

How to Work with Participants with Alzheimer's

Provided by the Alzheimer's Association

A recent survey of Chronic Disease Self-Management Program (CDSMP) trainers about the relevance of CDSMP for persons with Alzheimer's and other forms of dementia (ADRD) found that these persons and sometimes their care partners or other family members participate in CDSMP workshops in significant numbers.

www.umb.edu/gerontologyinstitute/publications/longterm_care/#alzheimers

With 95% of Medicare beneficiaries with Alzheimer's disease or related dementia having at least one other chronic disease (www.alz.org/facts), it is not surprising to see many participants with a cognitive impairment attending CDSMP workshops. As a result, CDSMP Leaders will find participants living with Alzheimer's disease in their workshops who may be challenged by some of the CDSMP workshop activities.

In the survey, trainers reported the adjustments they made to the workshop to accommodate the needs of persons with cognitive impairment while still maintaining fidelity to CDSMP. Often trainers were simply doing more of what is already integral to the program or using an existing recommended optional strategy.

After review of the survey results, Kate Lorig, DrPH, the researcher who developed CDSMP, suggested that the Alzheimer's Association compile a tip sheet based on the survey responses that will provide Leaders with useful ways to accommodate persons with a cognitive impairment. The following are presented to help you make the workshop more effective, maximize program benefits and create an atmosphere that is welcoming for the person with dementia.

When working with participants with Alzheimer's disease or other dementia, the following suggestions may be beneficial:

1. Do more of what is already integral to the program (repetition); consider presenting information at a slower pace and speaking more slowly.
2. Allow the person with dementia additional time to respond to questions or report back in group activities.
3. Use optional strategies within the program (such as the buddy system), or pair participants in activities.
4. Consider having another Leader present during breaks or before/after the workshop to provide extra detailed explanations of instructions, clarify questions or conduct

follow-up phone calls between sessions.

5. Ask the person with dementia what accommodations they may need to be successful; if the care partner is in attendance, they may be able to identify the person's residual strengths and weaknesses.
6. Try to reduce distractions or ask the person to sit in front or near the Leaders; provide more reinforcement (praise, encouragement), set more modest/attainable expectations and ensure action plans are clear, concise and contain achievable goals.
7. When possible, write down step-by-step directions and allow for more note taking and writing as this can be a way for the person with dementia to remember material from the workshop and serve as a memory tool for reminders.
8. Brainstorming may be a difficult process for persons with dementia; plan to repeat the process steps for brainstorming, problem solving, and steps for action planning every time you do any of these activities.

9. Remember to speak directly to the person with dementia even if the care partner attends the workshop with them.

10. Know the 10 Warning Signs of Alzheimer's disease; take the Alzheimer's Association's free online course *Know the 10 Signs- Early Detection Matters* at <http://elearning.alz.org/Default.aspx>.

11. Learn the facts about Alzheimer's disease, take the Alzheimer's Association's free online course *The Basics: Memory Loss, Dementia and Alzheimer's Disease* at www.alz.org/index.asp.

12. Contact the Alzheimer's Association's 24/7 Helpline for additional information and resources at 800-272-3900.

Participants with Care Partners

The survey of CDSMP trainers found that Care Partners attending workshops with a person with dementia (usually a spouse) could be an added resource that increases the benefits of CDSMP and provides some hands on assistance in the following weights:

- Provides a liaison between the person with dementia and the group Leader

- Assists with the Action Plan process (developing the plan and ensuring follow-through during the week)
- Helps the person with dementia by explaining and reinforcing instructions and information
- Helps the group understand the person's contributions in group activities by clarifying, interpreting, etc.
- Takes notes to facilitate follow through and carry-over between sessions
- Assists in recalling instructions and information presented in the workshops