

Our Solution: Quality Care for people living with dementia



Introduction

The new Aged Care Quality Standards (the Standards) aim to “focus on outcomes for consumers and reflect the level of care and services the community can expect from organisations that provide Commonwealth subsidised aged care services”.

However, people with a lived experience of dementia have expressed concern that the Standards will not necessarily ensure quality dementia care is delivered. This led to a series of discussions of what quality dementia care looks and feels like, and what the key points of difference are between quality dementia care and aged care more generally.

It is only by articulating clearly what defines and differentiates quality dementia care that we can provide clear and measurable expectations for aged care providers. The term ‘care’ is used here to refer to the full spectrum of support and care, from early supports that promote and maintain independence and reablement through to more intensive forms of care and support.

People with a lived experience of dementia want to ensure that their voices are heard, that quality care involves them and that their contribution leads to greater inclusion, support, respect and ultimately, improved quality of life. This is not just about quality dementia care; it is about providing quality aged care to people living with dementia as well as their families and carers.

The essence of quality dementia care is summed up in the quote below, which recognises that dementia is not only core business but is at the heart of good care for all.

1 Aged Care Quality and Safety Commission, 2019.

“ If you can get it right for dementia, you can get it right for everyone else. ”

Person living with dementia

The priorities and recommendations included in this Communique have been developed by people living with dementia, their families and carers in the context of the Standards. The Standards need to meet the physical, social, mental health and spiritual care needs of people living with dementia across all aged care settings and from all backgrounds. This care is about supporting people to lead the lives they want to lead, filled with purpose and meaning, and where individual needs are met, respected and valued.

The outcomes of the communique and summit provide the foundation for the next stages of this broader Dementia Australia initiative on raising the quality of dementia care through the creation of baseline and gold standards for quality dementia care. The next steps include a Stakeholder Roundtable later in 2019 followed by a Dementia Symposium in early 2020.

Dementia Australia conducted 31 focus groups across Australia with 137 people participating. A thematic analysis then identified solution-focused recommendations in the context of each Standard.



This communique was ratified by a diverse representation of people living with dementia, families and carers at a national Consumer Summit on 26 June 2019.



Recommendations

These recommendations outline what organisations need to do to make dementia core business. Each of the eight Standards has a dementia-specific recommendation on how that Standard needs to be met when providing any aged care service to a person living with dementia, their families, carers and advocates.

1.

Understand diversity and maintain identity through relationships

Standard 1 – Consumer dignity and respect

Key themes:

- Trained, caring and empathetic staff
- Relationship building and taking time to get to know the person
- Patience
- Respect
- Maintaining identity
- Human rights
- Confidentiality

The organisation demonstrates the following:

- The workforce understands and recognises the diversity of dementia through building personal relationships with the person living with dementia, their families, carers and advocates.
- Additional time is allocated for the workforce to care for a person living with dementia, to understand their needs, behaviours and potential triggers.
- All levels of the workforce are trained to communicate effectively with the person living with dementia, their families and carers, with a consistent focus on respect and empathy.
- There is a focus on active involvement with the person living with dementia, their families, carers and advocates in decision making and every day choices.
- The workforce demonstrates knowledge and practice of what is important to the person living with dementia and respects their preferences through a human rights and person centred approach to care.
- There is acknowledgement and inclusion of the person living with dementia as a valued member of the community through engagement, recognition and participation in activities and social gatherings.
- There is acknowledgement of dementia as a disability.

“ The most important thing is that the care worker has empathy and recognises that individual person not just as another person they need to shower and feed – this is Grace*, she likes wearing lipstick and these clothes, she still has her identity and this is very important. ”

Carer

“ It is having the time to spend with people. Getting to know who they are, their likes and dislikes. That’s what matters. ”

Carer

“ Every person with dementia is different and every day is different. ”

Carer

“ Maintain my identity – let me do the things I can do. ”

Person living with dementia



2.

