ALZHEIMER’S AUSTRALIA
DEMENTIA ADVISORY COMMITTEE

PRESENTATION BY KATE SWAFFER
COMMITTEE CHAIR

NO CONFLICT OF INTEREST
INCREASING CONSUMER FOCUS WITHIN ALZHEIMER’S AUSTRALIA

DRIVEN BY PEOPLE WITH DEMENTIA
AIMS OF THE COMMITTEE

Work with Alzheimer’s Australia to:

• Determine the priorities of people with dementia.
• Contribute to policy and advocacy work.
• Promote dialogue between those with dementia and service providers with a view to promoting a better understanding of their social and care needs.
• Assist in refining and evaluating Alzheimer’s Australia’s national programs.

“Being actively involved in shaping dementia policies and services, the very things that effect the daily lives of people with dementia.”
WHO ARE WE?

• 12 MEMBERS
• FROM ACROSS AUSTRALIA
• AGED 44-73
• PEER ELECTED CHAIR AND VICE-CHAIR
GETTING TO THIS POINT: THE INSPIRATION

IDEAS FROM OVERSEAS GROUPS

• The first group was the Scottish Dementia Working Group, founded in 2002
• The European Dementia Working Group was established in 2012.

POSITIVE OUTCOMES

• A review of the Scottish Dementia Working Group found that the impact from the group had been significant, and this ensured that the working group would have input into all future policy and service development in Scotland.
• For those involved it have them greater self confidence in speaking out in public and in raising awareness about dementia.
GETTING TO THIS POINT: ACTION

GATHERING SUPPORT

• Discussion with the existing National Consumer Advisory Committee.
• Consideration given by Alzheimer's Australia to the role and purpose of the group.
• Met with people with dementia to gauge interest and gain support.
• Sought support from key stakeholders in the sector who could see the benefits from being able to consult such a committee on their work.
NOTHING COULD HAVE HAPPENED WITHOUT THE INTEREST AND COMMITMENT FROM PEOPLE WITH DEMENTIA TO HELP TAKE THIS IDEA FORWARD
OUR STRUCTURE

• Free standing committee within Alzheimer's Australia.
• Members will determine direction, aims and priorities of the committee.
• Communication methods and meeting protocols are set by members.
• 12 core members of the group from across Australia.
WHAT WE HAVE WORKED ON

- Dementia Friendly Communities
- Improving dementia care in hospitals
- People with dementia living alone
- Volunteering and employment opportunities
- Younger onset dementia services and support
OUR JOURNEY OUR VOICE

BY RE-EMPOWERING PEOPLE LIVING WITH DEMENTIA TO SPEAK UP, FOR THEMSELVES, THIS GROUP WILL MAKE IT POSSIBLE FOR PEOPLE WHOSE VOICES HAVE PREVIOUSLY SELDOM BEEN HEARD, TO CONTRIBUTE TO SHAPING THE MATTERS THAT AFFECT THEM.

NO LONGER WILL WE BE TOLD BY PEOPLE WITHOUT DEMENTIA, HOW WE FEEL, OR WHAT IS BEST FOR US, AND WHilst WE STILL HAVE A VOICE OF OUR OWN, WE WILL BE ABLE TO ADVOCATE FOR OURSELVES.
“It will, I am sure, play a significant role now in mobilising our voice as people with dementia!”

- Person with dementia

“I thought this new group would be a waste of time and money, but am thrilled to see that people with dementia are still so capable of speaking up, and how productive it has been.”

- Carer, after Day 1

“Until this meeting, I feel I have not spoken for myself for over 5 years!”

- Person with dementia
“I too thought the inaugural meeting was really worthwhile and it was so good to talk to other people in our situation (both those with dementia and those who stand by us) and how we will now hopefully take a real part in the decision making that affects us.”

- Person with dementia

“It was an emotional and moving couple of days.”

- Alzheimer’s Australia staff member
WHERE TO NEXT?

CREATING A BROADER COMMITTEE NETWORK: ENSURING THE COMMITMENT AND LONGEVITY OF THIS NEW COMMITTEE WILL BE A KEY FOCUS OVER THE NEXT YEAR
At last...

It is NO LONGER

“ABOUT US WITHOUT US”