus groups that take place in medicalized settings—for example, a hospital—tend to take a more passive role and answer questions in ways that conform to ‘the system’ (Llwellyn, 2009). Conversely, focus groups in nonmedical settings such as day centers and self-advocacy organizations tend to encourage openness and frankness from participants with disabilities, facilitating a more active role in the research process (Llwellyn, 2009)” (Trevisan, 2020; emphasis added). While this specifically addresses focus groups with individuals with communication disabilities, it should also be considered for focus groups with elders.
  4. Having a **quiet area/safe space** can be helpful if any participants become disoriented or upset. Having something to do in the quiet area, like a coloring book can help to calm, as well (KeepingBusy, 2023).
- **Conducting the Focus Group**
  - “When necessary, **a team of three facilitators should be used** (Seymour et al., 2002): an experienced moderator leads the discussion, while a second person observes group dynamics and assists if disabilities interfere with the flow of the discussion, and a third works in the background assisting with personal needs of the group members” (Ataie & Morgan, 2015; emphasis added).

- **Beginning Meetings:**
  1. “**Ensure you have water, tea and coffee** (or whatever drinks the people prefer) close to people during the session
  2. Consider having **biscuits and fruit** available
  3. Ensure there is **someone to meet each participant** at the venue/the station etc as agreed...”
  4. “**Provide name cards and badges** [with each participant’s name in large block print]
  5. **Provide communication cards** as a constant visual permission for people to let you know of any needs to help them participate during the session. [RRB note: This can include cards to help flag someone that they are currently needing to use the restroom, for instance]
  6. Suggest **ground rules** or group contract: one person speaks at a time, respect each other even if you disagree with someone else's opinion or idea, there are no right or wrong answers” (Alzheimer’s Society, n.d.a)
  7. **Provide information** on **where to go** for different facilities and the accessibility accommodations that are available (such as having pads in the bathrooms)
  8. **Check in with people throughout** to make sure everyone still understands what is going on
- **Tips for Dementia-Friendly Group Discussions and Activities:**
  1. **Have a smaller group if there is a focus on discussions (between 3-6 people per group).**
    - “[S]maller groups are better suited to participants with communication difficulties for a variety of reasons (Fraser and Fraser, 2001). First, smaller groups tend to feel **less intimidating**. Second, they **allow more time** for each participant to articulate his or her thoughts, which can be especially useful for people with communication difficulties. Third, smaller groups **enable participants to learn about each other’s communication needs** and preferences more quickly than larger groups, which facilitates more *respectful and empowering exchanges*. Finally, smaller groups make it **easier to note nonverbal contributions and facilitate moderator interventions** to ensure that people with communication difficulties have appropriate opportunities to contribute meaningfully” (Trevisan, 2020; emphasis added).
    - “‘5 was optimal, 6 was manageable’ (Quine & Cameron, 1995)... groups with four participants ran the risk of being less dynamic whereas in groups with more than 6 members the challenge was to ensure audibility and eye contact” (Ataie & Morgan, 2015).
  2. Be careful to set a slow enough pace of conversation and use words that will be understood (**avoid jargon**). Allow plenty of time for people to process your questions and provide answers.
  3. Allow for one or two **breaks**.
  4. Use dementia-friendly documents, **offered in advance**.
  5. Make the atmosphere **relaxed**.

6. Provide a **roving facilitator**, if people break into small groups and might need help/might ask for support throughout
  7. “Consider using a **flipchart to write down key words and phrases** people use to help them know they have made points they wish to raise” (Alzheimer’s Society, n.d.a) and help people maintain focus.
  8. You can “**use post-it notes**... to ensure each person's ideas are included, not just those of one or two people more able, confident and/or anxious to make their points... ask people to write one idea per note. Collect the post-it notes... group them into themes” and discuss with the group (Alzheimer’s Society, n.d.a).
  9. “**Amplifying participants’ voices by repeating, summarizing, and paraphrasing** contributions fosters the participation of those who have difficulty hearing or comprehending the initial comment. However, attempts to facilitate mutual understanding must be tempered with the knowledge that **repeated moderator engagement interferes with participant interaction** and inhibits it from developing naturally (Morgan & Krueger, 1998)” (Ataie & Morgan, 2015; emphasis added).
    - **Include ice-breakers.** “[t]he initial ‘discussion starter’ question should be something that is both easy to answer and comfortable to discuss with others” (Ataie & Morgan, 2015).  
*Examples of conversation starters with older adults on pg. 8.*
- **At the end of meetings**
    - Summarize what people have said and tell everyone what to expect in the coming weeks.
    - **Make sure everyone has their things** (Alzheimer’s Society, n.d.a).
  - **Consent**
    - “On the day of the meeting, the **study should be explained individually** to each participant and his or her signature on the informed consent documents obtained” (Ataie & Morgan, 2015; emphasis added).
    - “Consent to participate is usually **obtained immediately prior to the focus group** and so researchers can be **reassured that capacity is unlikely to change in the short time elapsed** between consenting and participating in the focus group, although consent is always revocable. The feasibility of withdrawing consent during a focus group is, however, up for debate. Having to withdraw in a public manner that may disturb discussion is **likely to dissuade participants** from doing so... [it is recommended to use] **simple language and imagery**, such as pictures or diagrams, to improve the accessibility of information to those with reduced comprehension” (Jones et al., 2021; emphasis added).
    - If possible, include a visual stating the basics of participants’ consent, including a reminder that they do not have to participate and may leave at any time if they want.
    - “**Being asked to provide written consent can be perceived as threatening** by some elderly participants and may be met with considerable resistance, despite a stated willingness to participate in research. **Use of a standardized verbal consent procedure** has been found to **enhance research participation** among institutionalized older adults