Involve carers and advocates as vital partners in care

Standard 2 – Ongoing assessment and planning with consumers

Key themes:

- Important role of informal carers, family carers and advocates
- Shared and supported decision making that centres on the person with dementia
- Ongoing documentation of a person's life
- Participation
- Advance Care Planning
- Educating care workers and other staff

The organisation demonstrates the following:

- Active involvement of families, carers and advocates with the person living with dementia in supported decision making in all assessment and care planning processes.
- Advance Care Plans and Directives are created and in place at the point of dementia diagnosis, with involvement of the person living with dementia, their family, carer or advocate.
- Initiation of the review of care plans is undertaken in a collaborative process between the workforce families, carers and advocates.
- The workforce undertakes dementia-specific training and gains an understanding of the person's life to appropriately assess and respond to their personalised care needs.
- There is timely and ongoing communication between families, carers, advocates and other care staff to share information about the person living with dementia through written documentation.
- The workforce continually monitors, assesses and adapts their communication and engagement with the person living with dementia as their support and care needs change across the disease trajectory.

“ Carers know the needs and aged care workers need to respect the carer where the person living with dementia can't speak for themselves. ”

Carer

“ Having relationships with my carers will ensure I can access more services and supports when I need them. ”

Person living with dementia

“ Gold standard care can only be realised when there are true partnerships with everyone that interacts with dementia services. ”

Carer

“ Involve family who knows me well to make decisions. ”

Person living with dementia



3.

Flexibility in provision of care and how and when services are received

Standard 3 – Personal care and clinical care

Key themes:

- Flexibility and continuity of care
- Respect
- Hygiene
- Personal appearance
- Medication management
- Nourishment and diet
- End of Life Care

The organisation demonstrates the following:

- Personal care and clinical care is delivered flexibly (timing of meals, bathing and administration of medication) and is tailored to the needs of the person living with dementia.
- The workforce shares information about the person living with dementia with co-workers and communicates those needs across shifts.
- The workforce is trained to recognise triggers, verbal and non-verbal signs of pain/discomfort in the person living with dementia.
- The workforce meets the evolving personal and clinical care needs of the person living with dementia irrespective of the stage of dementia, geographic location, cultural needs/responsibilities, sexuality or financial status.
- The person living with dementia receives timely, respectful and holistic personal and clinical care involving families, carers, advocates and relevant health and clinical care professionals to assess and respond to ongoing care needs.
- End of life care is responsive to the individualised care needs of the person living with dementia, and involves their families, carers and advocates.
- Overprescribing of medication is avoided and families, carers and advocates are engaged in a timely way if considering any form of physical or chemical restraint.

“ I did handover of meds but the provider came and asked specific questions of her routine, waking, showering, breakfast preferences, bedtimes, bedtime routine, and they actioned this too. This has definitely helped. ”

Carer

“ Staff call the person living with dementia aggressive, but they are scared, have unmet needs and don't have a voice. ”

Carer



4.

Inclusion in community, meaningful activities and decision making

Standard 4 – Services and supports for daily living

Key themes:

- Meaningful activities
- Inclusion and participation
- Quality of life
- Independence and autonomy
- Risk taking
- Arts
- Nature

The organisation demonstrates the following:

- A range of meaningful activities are offered to include the person living with dementia (tailored to individual need, disability and stage of dementia).
- The workforce, families, carers and advocates assist the person living with dementia to participate in meaningful activities and maintain a sense of community connectedness.
- The person living with dementia is supported to take more risks to participate.
- The person living with dementia is given responsibilities (tailored to their abilities) to remain independent.
- Creative arts, music, access to nature, and physical activity are brought into all aged care settings to help improve the quality of life of the person living with dementia.
- Active care plans are developed and updated to promote physical health, ability and mobility as key elements of care for the person living with dementia.

“ I want to live a meaningful life with activities that suit my declining abilities and maintain my relationships with the people who are important to me. ”

Person living with dementia

“ For people living with dementia appropriate activity and entertainment is important. Inclusion and recognising their individuality. ”

Carer



5.

Community/home-like setting design, look and feel

Standard 5 – Organisation's service environment

Key themes:

- Home-like setting, look and feel
- Ability to move around freely – enabling
- Dementia villages
- Sense of community
- Personal belongings

The organisation demonstrates the following:

- Adjustments are made to the care setting/service environment to make a person living with dementia feel more at home, including the consideration of culture, language, religion, and sexual diversity.
- The workforce facilitates options for the person living with dementia to move freely around the space (indoors and outdoors) and live as autonomously as possible.
- Clear signage is displayed for where and what things are, which meets dementia friendly standards and is language specific.
- The layout of the service environment is dementia friendly. This could include using contrasting colours for floors, walls and furnishings for visual identification.
- The service environment allows for personal belongings, should the person living with dementia wish to have them, to create a sense of familiarity and identity.
- Where possible, the care setting should be set out as small group homes that welcome family and carers and allow them to come and go as they please, including encouraging flexible visiting hours.
- The built environment enables the person living with dementia to continue to participate in day-to-day activities, such as cooking and cleaning. It could also include pets/pet therapy where appropriate.

