IN INVOLVING PEOPLE LIVING WITH DEMENTIA AND THEIR FAMILIES IN YOUR RESEARCH

What does it mean to involve people living with dementia and their families in your research?
Traditionally people with dementia and their families (consumers) have been involved in research as participants in projects or focus groups. Many consumers are eager to have a more active role in research. This involvement can occur in any stage of the research process and may include:

- Identifying research priorities
- Reviewing research proposals
- Participating in advisory committees
- Assisting with recruitment
- Commenting on methodology from a consumer perspective
- Assistance with dissemination of research findings.

What are the potential benefits of involving people with dementia and their families in research?

- Research which has greater relevance to people living with dementia
- Consumers can provide valuable advice on research methodology that may lead to greater recruitment and retention of participants
- Involvement of consumers can facilitate the translation of research into practice
- Consumer involvement can lead to new ideas and innovative approaches.

What is the Consumer Dementia Research Network (CDRN)?
With support from the Dementia Collaborative Research Centres, Alzheimer’s Australia developed the Consumer Dementia Research Network as a way of facilitating the involvement of people living with dementia in research. The CDRN is a network of individuals who have dementia and family members who care for or previously cared for a person with dementia who want to be actively engaged in research and knowledge translation. Members have a wide range of professional backgrounds and skills including in research and aged care. The network is a resource for dementia researchers across Australia. The network is possible through financial support from the Dementia Collaborative Research Centres.

The CDRN assists the grant review process of Alzheimer’s Australia Dementia Research Foundation by providing feedback on consumer involvement in project grant applications. The CDRN also advises the Foundation on key research priority areas that are relevant to consumers.

Where can I get more information about involving consumers in a research project?
For more information about the network or to discuss ways that the network could be involved in your next project please contact Dr Ellen Skladzien at Ellen.Skladzien@alzheimers.org.au or 02 6278 8927.