who were reluctant to give written consent (Brod & Feinbloom, 1990)” (La Rue & Markee, 1995; emphasis added). *This information might be outdated.*

- Where possible, make the research available to participants, and let them check it before it is used to ensure that they agree with the representation (Trevisan, 2020).
  - **Ask: How will consent be ethically attained? What if the participants forget that they have given their consent? Do you know who will need caregivers and/or will not be able to give their consent?**
- 
- **Caregivers and Legally Authorized Representatives—2 Differing Opinions:**
    - Different sources state different recommendations:
      1. Consider having the discussion **without carers present** (Alzheimer’s Society, n.d.e; emphasis added).
      2. “We...recommend inviting relatives or staff members involved in participants’ care to attend alongside patient participants. In our focus groups, **the presence of caregivers alleviated communicative and cognitive deficits**, both in the recruitment process and during data collection; thus, their presence appeared to support participant comprehension and subsequent decision making. Involving caregivers also demonstrates the value given to the carer–patient relationship and allows carers to redirect the person they are supporting, clarify statements or even help them delve deeper into questions, although their input may influence patient participants’ opinions... However...moderators ensured that statements made by caregivers were **acknowledged by the appropriate patient**, for **verbal or non-verbal agreement**” (Jones et al., 2021; emphasis added).
    - Best practice includes involving participants in decision-making. **Ask the participants about their preferences of who attends** before the meeting.
- 
- **Research Design Considerations:**
    - “The affective content of the **recruiting message** has also been found to influence research participation (Schleser, West, & Boatright, 1986), with messages reflecting a **positive** (e.g., “increase your memory power”) or **neutral** (e.g., “learn memory skills”) approach **leading to greater response** among older adults than more negative recruitment messages (e.g., “avoid memory failures”)” (La Rue & Markee, 1995; emphasis added).
    - “When planning focus groups with older adults it is recommended to **increase** the generally suggested extent of **over-recruitment to 25 percent** (Barret and Kirk, 2000) as circumstances beyond an individual’s control (such as illness) may prevent attendance on any given day” (Ataie & Morgan, 2015; emphasis added).
    - “Short ‘**preinterviews**’ could also allow researchers to assess eligibility for participation, while still regarding comprehension and consent as an ongoing process” (Jones et al., 2021; emphasis added).
    - “Within samples derived from hospital and clinic populations, **other biases may result from underrepresentation** of ethnic and racial groups, individuals with low education

and income, or elderly people from rural areas, because persons with these characteristics may have limited access to urban medical centers where most cognitive aging studies are conducted” (La Rue & Markee, 1995; emphasis added).

- “Combining **a range of impairments in one group may seriously interfere with the interaction** among the group members and impact group dynamics. For example, group members in wheelchairs may not be able to sit close enough so that participants with hearing loss can understand them” (Ataie & Morgan, 2015; emphasis added).



## Templates and Tips:

- 33+ Engaging Conversation Starters with Older Adults: <https://multiculturalcaregiving.net/conversation-starters-with-older-adults/>
- Dementia-Friendly signs for disabled facilities, toilets, lifts, parking, and ways out: <https://www.alzheimers.org.uk/dementia-professionals/resources-professionals/resources-gps/dementia-friendly-signage>
- Dementia-Friendly forms, about me sheets, reminder letters, group contracts, handouts, etc.: <https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/real-life-examples/templates-examples-and-tips>
- Ex. Agenda for participants: [dohsc\\_resource\\_draft\\_agenda\\_for\\_a\\_service\\_review\\_meeting.pdf](#)
- Tips for recruiting people affected by dementia: <https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/how-recruit-people-dementia/tips-recruiting#content-start>

## Example of Focus Group for Elders with Cognitive Decline:

- <https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/real-life-examples/norfolk-and-waveney-stp-dementia-pathway-development>

## Checklist for Information to Support People with Dementia Attend Your Activity

(Developed by the Alzheimer's Society: [https://www.alzheimers.org.uk/sites/default/files/2019-04/checklist\\_-\\_what\\_to\\_tell\\_people\\_-\\_preparing\\_to\\_attend\\_activity\\_la\\_draft.pdf](https://www.alzheimers.org.uk/sites/default/files/2019-04/checklist_-_what_to_tell_people_-_preparing_to_attend_activity_la_draft.pdf))



