

Building a dementia tolerant society

- [Jill Sutton](#)
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These days I feel a persistent urge to speak out about the issue of ageing. This is hardly surprising in the midst of the work of Australia's Royal Commission into Aged Care Quality and Safety, in the midst of my own worsening memory for the names of things and my partner's lessening ability to remember what happened yesterday, and after the terminal dementia of both my beloved father and former husband.



The underlying tragedy will always be that the people who directly experience the condition of ageing and dementia do not survive to give us their evidence. But perhaps this puts more responsibility on those of us who can feel that they are drawing closer to it.

As I see our friends finding it harder to engage my partner and me in the entertaining conversation they have come to expect, I can see that our achievement and distraction-oriented culture is against us. But all may not be lost. Maybe we can change it. Look at the increased inclusion of disabled people in our community since the advent of the NDIS.

We are learning that people can be different in all sorts of ways so, why can't we accommodate people who are becoming repetitive or who cannot quite recall who they are? Surely we can learn to embrace such old friends and, if they become a risk to their communities, develop a signal like the white stick carried by the blind, so that we can look out for them in new and effective ways.

We must do something to hold our dear ones close to us and away from ghettos of so-called 'aged care' where their challenges are multiplied not only by under-qualified, underpaid and overloaded staff, but by engagement with others with the same problems.

Cultural change is what is needed. Most less developed countries do not share in our ever-expanding aged care industry and I suspect they have accommodated their aged, dementing and dying amongst them in, at least sometimes, more humane ways. How can we learn to do this? How can we, for instance, listen to friends who are becoming repetitive and forgetful so that we can meaningfully relate to them and keep them among us?

Vigorous conversation need not be our only meaningful link. Dementing people are the sum not just of what they can say to us today, but of what they symbolise about the parts of our lives that we have shared with them. They are a presence that can remind us that lives wax and wane, that our lives are vulnerable and that we become dependent on one another quite often. We have all been dependent as babies, in achieving joint outcomes in families, in work and in communities, and we become dependent as we become demented. Dependency is nothing to be ashamed of.

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True, in the last extreme stages, when such a person may not know us or even accuse us of betraying them, they are going to need special care. But maybe this difficult and unthinkable stage would be less likely to occur in the ongoing company of known personnel, and more easily accommodated with a bigger team of people which included their loved ones.

When we are losing our memories, we need more and more people who have learned to love us to help us, not fewer. This means that we need, more than ever, to remain in the community which has known us. How can we learn to accommodate these people whose conversational and independent living skills gradually but surely fade?

We need to focus more and more on the particularity of the people we have loved. And we need to learn new conversational gambits. One which I have found works for me is to adopt the view that, when repetitive questions or comments are occurring, I think of them as 'choruses' in a song, rather than as a new 'verse'. Psychology has long demonstrated that such a change in attitude to what we are hearing can change our perceptions. Choruses are times to rest, times to enjoy familiarity, without expecting new material.

I can see my closest family learning this new listening skill but, for friends, it's more difficult. However, in the best possible world, I would see the royal commission propose ways in which

we could all begin to learn to embrace and enjoy our ageing relatives and friends as part of a natural life span.

In this case I would expect it to recommend a massive increase in resources for mature and able adults to get together to enjoy sharing the presence and care of their ageing friends and relatives. This would involve considerable cultural change. But many of us learned to change the nappies of our kids in a loving frame of mind. Maybe we can develop the same tender intimacy with our demented friends in their final stages.

Learning to sing along with the chorus would only be the beginning.



Jill Sutton has written for government policy, for NGOs committed to social justice, for statutory bodies, for a leading activist, for her partner's sermons, for local poetry publications, for the Canberra Times and for Eureka Street. Her favourite things are teaching at any level and conversation over shared meals.

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