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Consumer Engagement
is everyone's business”

A Stronger Voice Together

Consumer Engagement Framework







A Stronger Voice Together

Genuine involvement of people with a living experience of dementia underpins the work of Dementia Australia.

Since 2021, Dementia Australia has collaborated with people living with dementia, their families and carers to co-design this **consumer engagement framework: A Stronger Voice Together**. The process included an interactive webinar on co-design, establishing a co-design working group, defining consumer engagement, identifying principles and consulting extensively with living experience experts and Dementia Australia staff.

A Stronger Voice Together commits Dementia Australia to engaging meaningfully with members of the community across the spectrum of dementia care.

Every Dementia Australia program will develop an action plan for meaningful consumer engagement. A Stronger Voice Together outlines the key factors required for the creation of action plans so we can track and measure our progress towards successful engagement and ensure continuous improvement.

Front cover: The National Consumer Summit where Dementia Advocates from every State and Territory came together to ratify **Our Solution: Quality care for people living with dementia**

Left: Dementia Advocate Steve Rule (WA)



Consumer engagement: a definition

People living with dementia and their carers are **decision-makers** in issues that impact them.

Consumer engagement is the **embedded practice** where people living with dementia and their carers are **empowered** to exercise their right to **influence decisions** on issues that impact them.

It is achieved through **accessible, intentional, respectful,** and **meaningful involvement.**

Consumers are **all** people living with dementia, their carers and families, and/or former carers who may or may not utilise Dementia Australia services.

Above: DAAC Co-Chair Dennis Frost (NSW) and Chair Bobby Redmond (NSW) hosting a meeting with members of the Dementia Australia Board, August 2023



A Stronger Voice Together Principles

Central to A Stronger Voice Together are five foundation principles that form the acronym **A.L.I.C.E.** These principles are intentionally ‘active’ and instructional in their language. This is to centre them in the minds and work of the people who will apply them most – Dementia Australia staff, Volunteers, Executive and Board.



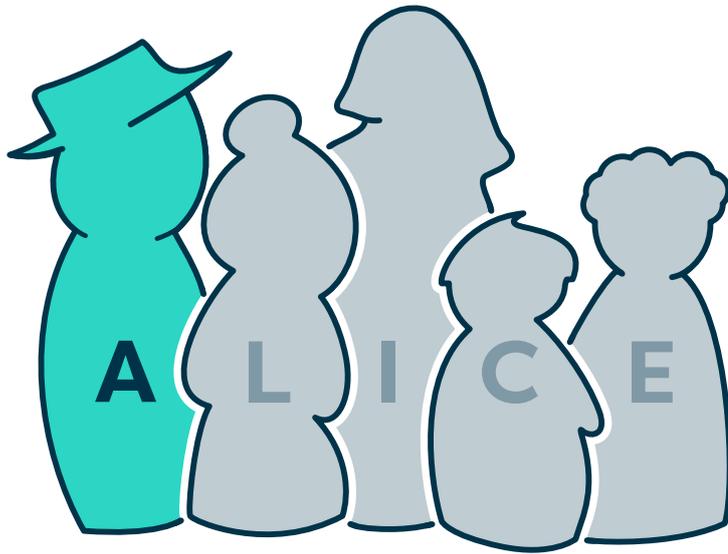




Left: Dementia Advocates, Dementia Australia staff, and Aged Care industry leaders at the National Consumer Summit in Canberra

“ It takes different experiences and expertise to understand an issue, together our voices are stronger, and together we can achieve so much more than we ever can on our own. ”

Living experience expert



Principle 1:

Authentic

Commence any involvement with authenticity. Authenticity comes from empathy. **It is a genuine desire to understand and respect the experience and perspective of a person, no matter the circumstance of the interaction.**

Being genuine in all forms of communication is critical. Patronising or non-inclusive communication undermines good intention. Choice of language is important. If you're unsure about something, seek to understand. Don't assume you are the expert. You may have knowledge and experience but authentic engagement honours all perspectives.

Authentic engagement can make a world of difference to the person accessing support from, or engaging with Dementia Australia.

