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6 March 2019

Jeanette Radcliffe Committee Secretary STANDING COMMITTEE ON COMMUNITY AFFAIRS References Committee

Dear Ms Radcliffe

Re: Questions on notice pertaining to the Inquiry into the effectiveness of the Aged Care Quality Assessment and accreditation framework for protecting residents from abuse and poor practices, and ensuring proper clinical and medical care standards are maintained and practised

Thank you for the opportunity to provide further information to the Senate Community Affairs References Committee regarding the effectiveness of the Aged Care Quality Assessment and accreditation framework and for the opportunity to present evidence at the Committee's public hearing held in Canberra on Friday 15 February, 2019.

Please find below responses to the additional questions posed.

1. Many Residential Aged Care Facilities (RACFs) allow Assistants in Nursing/Personal Care Attendants to assist residents in taking their medication or to distribute Webster packs. Is this appropriate for residents with cognitive decline? What should the role of Registered Nurses be in medications dispensing?

There are two components to consider in assessing whether it is appropriate for assistants in nursing/personal care workers are appropriate to assist residents in taking their medication or distributing Webster packs.

As highlighted in Dementia Australia's original submission and in our public hearing testimony, the first component is that a cohesive, structured and integrated national approach to dementia education and training for all staff, whether registered or enrolled nurses or personal care workers, is imperative. This education should include minimum standards for education and training for all those working with people with dementia and include strategies for interacting with people who are experiencing cognitive decline. This approach should also include a focus on leadership and cultural change at organisational level, to maximise opportunities to translate leaning into improved practice.

The second component is that the roles and responsibilities of medication management and dispensing need to be clear across general practitioners or specialists; nurses; and assistants in nursing/personal care workers. There is no reason why an assistant in nursing/personal care worker who is well trained in dementia cannot dispense medication to a resident with dementia in an effective way, but it is outside their scope of practice to assess medication levels or



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efficacy. Similarly, a registered or enrolled nurse who is well trained in dementia should be able to monitor on a regular basis a resident's symptoms, medications and medication response and implement medication reviews on a regular basis – including seeking the expertise of pharmacists, GPs or specialists like geriatricians to determine the most appropriate mix and levels of medications.

2. Does the current standard of clinical governance and record keeping in RACFs impact the standard of clinical care provided by external medical practitioners?

The clinical governance structures that underpin residential aged care and the engagement between aged care staff and medical practitioners in relation to clinical care is the subject of multiple current reviews, including the Royal Commission, the Australian Law Reform Commission, the Carnell and Patterson review and the recently announced review of chemical and physical restraint by Minister Ken Wyatt.

It is clear from what people living with dementia, their families and carers tell Dementia Australia that clinical governance and record keeping in residential aged care is not necessarily consistent and testimony from GPs and specialists participating in this Inquiry similarly demonstrate that their experiences also vary.

What is clear, however, is that the roles and responsibilities of aged care staff and medical practitioners as they relate to the personal care, clinical care and medical care of a resident with dementia, need to be clear, with clinical governance structures in place that underpin and enforce those roles and responsibilities. Similarly, the methods of assessing and reviewing clinical governance and record keeping need to be consistent with that framework and reflect 'on the ground' experiences of residents rather than existing as a comprehensive 'paper trail' that is removed from clinical practice.

3. Should the mandatory national aged care quality indicator program differ from the current voluntary program which measures weight loss, physical restraint and pressure injuries?

Dementia Australia has long advocated that consistent data on the performance and quality of aged care services should be routinely collected, analysed and made publicly available to assist consumers in making informed choices in regard to the services they receive. Similarly, we have highlighted a need for publicly available quality indicators that are published on the 'My Aged Care' website and include relevant information about a range of indicators.

The current measures of unexpected weight loss, physical restraint and pressure injuries are important, but the implementation of further indicators that address other key care needs of people living with dementia is also vital.

The use of medications, for example – especially antipsychotics – should be added to the national indicator program as a priority. Recent inquiries have established that about half of people in aged care and about 80% of those with dementia are receiving psychotropic medications, with a growing body of evidence to suggest that these medications have been prescribed inappropriately. Data also suggests that only 20% of people with dementia derive



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any benefit from antipsychotic medications, while the side effects are both serious and associated with increased mortality rates.

Arguably, information about staffing numbers and skills mix should also be explored, given the impact that workforce skills and composition have on the level of care provided.

In addition, Dementia Australia has in the past argued for a mix of clinical and wellbeing quality indicators that reflect more broadly the experiences of people living with dementia receiving services, though we acknowledge the complexity of developing appropriately nuanced and meaningful quality of life indicators.

4. Should data from the national aged care quality indicator program be publically released?

The regular and ongoing public release of data from the national aged care quality indicator program is critical.

