LEAD NETWORK

Lived Experience Panel: Key Takeaways

In early 2026, the LEAD Network organized a **Lived Experience Panel,** consisting of people living with mild cognitive impairment as well as family and professional caregivers of people living with dementia. The panel discussed priorities and strategies for measuring lucidity and for future research. These are their top priorities and suggestions for researchers.

Work towards a shared understanding

We need shared words that explain what counts as lucidity and how it differs from a more common “good day.”

Balance hope with honesty

Lucidity can be beautiful and connecting, but it may also raise false hopes, especially near end of life. Be clear and honest when explaining what it may or may not mean.

Keep measurement practical

Use short forms to record lucidity, including what happened, when and where it happened, who was there, and what was going on right before and after. Build these forms into everyday care.

Protect wishes & privacy

Get consent from the person living with memory changes, their family, and/or their authorized legal representative before enrolling in research.

Consider physiological measures

Pair real-world reports with brain and body measures to learn what’s happening in the brain and whether this differs by dementia type or stage.