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People who are authentic follow through on what they say, so you've got to **back up words with action.**”

Dementia Australia staff member



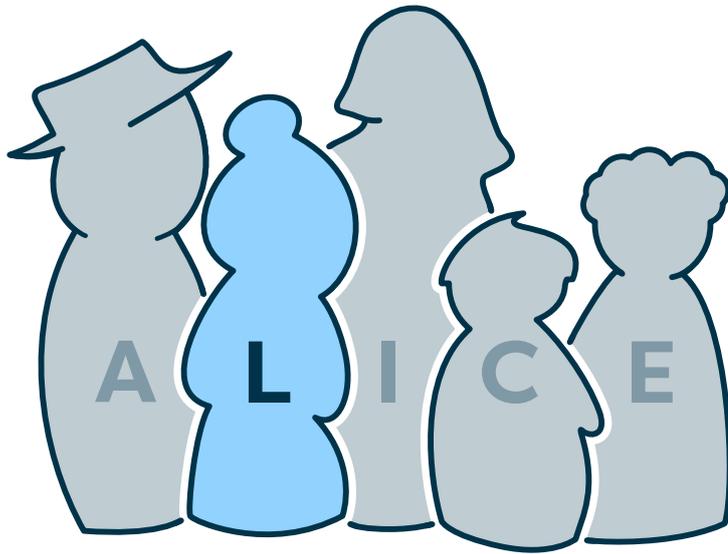
Dementia Australia Staff, Executive and Board:

- Take the time to get to know a person and have a genuine interest in them.
- Listen actively.
- Discuss people's ability to influence decisions.
- Back up words with actions.
- Are clear and real about expectations.
- Follow through on what they say and keep people informed.
- Uphold the values of the organisation.



I can **always tell the difference** between an authentic and an inauthentic experience. You may not think I can see through it, but I can. ”

Living experience expert



Principle 2:

Living Experience

‘Living experience’ is an important distinction.

We use the term ‘living experience’ to explain how someone’s experience has informed their perspective. The voices of people with living experience (people living with dementia, their families and carers) are central to our work and we elevate their voice to create positive change.

The principle ‘living experience’ challenges you to interact meaningfully with each person in the present moment, which is shaped by everything up to and including that point. Intentional and deliberate use of the current tense (living vs lived) focuses your attention on the person in front of you.

It is easy to assume that all experience is equal, but of course it is not. Ignorance and assumptions are barriers to understanding living experience. It’s important not to rely on past information. Experience is unique for each person and should not be generalised. It also changes over time - it is real and current.

“ The living experience makes it real and when I have heard someone share their experience, **I have never forgotten it.** ”

Dementia Australia staff member



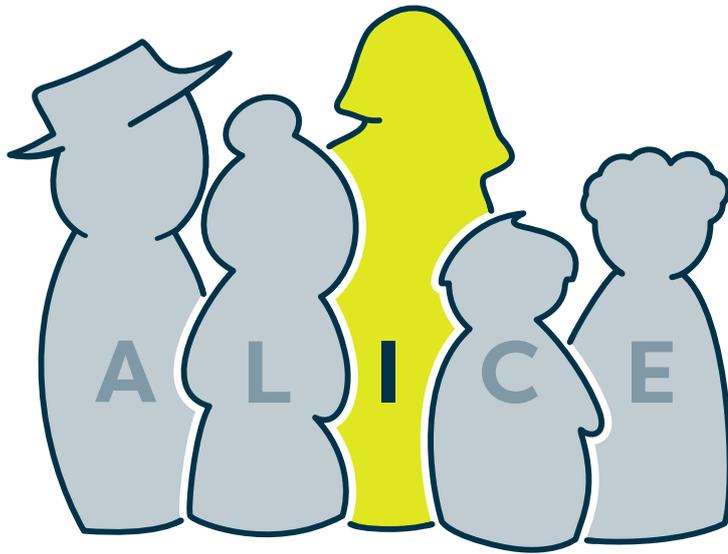
“ My own personal living experience is at **the heart of everything I am**, and I do. It’s the most important thing you need to consider when you interact with me. ”

Living experience expert

Dementia Australia Staff, Executive and Board:

- Recognise and respect the power of hearing from living experience experts.
- Are not afraid to ask hard questions.
- Don’t make assumptions.
- Know that people’s experience is insightful: it reflects an accurate and deep understanding of the complex condition of dementia as well as their cultural, spiritual, personal and professional life.

