

# CONSUMER ENGAGEMENT STRATEGY POLICY AND ADVOCACY

Presentation by Phil Saunders  
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– A Global Challenge  
ADI Perth 2015

**UNDERSTAND ALZHEIMER'S  
EDUCATE AUSTRALIA**  
FIGHTDEMENTIA.ORG.AU



# STRATEGIC CONTEXT

## Alzheimer's Australia SA Strategy 2017

- ❖ KPA 1: Service Innovation and Delivery
- ❖ KPA 2: Consumer Engagement /  
Policy and Advocacy
  - Consumer engagement
  - Organisational policy capacity
  - Influencing change
- ❖ KPA 3: Organizational Sustainability



# STRATEGIC CONTEXT

## Aims of Consumer Engagement

- ❖ Effective participation
- ❖ Build and strengthen organizational ability
- ❖ Contribute to, and influence policy and service delivery
- ❖ Raise the profile of consumer needs
- ❖ Position Alzheimer's Australia SA as the lead body for specialized, evidence based advice



# STRATEGIC CONTEXT

## The Political Framework

- ❖ Government strategic plans, action plans, inquiries
- ❖ Wide range of programs at local, state and national levels
- ❖ Political awareness of the 'dementia epidemic'



# STRATEGIC CONTEXT

## Community and Individual Capacity

### Alzheimer's Australia SA's Commitment

- ❖ Engage as many people as possible
- ❖ Support the building of individual capacity
- ❖ Provide resources for policy engagement
- ❖ Provide the outcomes of policy engagement



# STRATEGIC CONTEXT

## Principles of Engagement

### Alzheimer's Australia SA Core Principles:

- ❖ Promote awareness and understanding of dementia
- ❖ Respect the human rights of people living with dementia
- ❖ Recognize the role of families and carers
- ❖ Provide access to health and social care
- ❖ Stress the importance of optimal treatment after diagnosis
- ❖ Take action to prevent dementia through improvements in public health



# REFLECTING THE LIVED EXPERIENCE

## The Consumer Voice

Why is consumer engagement important?

Central to all the activity and engagement for Alzheimer's Australia SA is the question

**What do the people living with dementia, their families and carers want and need?**

# REFLECTING THE LIVED EXPERIENCE

*“We are the real experts.”*

*“It makes it real.”*

*“To help our voices be heard we would like to ask you to step back, take a breath and pause from everyday life, give time and think about what you are saying. Listen to us.*

*Hear us.*

*We are here.”*





# REFLECTING THE LIVED EXPERIENCE

## Principles of Engagement

- ❖ Having the information needed to be involved
- ❖ Knowing what the options are
- ❖ Feeling free to express views and wishes
- ❖ Being listened to and understood
- ❖ Having views respected and heard
- ❖ Being able to influence what happens and make decisions that matter



# REFLECTING THE LIVED EXPERIENCE

## Consumer Engagement Provides

- ❖ An ethical and democratic right
- ❖ Legitimacy to decision making
- ❖ Improves policy and health outcomes
- ❖ Improves relationships with consumers
- ❖ Support to political or democratic processes



# REFLECTING THE LIVED EXPERIENCE

## Benefits for the Consumers

- ❖ A sharing of ideas, collaborative decision making, partnerships
- ❖ Increased confidence and self esteem
- ❖ Providing positive examples of living with dementia, encouraging involvement by others
- ❖ Illustrating respect for individuals and communities
- ❖ Dignity, identity



# REFLECTING THE LIVED EXPERIENCE

## Commitment

Providing people with dementia  
the opportunity to directly  
participate

# ENGAGEMENT

## Principles of Engagement Policy and Consumer Engagement

Policy development should reflect consumer views through

- ❖ Consultations and surveys
- ❖ Consumer contributions in submissions
- ❖ Consumer inclusion in events
- ❖ Direct participation rather than electronic communication



# ENGAGEMENT

## Who Is Involved?

- ❖ Many cannot or do not want to be engaged
- ❖ Barriers include time, effort, resources, access to events, personal confidence and personal circumstances
- ❖ Inclusive engagement techniques
- ❖ Web and social media



# OPPORTUNITIES

## Consumers Forums

### Sharing, Learning, Challenging

- ❖ Update on Alzheimer's Australia SA's policy engagement activity
- ❖ Consumer story or guest speaker
- ❖ Round-table discussions
- ❖ Comment Sheets
- ❖ A message for Alzheimer's Australia SA



**CONSUMERS FORUM**  
**GETTING SERVICES THAT MEET YOUR NEEDS**  
**PEOPLE LIVING WITH DEMENTIA, THEIR FAMILIES AND CARERS, SHARING AND LEARNING**

**SOUTH AUSTRALIA**  
Date: Thursday 11 March 2022  
Time: 10:00am - 12:00pm  
Venue: Adelaide Convention Centre, Adelaide  
Topic: Dementia Services

**WESTERN AUSTRALIA**  
Date: Thursday 11 March 2022  
Time: 10:00am - 12:00pm  
Venue: Perth Convention Centre, Perth  
Topic: Dementia Services

**SOUTHERN CROSS ISLAND**  
Date: Thursday 11 March 2022  
Time: 10:00am - 12:00pm  
Venue: Cairns Convention Centre, Cairns  
Topic: Dementia Services

