

## Common Themes about the Training from Interviews from PLWD & CP



**Empowering  
Partnerships**

*Preparing People with Dementia  
to Partner with Researchers*

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Drawn from Interviews with Bob Savage, Pat Murphy, Charles Michalak, Geri Taylor, Jim Taylor, Teresa Webb

- Positive learning experiences are ones where:
  - Approached us as people – not disease. People who have something to contribute now and people whose previous lives and experiences matter.
  - Tied to personal motivation – what matters to me. My needs and hopes.
  - Communication is clear and respectful. Verbiage is very important. Keep in understandable terms, using examples and simple analogies.
- A draw for someone living with dementia to want to co-partner in research is that there is a strong understanding that “there is something in it for me.” Though being a participant in trials for the cure gives a sense of helping the cause, having a perceived specific benefit here and now is important. Part of the benefit is being ‘seen’, ‘heard’ and valued.

- Communication was a mentioned as a critical point in each interview. Everyone mentioned the importance of understanding terminology to help the communication process.

*Verbiage is VERY important. We are not ignorant or stupid, but we may not understand the words. We need things that we understand.*

- Communication also has to be respectful and not condescending. From a PLWD:

*Be patient. Don't dumb it down. Share the process by using examples vs. teaching actual terminology to make less intimidating.*

*DON'T ASK “DO YOU UNDERSTAND?” If you see someone looking like a ‘deer in the headlights’. “Let me explain this another way”.*

*You want to create mutual respect so that people feel free and are encouraged to speak out and ask people to slow down. Maybe raise hand.*

- Investment on the part of the researchers was also a topic that came up often—persons living with dementia want to know that researchers are ready and wanting to partner in a new way, and there is an appeal to see the humanness in both the person living with dementia, and the researcher.

*We are still valuable! There are still parts of our brains that work very, very well. Dementia doesn't take our intellect away right away. I'm just like you. I'm human, I have all the feelings you have, and I'm excited to be here.*

- One PLWD also felt it was important to do some “role-playing” and demonstration on how communication between a person living with dementia and a researcher might go, and some real examples of challenges and how to address them.
- All agreed that having breaks throughout the day was important for processing of information and getting opportunities to move. One PLWD was specific in his request to have a space where he didn’t feel cramped.
- Practical suggestions
  - 9-4pm. 1 hour lunch. Heavier learning in morning. People get tired.
  - Need to create atmosphere of mutual respect so people feel free and are encouraged to speak. Where everyone is patient.
  - Provide material ahead of time – to familiarize beforehand.
  - Don’t give too much in session – make additional information available for those who want more
  - Provide a bio for all participants
  - May want to split PLWD from CPs so CPs don’t take over conversations.
  - Need a quiet space to take a break.