Above: Mike Barry (WA) participating in music therapy



Principle 3:

Inclusive

To be truly inclusive, it's important to consider the multiple ways someone is either included or made to feel excluded. People aren't their dementia; their diagnosis is one part of them. People aren't just one 'thing'. To truly be inclusive is to see the whole person as they are, not as they have been categorised.

It is always one person you are talking to – not a group. If it's multiple people, it's a collection of individuals, each bringing their individual self to the interaction you are having with them.

When being inclusive of Aboriginal and Torres Strait Islander, LGBTI+ and culturally and linguistically diverse communities, it is important to seek guidance from 'living experience' experts to help you effectively, respectfully and safely engage.

When we consider being inclusive, it is important to understand that:

- People can have many diversity characteristics. For example, an Aboriginal person can also be LGBTI+.
- People are more than their diversity characteristics. For example, a person from a culturally diverse background may first and foremost identify with their career as a pilot rather than their cultural background.
- People have specific experiences that cannot be generalised within diverse groups. For example, people don't live in 'regional' Australia, they live in their town or city.



Dementia Australia Staff, Executive and Board:

- Prioritise making it easier for people living with dementia, their carers and families above what's easiest for staff. We will meet people where they are, at their preferred times, places and ways.
- Are clear about the reason for engaging.
- Understand that ongoing research, consultation, and skill development is required to safely engage with people from diverse communities.
- Welcome and receive each person as equal.
- Ensure methods of engagement are accessible.

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If you want to include me - **see me as the person that I am.**

The first letter of Inclusive is 'I' ”

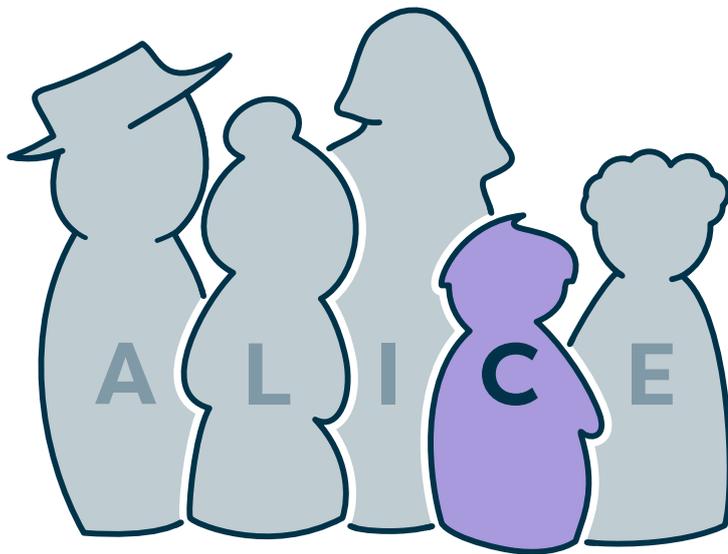
Living experience expert

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Nothing changes unless **we engage** with all our stakeholders. ”

Dementia Australia staff member

Above: Dementia Australia staff with Dementia Advocates Gwenda Darling (NSW), Natalie Ive (VIC) and Eileen Taylor (QLD) who presented at the National Dementia Conference



Principle 4:

Collaborative

Collaboration is more than a collection of people coming together to work together.

Any collaboration has a direct impact on the lives of people living with dementia, their families and carers. It's important to remember that tokenistic collaboration is transparent to those it affects. If you are 'ticking a box' by including someone in the collaboration process, it will be obvious. **Collaborative effort should start at the beginning of any engagement, not at the end as the 'final check'.**

The person living with dementia, their families and carers will feel the result of that collaborative effort more than you. It's important to ensure the collaboration has appropriate balance in the way it's constructed and delivered. One of the best things about working collaboratively with people who bring different skillsets and backgrounds to the table is learning from their experience. Being collaborative means listening and acting, not just talking.

“

If a collaborative culture is embedded from the start and with living experience experts, then **great things naturally and organically happen.** ”

Dementia Australia staff member



Above: Former CEO Maree McCabe with DAAC members Val Schache (NSW), Ann Pietsch (SA), and Dennis Frost (NSW) at a DAAC meeting

Dementia Australia Staff, Executive and Board:

- Continually build on their knowledge of co-design and co-production.
- Question from the start: ‘How is the voice of living experience being heard?’
- Are committed to a culture that includes communication and transparency.
- See people living with dementia, their families and carers as partners in their endeavours.
- Work together and communicate with each other and with people living with dementia, their families and carers for a greater outcome.
- Know that we do not always have the most accurate perspective; we understand that it takes many people, a variety of views, different types of expertise, lots of listening and working together to achieve collaborative outcomes.
- Value contribution and enjoy seeing others contribute with passion and joy, watch their confidence grow as they realise their contribution is valued.