“ Having chooks and animals, I think is fantastic. One of the fellow's job is to collect the eggs. It is like a colonial cottage. It doesn't look like a hospital, it doesn't feel like a hospital. ”

Carer

“ A good aged care service would allow people to attempt things. Where everyone has their own space in the community and are free to move around, get a coffee and cake. It's like being at home. ”

Former carer

“ At a minimum, environments must be enabling. ”

Carer



6.

Feedback and complaints taken seriously

Standard 6 – Feedback and complaints

Key themes:

- Enabled participation
- Issues raised taken seriously
- Involvement of carers and families
- Alternative communication
- Ongoing and continuous assessment

The organisation demonstrates the following:

- The workforce takes feedback and complaints raised by the person living with dementia seriously and does not discount it because of their dementia.
- The workforce actively involves carers, advocates or family members in feedback and complaints processes to get a fuller and more accurate picture when the person living with dementia is unable to communicate their own concerns effectively.
- The workforce is trained to understand non-verbal communication and recognise when there is a potential issue to address for the person living with dementia.
- The workforce actively seeks feedback from the person living with dementia as they may not initiate this themselves or know how to.
- There are a number of alternative ways to engage the person living with dementia in the feedback and complaints process through collaboration with families, carers, advocates and the person themselves; for example, understanding behaviour, frustration, changes in mood as indicators of potential concerns.
- No negative repercussions come to the person living with dementia, their family, carer or advocate for raising a concern or making a complaint.

“ There needs to be partnership with carers – the person living with dementia may not realise there is an issue and it is the carer who notices. ”

Carer

“ Everyone needs an advocate. Advocates need to be appropriately informed of all the governance issues of the organisation. Need to know all the government stuff and the advocates need to understand the individual person – their background and surrounding issues. Sort out the issues. Advocates separate from family when there is no family. ”

Carer



7.

Dementia trained staff

Standard 7 – Human resources

Key themes:

- Dementia specific training for all staff and carers (including family carers)
- Empathy and compassion
- Ongoing workforce training and development
- Dignity and respect
- Respectful communication

The organisation demonstrates the following:

- Mandatory training in dementia for all people studying aged care.
- The workforce receives ongoing, competency based education and training about dementia while in caring role.
- The workforce is tested on their level of dementia awareness, knowledge and friendliness across the different stages of the disease.
- An increase in the number of staff to create the right mix of skills to meet the needs of the person living with dementia. A combination of clinical, allied and occupational health staff are in evidence.
- When recruiting care staff, organisations ensure personal qualities of empathy, respect, compassion, kindness and patience if they are to be caring for a person living with dementia.
- The workforce forms mutually respectful relationships with families, carers and advocates of the person living with dementia and seeks information from them to better meet the care needs of the person.
- There are aspirational goals for an equal gender ratio of staff.
- The workforce receives end of life care training (including grief support).
- All staff (regardless of role) and residents receive dementia awareness and inclusion training to meet the needs of the person living with dementia, their families, carers and advocates.

“Caring for people with dementia you have to have tremendous patience – the levels of frustrations can rise very quickly and for some people it can lead to intolerance of the person you are caring for.”

Carer

“Home and aged care facility staff would: Have skills in empathetic communication and validation of a person's needs. Know what activities are meaningful to a person with dementia based on their life history. Know how to deal with behavioural symptoms of dementia that arise from unmet needs.”

Carer

“If people are happy in the facility that is the bottom line. If you walk into a facility and the residents are calm and relaxed are moving around and equally the staff are happy and outwardly acknowledging people – that's the sort of thing you want to see that's the atmosphere you want and staff need to create this.”

Carer

“Consistent and knowledgeable staff improves my wellbeing and makes me feel safe.”

Person living with dementia

“For any worker coming into my home they need an understanding of what dementia is, we need real education not just the book work. People need to UNDERSTAND IT (dementia).”

Person living with dementia

8.

