Experiences of dementia: stories from those who care

A recent symposium in Sydney for family carers and friends of people living with dementia was an opportunity for participants to share their stories and ideas, and access support from each other. The stories also offer valuable insights for professional carers.

Katherine Guinane, Jane Mears and **Gaynor Macdonald** report

Caring in the context of dementia is unlike any other experience. Carers can learn so much from those who have walked similar paths. In September 2018 a one-day symposium, *Experiences of dementia: stories from those who care,* brought together over 50 familial carers (family members and friends) to do just that. It was an event of the Dementia Reframed project, which we launched in 2016 to examine ways of looking at dementia beyond the medical understanding of cause and treatment. The symposium, at the University of Sydney, provided a unique opportunity to hear from those with first-hand experience of the day-to-day of 'living with dementia' as a carer – those who are the experts in what it means to care at home for someone with dementia.

Co-author Dr Gaynor Macdonald's husband Charlie Eldridge didn't let advanced Alzheimer's stop his enjoyment of family photos and the company of his granddaughter, Natalie Anderson, who has just begun her nursing training. Photo: Gaynor Macdonald

Stories and their value to carers

Stories are an important way for carers to access ideas and support. We put out a call for informal carers to 'tell their own story'. We asked people to focus on their personal experiences of caring at home rather than institutionally-based care, or work done with care organisations. We were delighted to have people with dementia share their strategies for remaining independent as well as being cared for. Some participants used PowerPoint or notes, others spoke more informally.

Stories are not like 'advice': as one listens, one can imagine, reflect, work out what is and is not like one's own experience. As one of the symposium participants said: *"I liked the idea that experiences are often more helpful than blanket advice"*. So when we listen to someone explaining how she helped her father come to terms with the fact that he couldn't drive anymore, it isn't exactly our situation but we recognise parallels, see things that might work, because we're about to confront a similar issue. So stories help us imagine our own possibilities. *"So much of what was talked about really resonated with me in relation to both my father's situation, as well as the stories of many families that I have worked with over the years."*

A universal concern expressed by those at the symposium was that skills and insights acquired by carers are overwhelmingly undervalued, particularly in an arena dominated by biomedical models and the expertise of professionals. The stories shared made clear that there is no 'one size fits all' but that sharing experiences does communicate a range of strategies as well as being emotionally supportive. *"I learned so much and was particularly interested in the different ways different people dealt with the issues as they arrived,"* explained one participant.

"It was a most enjoyable and stimulating day – the problems and issues are all similar and there is a common thread," said another. These threads included*:*

- the need to understand the importance of supporting familial carers
- ways to involve the wider community in support
- developing effective advocacy (both at the level of individual cases but also at the level of government planning)
- awareness of the importance of self-care and what this means in practice.

What really stood out were the amazing ways in which people had been able to turn around very burdensome, negative experiences with the support and insights of others. For some, this meant relationships with other carers, or engagement with carer networks; for others there had been transformative educational experiences – including two great stories about the positive impact of doing the courses offered through the Wicking Dementia Research and Education Centre (University of Tasmania).

The importance of 'home care' and support for carers

The stories were also ways to see what is needed to make our society one that really does care for its most vulnerable members. The carers told us that too little attention is given to people being cared for in the familiarity and safety of their own home, by people who know the person requiring care. They felt excluded and devalued. It is not hard to understand how a person may like the comfort of their own bed and bedding, as well as surroundings they are familiar with, particularly when they are experiencing the anxiety and uncertainty that dementia can bring.

New website, resources for carers

The *Experiences of Dementia* Symposium was an event of the Dementia Reframed project (see *AJDC*, Aug/Sept 2018, pp22-24, *Reframing dementia: the challenge to change*). The Project's revamped website (www.dementia-reframed.com.au) will be available soon.

This project has two foci: changing social attitudes to allay fears and ignorance about dementia; and providing resources for informal carers that are grounded in the experience of those who care. This is an initiative of carers, for carers.

We are committed to bringing the needs of dementia carers to the fore, providing ways to learn from each other, letting them know they are not alone, and pointing them to resources that are not always easy to find. With this in mind, participants to the symposium were asked to contribute their stories in written form. These will form the core of a publication for dementia carers (working title: *Stories from dementia carers: learning through sharing*).

They will also contribute to a new website for dementia carers, Dementia Carers Australia, which we will launch by mid-2019 (www.dementiacarers-aust.com.au). It will include insights from experienced carers, enriching stories, and links to useful resources and organisations.

We are planning another workshop for carers in late 2019/early 2020, titled *Dementia carers supporting each other: a knowledge and skills exchange*.

To join the Dementia Reframed project mailing list to receive future updates, email Gaynor Macdonald at gaynor.macdonald@sydney.edu.au.

Katherine Guinane, Jane Mears, Gaynor Macdonald

Similarly, it is more likely that familiar people will understand the personality and needs of the person for whom they are caring, the things and forms of care this person enjoys – like wanting their scrambled eggs soft – and even the types of things that annoy. Passing on such understandings to a professional carer can risk locking a person into an idea of them that doesn't adjust over time. Several presentations indicated that knowing a person in such a way as to develop a level of intuitive understanding lessens anxiety for both carers and those being cared for.