“

Genuine collaboration is achieved when you both have **strong feelings** that you have equally contributed to the outcome. ”

Living experience expert



Principle 5:

Empowering

True empowerment comes when people are part of decision-making. Empowering people is not tokenistic. You shouldn't feel like you are empowering people simply by involving them - although it starts with involvement.

Empowerment is when the person living with dementia, their family member or carer has a seat at the table - not just as a voice, but as a decision-maker.

To empower people means relinquishing some degree of control and being comfortable with people making their own decisions.

People are empowered when they are respected and treated as equals and can influence decisions that impact them. It is more than consultation.

“ Empowerment is when we demonstrate that **we value and trust people** to make their own decisions. ”

Dementia Australia staff member



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Underpinning our dementia training is enabling care workers and nurses to listen to the person living with dementia. They can then empower the person they care for, while also acknowledging how disempowered the individual living in residential aged care can be. ”

Dementia Australia
staff member

Dementia Australia Staff, Executive and Board:

- Value and trust people living with dementia, their families and carers as decision-makers.
- Highlight the skill, passion, and strength of people’s living experience.
- Focus on the strengths and abilities of people living with dementia, their families and carers.
- Support and encourage involvement in decision-making.
- Respect the decisions a person makes about their own life.
- Look for opportunities for people living with dementia to find and use their power.

Above left:
Dementia Advocate
Sharon Jan (NSW)
with her father

“

The decisions you make have a real impact on my life as **I am the expert of my dementia.** Nothing about us, without all of us. ”

Living experience expert

Right: Dementia Advocate
Kevyn Morris (VIC) presenting
at the National Dementia
Conference

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Empowerment is
about respecting
me and hearing my
voice; encourage
me, listen to me, and
always include me. ”

Living experience expert





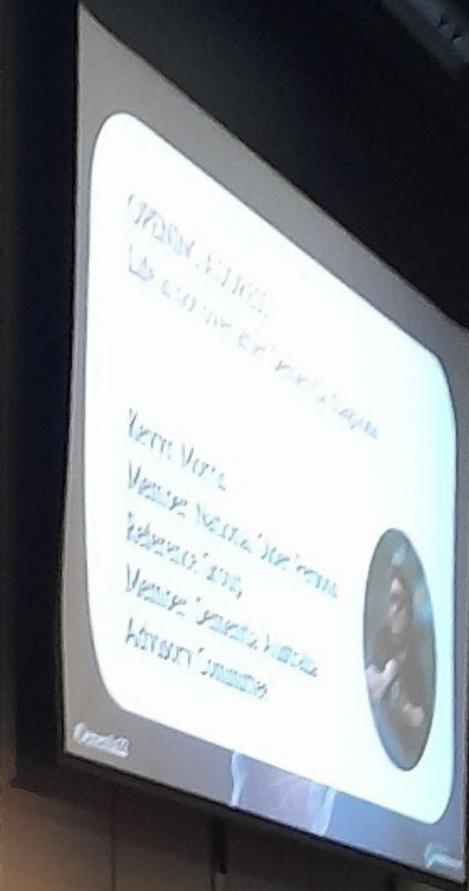
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5th annual
**National
Dementia
Conference**



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OPENING SPEECH
LIFE & DEATH OF THE MIND

Yvette Morris
Vernice Nazzari, MD, PhD
Rebecca Long
Vernice Nazzari, MD, PhD
Advocacy Committee



National Dementia Helpline

1800 100 500



For language assistance
call **131 450**

Find us online
[**dementia.org.au**](https://dementia.org.au)



Dementia Australia acknowledges the Traditional Owners of Country throughout Australia and recognises their continuing connection to lands, waters and communities. We pay our respect to their Elders past and present, and extend that respect to all Aboriginal and Torres Strait Islander peoples today.

Dementia Australia acknowledges the contribution of everyone who gave their voice to the development of this Consumer Engagement Framework and, in particular, the following members of the A Stronger Voice Together co-design group (2021-2023).

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