

Media Release

Thursday, 28 November 2019

Discussing the palliative care needs of people living with dementia

Palliative Care Australia (PCA) and Dementia Australia have partnered with the Parliamentary Friends of Palliative Care and the Parliamentary Friends of Dementia today in Parliament House Canberra to bring attention to the palliative care needs of people living with dementia. Launching a suite of resources specifically designed to ensure they meet the needs of people living with dementia, the event was attended by the Governor-General, His Excellency David Hurley, and Her Excellency Mrs Linda Hurley. His Excellency is Patron of Dementia Australia and Their Excellencies are joint Patrons of PCA.

“As Patron of both Palliative Care Australia and Dementia Australia, I am very pleased the organisations are working in partnership,” the Governor-General said.

“Both organisations bring expertise, compassion and commitment to their mission and the services they provide to Australians when they, their families and loved ones, need them the most.”

During the event PCA CEO Rohan Greenland and Dementia Australia Board Chair, Professor Graeme Samuel AC highlighted the work both organisations have accomplished to support people living with dementia, particularly as they start to have conversations about what matters most to them and their preferences for care towards the end of their life.

Mr Greenland said “we know that dementia is already the leading cause of death for women in Australia, and the second overall. Those who provide palliative care, including specialists, general practitioners and other health and aged care professionals are working with people living with dementia and their families on a daily basis to meet their unique care needs.”

“For this reason, the relationship PCA has with Dementia Australia is essential as we work together to advocate for the growing number of people who will live with and eventually die with their dementia diagnosis and require appropriate, timely palliative care.”

Dementia Australia CEO Maree McCabe said, “dementia is a terminal illness and appropriate palliative care is an essential element of quality care and end of life care for people with dementia, and for their families and carers”.

“While we acknowledge the contextual complexities of dementia care within the different health care and community settings, it is essential that streamlined services are developed and accessible for more effective home and community palliative care experiences.

“Improving palliative care for people with dementia, no matter where they live, must be a policy priority, Australia-wide, across the states and territories.”

Speaking at today’s joint Parliamentary Friends event, Mr Greenland and Professor Samuel launched a suite of resources specifically designed to ensure they meet the needs of people living with dementia.

Mr Greenland was pleased to present the **What Matters Most** resources as a new addition to the PCA Dying to Talk Initiative. Mr Greenland stated that “these resources were developed for health

and aged care workers to support older people, including those living with dementia, to reflect and have conversations about *What Matters Most* to them and what they might want if they were very sick or at the end of their life.”

Mr Greenland thanked the Australian Government and the Department of Health for the Dementia and Aged Care Services (DACs) fund which supported the production of these resources. “These resources are incredibly valuable to support health and aged care workers to have early conversations with older Australians about their end of life preferences, and were only made possible with this funding from government.

“PCA also acknowledges Dementia Australia, Aged & Community Services (ACSA), Leading Age Services Australia (LASA), HammondCare and the aged care providers involved in development of *What Matters Most*, and importantly the people living with dementia and their carers for their invaluable feedback. I am also pleased that Mr Les Makai, the person responsible for the amazing artwork used in the resources was able to join us,” said Mr Greenland.

A full set of resources will be sent to all aged care providers, including:

- A *What Matters Most Discussion Starter* written from the perspective of the older person, with questions about the person, their health and what they might want at the end of their life.
- A *Health and Aged Care Worker Facilitator Guide* to assist workers to prepare for and have these important conversations with older people noting the specific needs of people living with dementia
- A set of “*What Matters Most Discussion Cards* that can be used as an ice breaker or prompts when working through the other materials.

“PCA is very pleased that the full suite of resources will soon be available for everyone to access on the Dying to Talk [website](#), including the Discussion Starter and Discussion Card sets in 10 languages: Arabic, Croatian, Greek, Hindi, Italian, Maltese, Polish, Simplified Chinese, Spanish and Vietnamese,” Mr Greenland said.

The Dementia Australia discussion paper, *Dying well – Improving palliative and end of life care for people with dementia* is available [here](#).

Both PCA and Dementia Australia are calling on all Australian governments across systems to consider a flexible model of care that enables the right care, at the right time, and within the right setting to accommodate the changing needs of people living with dementia, and their carers, as the disease progresses.

“Good palliative care is an essential element of quality care and end of life care for people with a terminal illness. I am seeking a commitment from all Members of Parliament to advocate in their party rooms and with colleagues to elevate this message together,” said Professor Samuel.

“People with dementia deserve to experience dying well and it is our collective responsibility to make that happen.”

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