

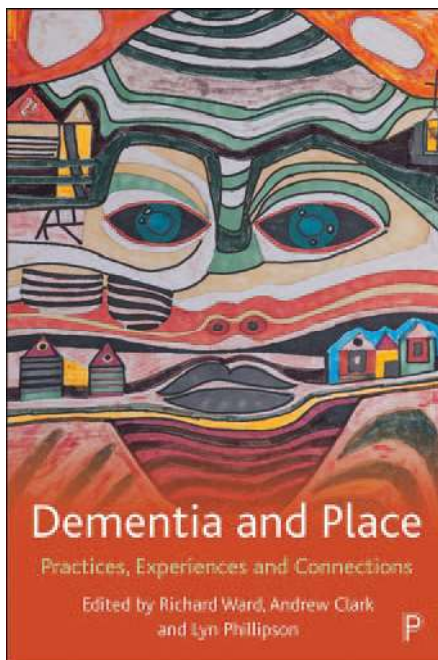
Dementia and Place: Practices, Experiences and Connections

By Lyn Phillipson

Is there somewhere that dementia belongs? If we had asked this question 20 years ago the responses would likely have emphasised institutional settings such as hospitals and care homes. Historically, independent movement beyond the home for people with dementia has been positioned as fraught with risks, such as becoming lost.

Fast-forward 20 years and much is changing. Arguably, if we posed this question now a more diverse set of responses would ensue. Hopefully a more diverse range of people would offer their perspectives, including the direct views of people living with dementia and their carers and supporters. In the new book *Dementia and Place: Practices, Experiences and Connections*, edited by Richard Ward, Andrew Clark and myself, we aim to profile the significance of the situations and conditions in which people live and manage life with dementia beyond care settings.

The particular focus is on outdoor, public, and shared spaces, especially neighbourhoods. In the book, we draw



upon a range of perspectives to explore and demonstrate the significance of place and neighbourhoods to life with dementia, to dementia care practice and to evolving policy goals.

In the following extract from the book, we invite you to sample one of these perspectives – a first-hand account of neighbourhood and community written by an Australian care partner of a person with dementia (Lynda Henderson) with support from researcher Dr Louisa Smith. Lynda writes from the perspective of a friend and housemate of Veda. She reflects on the changes and continuities from their time as activists in the LGBT community to now advocating for social change concerning dementia. ■

***Dementia and Place: Practices, Experiences and Connections* (2021, Policy Press), edited by Richard Ward, Andrew Clark and Lyn Phillipson, is out now and available at 20% discount when you order from Policy Press at <https://policy.bristoluniversitypress.co.uk/dementia-and-place>**



■ Associate Professor Lyn Phillipson is a Principal Research Fellow at the University of Wollongong whose work focuses on promoting aged and dementia-friendly communities, and AJDC Co-Editor

The extract below, originally titled *We're Known As 'The Girls' Around Town: Support, Isolation and Belonging For A Lesbian Couple Living With Dementia*, is from the book *Dementia and Place: Practices, Experiences and Connections* (2021), edited by Richard Ward, Andrew Clark and Lyn Phillipson. It is reproduced in the *Australian Journal of Dementia Care* with the permission of the Licensor for the publisher, Policy Press, through PLSclear.

Support, isolation and belonging

By Lynda Henderson and Louisa Smith*

Veda and I live in Gerringong, a coastal town of approximately 4000 people, about two hours south of Sydney, Australia. Gerringong is still a farming area, with dairies and vineyards, but is also a tourist destination because of its beaches. We're lesbians: we've never encountered any discrimination down here. We're known as 'the girls' around

*Louisa supported the writing of Lynda's story by conducting a two-hour interview with Lynda about her experiences of neighbourhoods, transcribing this interview and then editing it into a narrative. Lynda then reviewed and edited the narrative. Louisa is Co-Editor and Lynda an Editorial Advisor with the AJDC.



Lynda Henderson (left) and Dr Louisa Smith

town. Being well known in such a small town has been particularly important as Veda's dementia symptoms have progressed since her diagnosis of a rare form of younger onset dementia in 2012 at the age of 61.