### Checklist for information to support people with dementia attend your activity

#### Initial invitation

Information about me form (to RSVP with needs)	<input type="checkbox"/>
Invitation letter or poster	<input type="checkbox"/>

#### Travel arrangements

Train times	<input type="checkbox"/>
Train booking reference	<input type="checkbox"/>
Taxi booking details	<input type="checkbox"/>
Bus times	<input type="checkbox"/>
Bus stops	<input type="checkbox"/>
Contact details of the taxi company	<input type="checkbox"/>
Full address of venue including post code	<input type="checkbox"/>
Photos of outside and inside of venue	<input type="checkbox"/>
Directions	<input type="checkbox"/>
Map	<input type="checkbox"/>
*Nearest station	<input type="checkbox"/>
Travel expenses and offer of help claiming them	<input type="checkbox"/>
Does the person need meeting at the station/bus stop?	<input type="checkbox"/>

#### Accommodation

Hotel details (full address, photo of what to expect)	<input type="checkbox"/>
Booking reference	<input type="checkbox"/>
Meal expenses/meals included	<input type="checkbox"/>

#### Event details

Time of event – start and finish	<input type="checkbox"/>
Venue – address / map	<input type="checkbox"/>
Purpose of the event	<input type="checkbox"/>
Quiet space	<input type="checkbox"/>
Contact names / numbers on the day	<input type="checkbox"/>

#### Pre-event information about what will happen on arrival

Who will meet them?	<input type="checkbox"/>
What are they expected to do on the day?	<input type="checkbox"/>
How much time will it take?	<input type="checkbox"/>
Who else will be there?	<input type="checkbox"/>
How many people will be there?	<input type="checkbox"/>
Whether/Where there will be a quiet area if they need to take a break before or during the activity	<input type="checkbox"/>

#### Additional needs/Reasonable adjustments

Action taken to meet all needs identified in Information about me form (for example dietary, large print, prayer space, induction loop or sign language interpreter) and person with dementia has been informed about this.	<input type="checkbox"/>
---	--------------------------

\*Check and advise about whether the station has level access – this can be helpful for wheelchair users and people with balance and co-ordination difficulties.

## Resources

- Alzheimer's Society. (n.d.a). *Dementia-Friendly Focus Groups*. Alzheimer's Society. <https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/research-methods/dementia-friendly-focus-groups#content-start>
- Alzheimer's Society. (n.d.b). *Dementia friendly signage*. Alzheimer's Society. <https://www.alzheimers.org.uk/dementia-professionals/resources-professionals/resources-gps/dementia-friendly-signage>
- Alzheimer's Society. (n.d.c). *Pads in bags—including people affected by incontinence*. Alzheimer's Society. <https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/real-life-examples/supporting-inclusion/pads-bags-including-people-affected-incontinence>
- Alzheimer's Society. (n.d.d). *Round-table workshops*. Alzheimer's Society. <https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/research-methods/round-table-workshops>
- Alzheimer's Society. (n.d.e). *Tips for dementia-friendly group discussions and activities*. Alzheimer's Society. <https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/research-methods/tips-dementia-friendly-group>
- Ataie, J. E. & Morgan, D. L. (2015). Focus groups with older adults. In S. K. Whitbourne (Ed.), *The encyclopedia of adulthood and ageing* (pp. 515–519). DOI: 10.1002/9781118521373
- Graff-Radford, J. (2022, May 27). *Sundowning: Late-day confusion*. Mayo Clinic. <https://www.mayoclinic.org/diseases-conditions/alzheimers-disease/expert-answers/sundowning/faq-20058511>
- Jones, A., Morgan-Jones, P., Busse, M., Shepherd, V., & Wood, F. (2021). Conducting focus groups in neurodegenerative disease populations: ethical and methodological considerations. *BMJ Open*. DOI: 10.1136/bmjopen-2020-041869
- KeepingBusy. (2023). *Coloring Books for Adults with Dementia: A Tool for Coping with Memory Loss*. KeepingBusy. <https://keepingbusy.com/blogs/dementia/coloring-books-adults>
- La Rue, A., & Markee, T. (1995). Clinical assessment research with older adults. *Psychological Assessment*, 7(3), 376-386. <https://doi.org/10.1037/1040-3590.7.3.376>
- MacIntyre Dementia Project. (2018). *Wellbeing for Life: Dementia Friendly Environment*. [PowerPoint slides]. MacIntyre. <https://www.macintyrecharity.org/download/file/512/>
- Trevisan, F. (2020). Making focus groups accessible and inclusive for people with communication disabilities: a research note. *Qualitative Research*, 21(4), 619-627. <https://doi.org/10.1177/1468794120941846>