Change in leadership and culture to understand and support dementia

Standard 8 – Organisational governance

Key themes:

- Leadership
- Cultural shift
- Appropriate resourcing
- Accountability with a major focus on clarity and measurability
- Transparency
- Communication and information sharing at all levels of the organisation

The organisation demonstrates the following:

- There is a cultural change at all levels of the organisation, with overarching accountability measures and monitoring mechanisms that meet the needs of the person living with dementia, their families, carers and advocates.
- Leaders promote a culture which focuses on understanding and responding to the needs of the person living with dementia and supporting staff to provide support and care from a sound understanding of the person.
- There is a cultural shift in valuing dementia care and educating staff at all levels of the organisation of the specific needs, forms and stages of dementia.
- The workforce is collaborative and exchange information about the person living with dementia across all levels of the organisation while maintaining the person's privacy.
- There is transparent accountability for quality dementia care, with key performance indicators that are specific, clear and measurable, and embedded into practice (as informed by the eight recommendations).
- Experts in dementia and/or people with a lived experience of dementia are included on organisational boards to help inform service delivery.
 - Leaders interact with the person living with dementia, their families and carers.

“ People with dementia need to represent themselves and be included as equal partners and decision-makers on boards and advisory groups. ”

Person living with dementia

“ There must be the 5 Rs – Right People, Right Training, Right Place, Right Time and Right Pay. ”

Former carer

“ At the end of the day – quality of care comes down to the personal relationship between the individual resident and the care worker. The super-structures around it have to support the development of this core positive relationship. ”

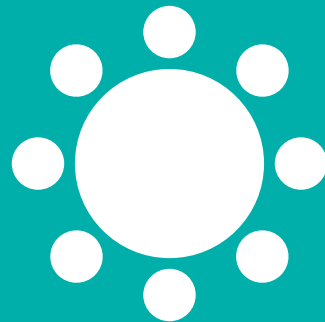
Carer

“ As the person with dementia on the panel, I remind everyone why we are here and who benefits from the decisions being made. ”

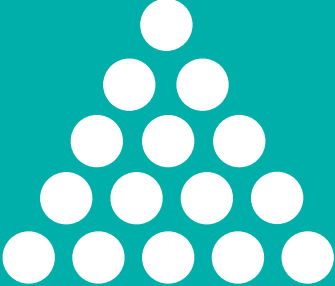
Person living with dementia

“ The risk averse culture needs to change. It's about trust and sharing. ”

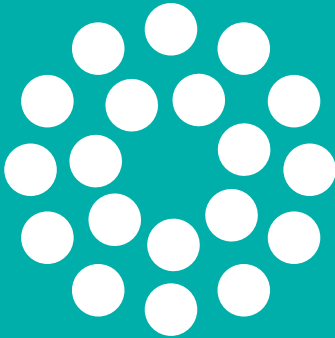
Carer



**Stakeholder
Roundtable
2019**



**Consumer
Summit
2019**



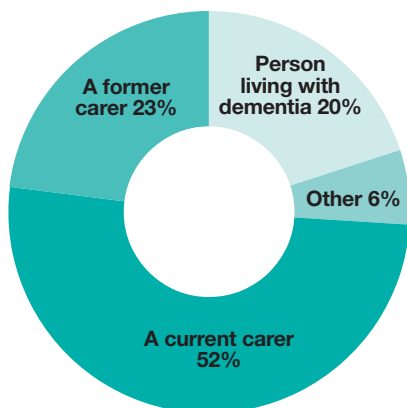
**Symposium
2020**



Who are we?

The voices behind the recommendations.

Participants



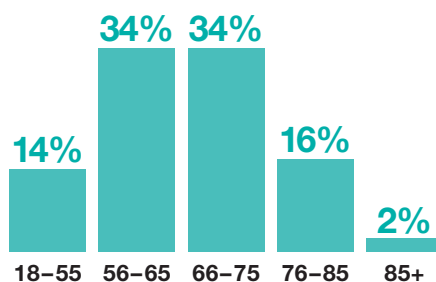
Diversity



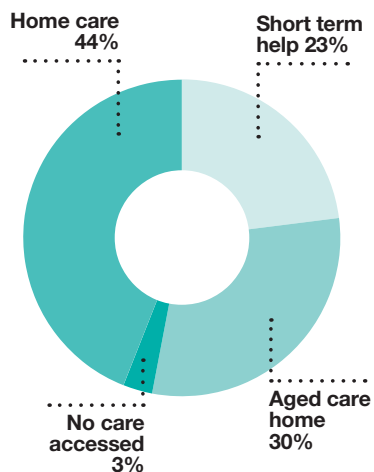
Gender



Age breakdown



Services accessed



Location

Focus groups

Where we live