Even though I've had this house for about 25 years, neither Veda nor I

planned to live here in such a full-time way. Veda moved here in 2007 to live with me. Both of us love natural beauty, but also wanted to get to Sydney easily. We liked the idea of a country and a city life. Veda and I have always been travellers. It's something we have in common. We didn't do the usual things that our peers did in their 20s. I went over to France to study and Veda was touring as a member of a rock band.

When I came back from travelling and studying overseas, I lived and worked in the middle of Sydney. It was the '80s and there was a vibrant gay and lesbian culture where I lived, but there was also HIV / AIDs. I worked in the education sector, eventually for the State



Veda Meneghetti (left), who is living with dementia, with Lynda Henderson: “It’s important for Veda to be able to go out in the community with people who support, respect and understand her”. Photo courtesy Lynda Henderson

Government with a particular focus on disability and equity. I was called the ‘equity policy queen’, one of ‘the lesbian mafia’. I applied the Anti-Discrimination Act, the Disability Discrimination Act and the Convention on the Rights of People with Disability to state education policy. I’m a speed reader and cope with struggles by learning as much as I can. It turns out that that professional experience and skill have been particularly useful since Veda’s diagnosis.

Veda had a completely different history. She started performing as a musician at the age of 15. By 17 she was leading some Adelaide bands and then toured in Australia before going overseas at 20. In Kuala Lumpur, she met and joined a women’s band. That was the beginning of what would become the hit band, the Party Girls. The Party Girls was the only women’s band of 20 Australian bands chosen to kick off the first leg of the first world simulcast, Aid for Africa 1985 [Live Aid]. They had a dedicated fan base.

Before Veda’s diagnosis, when I first started living in Gerringong full time in 2004, I started to connect to a group of lesbian women down here. When Veda moved here, I met some of her local old fan club and I was so happy. I thought, “Oh, this is great. You know, now we can have parties and stay at one another’s places.” We were still going to Sydney, but I was also feeling that I had a very nice life down here. But just when these relationships started to take hold, Veda got her diagnosis. She didn’t want to tell anyone but started shutting herself off from other people, and she started to get

really quite rude. She sort of scratched some friends out of her life and so they walked out of mine as well. That was very hard. I don’t think Veda realised how dementia was going to impact her life. I think that she thought she could remain totally independent for a lot longer. She pushed a lot of people away who were offering support.

We used to go to Sydney regularly, stay the night at friends’ houses and have long dinners. For quite a while after Veda’s diagnosis, our friends in Sydney were a real support to us. Even old work friends of mine would spend time with Veda if I was going to a conference, for example, and she needed a few hours break. However, most of our friends were still working. I’d been forced to retire early to support Veda, and we had to fit in around our friends’ working lifestyles.

It became a lot more difficult to go to Sydney and stay as Veda’s speech started to change. She went through some really horrible symptoms at times, which meant that it was getting more difficult for people to relate to her and more difficult for her to relate to them. We stopped going to Sydney a couple of years ago. We’ve had some invitations to go and stay with new friends living with dementia but because of the impacts of dementia itself, we’ve not yet managed to do that: we’re pretty much ‘grounded’.

We used to have a big lunch here, usually on Boxing Day or the day after. People would bring food and drink and we’d have a wonderful party. We did that for years. We had some good friends – gay boys – living nearby. I went to school with one of them when I was 10, so we’re like

brother and sister. But the thing at our age, in our sixties, people start retiring, moving, moving on to the next phase of their lives. Those good friends have moved away: I miss having the dinners and lunches together. The isolation is really a killer.

We’ve become much more isolated from friends and family. We’ve also become symbiotic. It can be a dangerous co-dependency. I have a physical disability myself, for which I also need support, or at least time for rehabilitation and exercise. My health has definitely suffered as a consequence of the time it takes to be a care partner. You end up having to live as a unit, just in order to get everything in place and make life as good as it can be. Years ago, one of our friends introduced me to someone by saying, “Oh, this is Lynda. She hasn’t got a life. She’s a carer”. But actually, that is true. There are a lot of people who want nothing further to do with me because I haven’t put Veda away with the old people in residential aged care. They think I should be getting on with my life.

