CONSUMER ENGAGEMENT STRATEGY
POLICY AND ADVOCACY

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Carer, Cure and the Dementia Experience
– A Global Challenge
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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
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
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
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?
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