All the speakers were concerned about how little support there is for home carers – except providing professional carers if they are eligible. It was not uncommon for carers to be told, 'you've used up all our services'. There is little community and educational support for familial carers. Presenters spoke of the need for support from a wide range of people in the community if they are to effectively provide care: this is not something any single individual can provide.

Participants had lots of ideas to encourage better understanding of dementia across the community, including: children's books about people with dementia; involving schools in changing attitudes towards dementia; and dementia-friendly cafés where people can feel safe and understood. One participant spoke of what it had meant to her to receive support from a local surf life saving club.

Some carers had supportive workplaces that provided flexible hours, while others felt they needed to give up working, sometimes because of unsympathetic employers, or to move to a different area to gain access to services. But the benefits of carers being able to stay in their chosen field of work were also evident.

A wonderful treat on the day was the specially-created performance of *Don't knock your granny*, by the Older Women's Network (OWN). They had us laughing, crying and thinking hard – all at the same time!

Relationships and networking

These carer stories indicated that, in most cases, current systems (medical, government) failed them and were ill-equipped when it came to providing support on how to care. They talked of the stress and confusion of navigating a complex and incoherent 'system'. *"Even with my background I had such a hard time getting my father's needs recognised and was minimalised* [sic] *at every turn by health professionals."* Presenters remarked on the lack of collaboration between service providers, and too little attention given to involving family.

While some spoke of the helpfulness of professional workers, others spoke of feeling powerless in the face of what they were 'told to do' by experts. They spoke of how difficult it was to deal with 'professionals' whose (usually biomedical) understandings of illness often meant they were not insightful in communicating how to care for someone with dementia, or they made well-meaning but onerous suggestions. One participant commented, *"There are lots of ideas and activities 'out there' but what do we actually know about carers' perceptions of the practicalities and the payoff for what these involve?"*

The need for effective advocacy was a strong theme. Comments included: *"There is an ongoing need to be vocal in opposition to government policies which further disadvantage the vulnerable"* and *"There must be an equal focus/inclusion on home care compared to residential care"*.

Stories highlighted the critical importance of effective self-care. Perhaps the strongest theme to emerge was the need for effective ways to network – to share knowledge and gain support; for instance, more community-run workshops providing opportunities to learn from other carers. Carers need to be able to communicate the difficulties of caring and explore ways these might be overcome.

The act of sharing the stories was clearly a source of comfort and was inspirational – with lots of excellent, practical ideas for dealing with the emotional experiences of care. One

Co-author Katherine Guinane made this tree for the symposium and distributed paper leaves on which participants could write their ideas and comments. These were then added to the tree during the day

person described having felt “trapped in someone else’s disease”; others spoke of powerful feelings of guilt as they negotiated the tensions between their own needs and those for whom they cared. They shared feelings of isolation and loneliness as intimacy in a relationship changed. Learning that one was not alone, even if there were no easy answers, was a support in itself. Caring involved learning to “let go of what you thought life would be like”, to “roll with the punches”, and accepting there “is no right way”, one does what one can.

“It was a very moving experience to listen to the stories of many other caring women and men … my own caring journey has changed my life in so many ways, so many stories resonated with my own and in particular the refusal to be defined or stigmatised by the unexpected changes”. “I cherished the insight [from another participant], ‘You don’t know how strong you are until strength is the only way forward’ ”.

From left: Katherine Guinane is a Research Assistant in the Department of Anthropology, University of Sydney; Dr Jane Mears is an Associate Professor in the School of Social Sciences and Psychology at Western Sydney University; Dr Gaynor Macdonald is a Senior Lecturer and Consultant Anthropologist in the Department of Anthropology, University of Sydney. To follow up on this article, contact Gaynor at gaynor.macdonald@sydney.edu.au

Many attendees said how moved they were by the stories, finding them emotive and informative: *“I found today an awesome experience – listening, hearing the voices of carers and those with experience of this challenging illness.”*

Conclusion

The voices heard during this symposium are important because the majority of people with dementia (70%) are living in their own homes in the community and rely on familial carers – family members, neighbours and friends (Alzheimer’s Australia 2013). Of the 1.2 million Australians involved in caring for people with dementia (Dementia Australia 2018), an estimated 500,000 are informal carers, including over 350,000 primary carers.

Most older Australians prefer to stay in their homes, in the communities where they have lived for decades (Department of Health 2017). That means we will be forced to rely on our family and friends to support us as we grow more dependent and vulnerable. Many are prepared to do so, but need to be recognised, supported and equipped to make this happen. ■

References

Alzheimer’s Australia (2013) *Living alone with dementia: research to practice guide.* Available at: https://bit.ly/2VovvEX

Dementia Australia (2018) *Inquiry into the implementation, performance and governance of the National Disability Insurance Scheme in the ACT. Submission from Dementia Australia.* Available at: https://bit.ly/2ECmORY

Department of Health (2017) 2016-17 *Report on the operation of the Aged Care Act 1997.* Commonwealth of Australia. Available at: https://bit.ly/2Xr5oiu