Not only will this facilitate a shift towards transparent, comparable service quality but it will enhance consumer choice, stimulate a culture of openness and transparency about service quality – and quality improvement mechanisms – and play a role in shifting the sector from a compliance-driven culture to a quality-driven one.

5. Is there a conflict of interest for families asked to provide consent to physical or chemical restraint, where they may be concerned that the person with dementia may otherwise be asked to leave the facility?

Existing legislation and guidelines stipulate that consultation on the use of restraint should take place with a resident or their legal representatives (e.g. guardian, power of attorney) and that informed consent must be obtained where possible.

However, recent commitments by government to amend the aged care principles to strengthen the regulation of restraint, combined with experiences reported to Dementia Australia, have highlighted the challenge that regulators, providers and people living with dementia, their families and carers have in being able to manage decisions around the use of restraint.

Concerns have also been raised by families and carers (and reported in our previous submissions to this Inquiry) about the consistency of providers in seeking and securing consent – especially for the use of chemical restraint – and the pressure that some families feel in consenting to the use of chemical or physical restraint because of the lack of alternative options being offered. Some individuals have expressed to us their concern that, if consent is not granted, the resident will be sent to hospital as an emergency patient or that they will be asked to leave the service because of an inability to meet their care needs.

These types of concerns can also permeate the culture of complaints management, with some families and carers reporting that they are reluctant to complain about a service in case there is a negative impact on the resident in question.



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It is therefore imperative that a more transparent approach to obtaining consent – and, more importantly, a shift away from the use of physical and chemical restraint as a front line response to managing changed behaviours in residents with dementia – is implemented. In doing so, the question of whether there is or not a conflict of interest in families providing consent to restraint will be ameliorated.

6. There has been different language used around age care funding and it depends which side of the ledger you are looking on. Would it be fair to say that funding in total and for each resident continues to increase each on average?

Dementia Australia does not collect data on the average amount of funding provided per resident, nor is there adequate transparency of data to determine what types of services people with dementia receive in residential aged care (e.g. access to allied health, mental health or other specialist supports).

While it would be accurate to say that, at a broad economic level, health and aged care funding continues to grow, year on year, this assertion does not address the broader systemic concerns of people with dementia, their families and carers in having access, choice, transparency or service quality in residential aged care. Nor does a broad statement about year-on-year funding increases address the real or perceived gaps between what is and is not funded, or whether funding levels are adequate to meet the needs of people in residential aged care.

7. It was mentioned that aged patients in acute hospital beds were being pushed out to aged care facilities prematurely – is there evidence about how widespread this practice is? Is this in the best interests of the patient?

Dementia Australia does not have data on how common it is for people in acute care with dementia to be transferred prematurely to a residential aged care setting.

Typically, the key issues that people living with dementia, their families and carers report to us in relation to the acute sector include:

- Challenges with the transfer of residents from residential aged care to hospital (and back again);
- The appropriate management of dementia in acute care settings;
- The healthcare complications often experienced by patients with dementia (e.g. delirium, urinary tract infections, appropriate wound care etc.).
- 8. There seems to be a lack of linkage between hospitals and aged care facilities in regard to the transfer of patients who need hospital care. How might this be improved or addressed?

There are a number of challenges relating to the interface between the residential aged care and hospital/acute care settings, not least the aforementioned lack of clarity in the roles and responsibilities of residential care staff, GPs and specialists in addressing the personal, clinical and medical care needs of a resident.



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To improve outcomes for people with dementia in the acute hospital setting, the key issues that need to be addressed include:

- Better identification of cognitive impairment in hospitals:
- Increased training for all staff including how to communicate with a person with dementia and how to respond to behavioural and psychological symptoms/changed behaviours (which can be heightened in unfamiliar acute care environments);
- More extensive and systematic involvement of carers as partners in the health care of people with dementia; and
- Creation of appropriate physical hospital environments to reduce confusion and distress of people with dementia.

Strategies to improve the outcomes for people with dementia may include:

- Learning from existing programs and initiatives see, for example, the Dementia Care in Hospitals initiative www.dchp.com.au/
- Consistent identification and management of dementia at hospital admission and a comprehensive plan for discharge from the outset;
- Involvement of family carers in the care and support of patients;
- Training hospital staff to better understand dementia and communicate more effectively with people with dementia;
- Consistent use of alternatives, such as psychosocial interventions, to the use of antipsychotic medication and sedatives;
- Adapting the hospital physical environment to reduce distractions and help orientate patients with dementia; and
- Reducing avoidable hospital admissions.

I hope that the supplementary information we have provided here is helpful to the final stages of this important Inquiry.

Please do not hesitate to contact Dementia Australia if you require further information or wish to discuss further any of the content provided above.

Yours sincerely

Kaele Stokes

Executive Director Consumer Engagement Policy and Research

Dementia Australia