I wish people had offered something regularly, like, “I’ll take Veda out one Saturday a month”. People don’t stop to think about that. They do with cancer. We did that for people with HIV / AIDS. I remember our community being so supportive of one another during the ’80s, caring for one another, visiting. But not for people living with dementia.

Feeling physically and socially isolated, I decided I needed to look for a dementia community. A good friend of mine, who was experienced in aged care said, “If you want to learn fast get back on Twitter”. So, in 2014, I did. That’s how I’ve made connections with other people with dementia, carer partners, activist and academics.

Being on social media has changed my life. It’s changed Veda’s life too. It brings the world closer to us, especially now that we can’t travel. Veda can watch anything she wants from around the world. She is addicted to documentaries, independent cinema and rock concerts, of course. It was because of the Internet that the dementia community started to reveal itself to me.

In 2014 Veda and I became involved in the Dementia Friendly Kiama project and that project has sustained me. Kiama is another small town just near Gerringong, and it was selected as a pilot for Dementia Australia’s Dementia Friendly Community program. Kiama has a progressive council and it partnered with the University of Wollongong to become a flagship dementia friendly program in Australia. We’ve had lots of international advocates and activists come and visit us



Veda Meneghetti and Lynda Henderson (centre back row) pictured on the stairs of the Kiama Council Chambers with other members of the Kiama Dementia Advisory Group in 2016

in Kiama to see how dementia inclusive communities can work.

Members of the Kiama group have become supports for one another. At one point, I wanted to go to Sydney, just overnight for a conference. Between my friends in Sydney, friends down here and members of the Kiama project, everybody volunteered to spend a bit of time with Veda over those two days. Even during COVID-19, we still meet on Monday mornings over Zoom, just to have a social chat.

Being involved in the Kiama project for the last six years has actually made our neighbourhood more understanding of Veda, particularly as her symptoms progress, because we're familiar faces. As part of the project, we've developed our own resources and run community awareness sessions for diverse groups. One of the things that Veda and I do is run around town sticking up posters: we're known as "the girls with their dementia stuff". Veda is well known in

this neighbourhood. If I'm in town by myself and she's not with me, people say, "Where's your girl?" or "Where's the girl?" or "Where's Veda?" And that's very, very important for her to be known. It's a lot easier in a small country town than it is in the heart of Sydney.

One day Veda disappeared, wearing her red dressing-gown. She'd been gone for half an hour, when someone called me and said that there was a picture of Veda on the community Facebook page, saying, "Does anybody know this woman?" She was found.

After that, I thought I really need to thank the locals for having looked after her. I put up a post on the Facebook page with a normal picture of Veda and the picture of her in the red dressing gown, with a small paragraph about who she is. There were over 100 comments in just a day or two. It is a beautiful community.

Some years ago, Veda said to me, "I suppose if people still remember me, I'd

better do something about it". So, Veda and I started presenting at conferences. We included her songs and talked about our work in Kiama, and her life in the community. At the LGBTI Ageing [and Aged Care] Conference in Melbourne, Veda surprised me and sang a song she'd written for me. I cried. At the end of that, all these old gay boys up the back who would have been in their seventies, they remembered her, of course, they were howling and screaming "Where can we get those songs?" Veda's become a real advocate, honestly answering people's questions to the best of her ability, which has become more and more difficult as time has gone on.

In the last few months, I've started to manage Veda's government funding and care planning myself. That means that instead of using an aged care provider to organise all her support, she and I employ the people we choose by using a broker who supports payments from Veda's care budget. It's hard always having people in your house, but our support people are invaluable. In some ways it's much better organising it ourselves because we can keep our gardener and our cleaner, who are both personal friends now. We joke that Veda's carers are her harem of women. But they are all totally respectful of her background, her sense of humour, her reactions to things, and it's really quite lovely to see these friendships develop. They are all younger than her because she power-walks.

When we were trying to choose Veda's new team of support workers, I made sure that she was the one who chose. They went for a walk into town by themselves without me, at their first meeting. It's important for Veda to be able to go out in the community with people who support, respect and understand her. She teaches us all. ■

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