**NORTHERN AUSTRALIA**  
Date: Thursday 11 March 2022  
Time: 10:00am - 12:00pm  
Venue: Darwin Convention Centre, Darwin  
Topic: Dementia Services

**ACT**  
Date: Thursday 11 March 2022  
Time: 10:00am - 12:00pm  
Venue: Canberra Convention Centre, Canberra  
Topic: Dementia Services

**NT**  
Date: Thursday 11 March 2022  
Time: 10:00am - 12:00pm  
Venue: Darwin Convention Centre, Darwin  
Topic: Dementia Services

**QUEST ACTIVITY**  
Date: Thursday 11 March 2022  
Time: 10:00am - 12:00pm  
Venue: Darwin Convention Centre, Darwin  
Topic: Dementia Services

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www.alzheimers.org.au

**CONSUMERS FORUM**  
**DEMENTIA FRIENDLY COMMUNITIES**  
**CREATING DEMENTIA FRIENDLY COMMUNITIES FOR PEOPLE LIVING WITH DEMENTIA, THEIR FAMILIES AND CARERS**

**NORTHERN ADELAIDE**  
Date: Thursday 11 November 2021  
Time: 10:00am - 12:00pm  
Venue: Adelaide Convention Centre, Adelaide  
Topic: Dementia Services

**FIGHT ALZHEIMER'S SAVE AUSTRALIA**  
www.alzheimers.org.au



# OPPORTUNITIES

## Reference Groups

- ❖ Regular discussions and making comment on issues as they arise
- ❖ Providing advice and guidance on issues affecting consumers
- ❖ Facilitate collaboration and sharing between stakeholders
- ❖ Identify and promote strategic partnerships
- ❖ Ensure that diverse groups contribute





# OPPORTUNITIES

## Political Representation

- ❖ Membership of delegations
- ❖ Supporting individual advocacy
- ❖ Visiting local members of council or parliament
- ❖ Letters to the editor
- ❖ Social media
- ❖ Personal submissions



# OPPORTUNITIES

## Ongoing Feedback

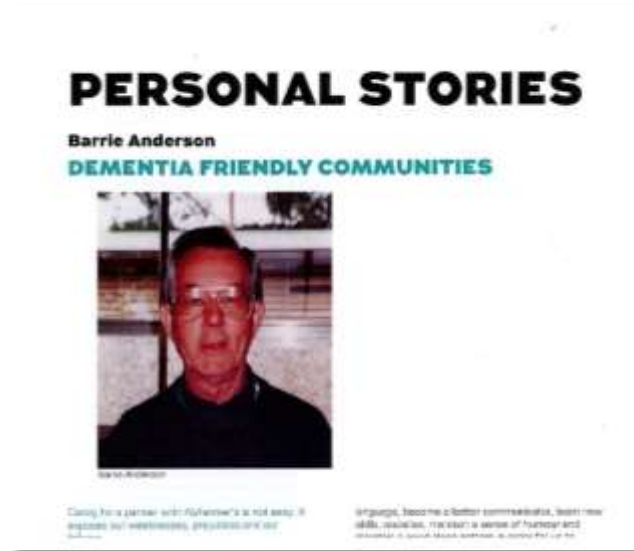
- ❖ Special Projects
- ❖ External Committees
- ❖ National Consumer Summits



# USING THE STORIES

Engagement opportunities provide the consumer voice

Consumer stories form the backbone to Alzheimer's Australia SA's policy reports and submissions



David Anderson  
**CREATING DEMENTIA FRIENDLY  
COMMUNITIES AND ORGANISATION!**



# EVALUATING ENGAGEMENT

## Questions for Evaluation

- ❖ Use of information provided
- ❖ Consumer ability to participate
- ❖ Consumer access to participation events
- ❖ Level of consumer participation
- ❖ Consumer satisfaction at their participation
- ❖ The effectiveness of the process
- ❖ Use of resource to enable participation
- ❖ The outcomes of the participation



# KEY QUESTIONS FOR ENGAGEMENT

## Themes

- ❖ The purpose of consumer engagement
- ❖ The type of consumer engagement activity
- ❖ Who initiates the engagement
- ❖ Who gets engaged
- ❖ At what stage engagement occurs
- ❖ What type of decision consumers can contribute to
- ❖ Whether consumers want to be engaged
- ❖ Choices about engagement techniques



# KEY QUESTIONS FOR ENGAGEMENT

## Organisational Commitment

- ❖ Where do we sit in the engagement participation continuum?
- ❖ Where do we want to sit?
- ❖ How can we do it?
- ❖ What do we do now?
- ❖ What do we want to do in the future?
- ❖ What can we do?



# KEY QUESTIONS FOR ENGAGEMENT

## Resourcing

- ❖ What resources are available for engagement?
- ❖ How much effort and investment is appropriate?
- ❖ How can in-kind resources be best used?



**FOR MORE INFORMATION  
CONTACT ALZHEIMER'S AUSTRALIA**

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**NATIONAL DEMENTIA HELPLINE  
1800 100 500**

AN AUSTRALIAN GOVERNMENT INITIATIVE



**TELEPHONE INTERPRETER SERVICE  
131 450**

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