

Summer 2019

COMMUNITY *Care* REVIEW

Australia's magazine on home and community-based care and support



Dementia Australia

National Symposium sets priorities for change

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Quality time with dementia

Dementia care IS quality care, Dementia Australia tells CAROLINE RICHES, and it's time to talk priorities.

The stories of neglect unveiled by the Royal Commission into Aged Care may have shocked Australians, but within the aged care sector, they've stirred mixed emotions.

In the industry, there's a gratitude for a spotlight on problems that must be fixed, alongside a sadness, almost indignation, over the wonderful policies and care that remain in the shadows.

But perhaps overriding even that is a sense of hope. Those in the residential and community aged care sectors seem united in the belief that now is the time for change. Big change.

When Dementia Australia (DA) was formed back in 2017, following an amalgamation of separate bodies, its key figures also believed it was time to set a new strategic direction.

"Despite significant reforms, reviews and changes for those with dementia, there has not been substantial change in 10 years," Dr David Sykes, Director of DA's Centre for Dementia Learning, says. "It still hasn't."

With the royal commission's current focus on poor performance, Dr Sykes believes it's even more crucial to look at all the good that is happening and what else can be done.

"It's a watershed moment in aged care and dementia care," he



Dr Lisa Trigg



Dr David Sykes

says. "It's about balancing out the negativity by saying 'what can we do, what are the priorities we need to focus on?'"

DEMENTIA CARE IS QUALITY CARE

This is the task of the upcoming Dementia Australia National Symposium - Dementia Care is Quality Care, which will take place in Sydney on the 24th March 2020. Both local and international speakers will present on how to raise the quality of dementia care both in residential aged care and in the community.

The symposium will also hear from key providers across the country on what they're already doing right.

The event constitutes the third stage of one of DA's strategic priorities, which focuses on quality dementia care – what it looks and feels like, how it is different

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or distinct from quality care more generally, and how to embed it constantly into practice.

This initiative on quality care is closely linked to the other two priority areas in DA's five year strategic plan: timely diagnosis and support, and reducing discrimination.

"On average it takes someone three years to get a dementia diagnosis so that's three years where someone doesn't know what's going on, isn't getting support and can't plan for their future," says Dr Sykes.

"What flows on from that is poor data sets on the number of people who have dementia, which makes it hard from a service planning point of view. In residential care it's hard to determine what percentage of people have dementia; in community care it's even harder.

"This is why we need to make dementia care central to aged care."

When you're not sure how many people in your service have dementia, and you have many staff without dementia training, that's a "pretty dangerous combination", says Dr Sykes. "It's not surprising we have a royal commission called to look at quality of care."

"There is a lack of capability around dementia, and a lack of support, guidance and assistance with the delivery of care," he adds. "That combined with the strong stigma around dementia adds to the problems of identifying it and stops people talking about it more openly. Essentially," he says, "it's a human rights issue."

PRIORITIES SET

With the agenda of priorities set, DA went on to the first stage in its plan, holding the National Consumer Summit in Canberra in June, which resulted in the communique *Our Solution: Quality Care for People Living with Dementia*.

This communique was presented in July to Senator Richard Colbeck, Minister for Aged Care and Senior Australians.

The communique recommends eight standards that are based heavily on the views of those with a lived experience of dementia. These include understanding diversity and maintain identity

“This is excellent timing for Dementia Australia’s national symposium to discuss quality care - and human rights needs to be at the centre of how it is delivered” – Dr Lisa Trigg

through relationships; involving carers and advocates as vital partners in care; flexibility in provision of care; inclusion in community, meaningful activities and decision making; a community/home-like setting design, look and feel; feedback and complaints taken seriously; dementia trained staff; and change in leadership and culture to understand and support dementia.

But while having these steps is one thing, engaging peak bodies, providers and regulators in the aged and community care sectors to adopt them is quite another.

This was the aim of DA's National Stakeholder Roundtable, the second stage of the plan, which took place in Melbourne in November. Key points were presented to around 25 key industry figures to seek their agreement and develop an action plan.

"We want to make these points part of an experience that is consistently something that someone living with dementia is likely to have," says Dr Sykes. "And we need to develop a plan with the sector to make this happen."

DA is currently working with the key stakeholders to achieve consistently quality dementia care through the development and implementation of the action plan. Alongside existing work that's evolving, partly in response to the royal commission, there is hope that this will help the industry lift its game, combat key issues and be more inclusive of people living with dementia, says Dr Sykes.

The third stage of the DA's work to improve the quality of dementia care is next year's national symposium. This will provide an opportunity to report to a wider group what is being done on the back of the communique's recommendation of standards and the roundtable discussion, as well as focusing on key issues around leadership, the definition of quality care, and the importance of workforce and training.

