

Patient leadership in aged care

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With a little over a year since the Final Report and Recommendations from the Royal Commission into Aged Care Quality and Safety was published in March 2021, it is timely to consider what is happening now and what we think should be happening for people living in residential and aged care facilities, and for those receiving care at home.

First, the people receiving care should be at the centre of our concern and efforts of time and investment. I am not paying lip-service to the international movement towards patient-centred integrated care, or mentioning the Consumers and Families Panel with the Aged Care Quality and Safety Commission, or talking about customer feedback data gathering programs in the aged and home care sectors. I am talking about the real ‘*patient leadership*’ that is proposed by the Consumers Health Forum of Australia¹ and is also taking hold in the United Kingdom through David Gilbert and his team at InHealth Associates.²

The only people who can really tell us what it is like to live in a residential facility or receive care at home are the people and their families themselves. Furthermore, as David says, people with lived experience need to be equal partners in the design, production and decision-making processes, such as about funding and staffing – ‘*nothing about us without us*’ (p. 237).² In reality this means, patient leaders need to occupy executive leadership positions in for-profit, not-for-profit and charitable organisations and companies in the aged and home care sectors. In an ideal world, a formal ‘patient leader’ position at the board-level could result in patient voices, experiences and suffering being heard and responded to appropriately across boards, committees and working groups.

Second, as aged and home care is part of the wider health care system, the new federal government health and aged care ministers and state and territory health ministers must work together to reduce the backlog of patients in acute care waiting for weeks and months for a home care package or a place in a residential care home. The continuing adverse effects of the COVID-19 pandemic and the winter flu season that is upon us, means that some of our private and public hospitals are now cancelling elective surgery. Our system cannot afford a backlog of sick, aged and frail patients and, most importantly, they deserve better.

Third, the election of a new federal government has provided hope that the current situation can be fixed. Restoring faith and hope in our health system is important for everyone. The solutions do not just lie in bolstering the ranks of health care workers in the aged and home care sector who are potential members of unions affiliated with political parties. Staffing levels are especially important but clinical governance across all levels of an organisation and real ‘patient leadership’ are also required for improved patient experiences and outcomes.

References

- 1 Consumers Health Forum of Australia. Consumer enablement. Interview with David Gilbert. 2021. Available at <https://www.dropbox.com/s/unkvci3qt6yk9m8/Day%2022%20-%20Consumer%20Enablement%20-%20201315%20%201330%20-%20David%20Gilbert%20-%202021.43mins.mp4?dl=0>
- 2 Gilbert D. The Patient Revolution. How we can health the healthcare system. London: Jessica Kingsley Publishers; 2020.

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