Speakers at the symposium will include Janet Anderson, Aged Care Quality and Safety Commissioner; Professor Dawn Brooker, Director of the University of Worcester Association of Dementia Studies UK; Dr Lisa Trigg, Assistant Professorial Research Fellow in the Personal Social Services Research Unit of the London School of Economics; and Professor John Pollaers, Chancellor of Swinburne University and former chair of the Aged Care Workforce Strategy Taskforce.

Ita Buttrose, Ambassador of Dementia Australia and Chair of the ABC, will close the day by sharing her insights on her own leadership and culture change experience.



Delegates at a recent Dementia Australia symposium.

Delegates will learn new tools, including how to ensure a quality workforce that is engaged to create change and how to better use technology in care. They will also have a fresh understanding of examples of alternative care models and how the co-creation and co-design of services can better meet the needs of those living with dementia.

THREE CONSIDERATIONS FOR QUALITY CARE

When it comes to quality care, UK-based Dr Trigg will explain that there are three types of quality that need to be considered, based on her extensive research in residential aged care homes in both England and Australia.

These are outlined in her report, *Improving the Quality of Residential Care for Older People: A Study of Government Approaches in England and Australia*. The first is organisation-focused quality, where providers are most interested in making sure their residents are safe and well, and receive the same standard of clinical care. "This type of quality is important for all residents, but for some providers, it's as far as they go," she says.

The second is consumer-directed quality, where providers treat residents and their families like customers or "consumers". They focus on things that help them attract new residents and their families, like the design of accommodation or type of activities on offer.

The third is relationship-centred quality, the best type of quality, where the person needing care is treated as an individual with his or her own personality, regardless of how unwell they are.

"This is being cared for by someone in a compassionate and supportive reciprocal relationship," says Dr Trigg. "Even though someone may have the late stages of dementia, they are still a person with their own individuality and personality."

Dr Trigg is grateful for the Royal Commission, at which she has presented, for highlighting what she describes as the reality of aged care in Australia. "There are some providers out there doing a brilliant job, but when it's awful, it's really awful," she says.

"This is excellent timing for Dementia Australia's national symposium to discuss quality care - and human rights needs to be at the centre of how it is delivered."

Dr Sykes says he believes that whilst there is poor data he suspects that the percentage of the aged and community care sectors that are already adhering to the standards outlined in Dementia Australia's communicate to be "very low".

"The commission has been an important wake-up call and is a great opportunity for the sector to really address those poor performers, and get some greater focus from government."

Dr Sykes felt "With the changes we've spoken about, I think we can really commit to seeing a change - consistently - in dementia care."

It all comes down to leadership, he says.

"Leadership shapes culture and culture shapes practice and practice has the ultimate impact on the person with dementia. It's time for people to stand up and take up that leadership responsibility, in government, within their organisation and across the sector."

"This symposium is about seeing what's possible." ■

The Dementia Australia National Symposium will be held at The Fullerton Sydney on March 24 2020 with early bird tickets on sale till 15 January. To register, please visit www.dementia2020.org.au

THE CONSUMER MYTH

People living with dementia should not be treated or referred to as consumers, says Dr Lisa Trigg at the London School of Economics, because the term is inaccurate and therefore, problematic.

Consumers have agency and power, she says. People with dementia often do not.

"I want to dispel the Australian idea of people with dementia being 'consumers'," she says. "Consumers are people who are empowered. They have the opportunity and the information to make good decisions."

"Consumers buy a laptop, they'll take time to ask around, they'll look online and go and look at some. They have the opportunity and the information to think about the purchase very carefully. And if that laptop breaks down, they can do something about it."

For people with dementia, they often don't enjoy such luxuries. Take someone in community care, who in a time of crisis - say they are injured or ill or have lost a partner - is looking to move into residential care. It is extremely hard for them to make an informed choice as a consumer, says Dr Trigg.

"The information available on residential homes in Australia isn't meaningful or adequate," she says. "There are

no reviews or honest accounts of what it's like to live there, or what it's like to access those services."

Plus if there is a problem, it's hard to have a voice.

"The complaints process is often inadequate or informal," says Dr Trigg, who will speak at Dementia Australia's upcoming National Symposium. "If you're an 85-year-old woman in a care facility and you're incontinent and you have dementia, your daughter is unlikely to complain because of retribution, which has been highlighted in the commission."

She believes Australia needs a definition of quality that reflects the needs of people with dementia, and not consumers. "The government needs to be clear what quality care looks like and what can we expect from our providers."

Consumer-directed quality must be replaced with relationship-centred quality, she says. We're not trying to attract the business of someone with dementia, we're trying to look after them.

"The most important priority for these care homes is to help families form good relationships so that everyone feels that they matter," she says.

And this applies to community care as much as residential aged care.

"People just need to be nurtured."