

4 November 2019

Royal Australian College of General Practitioners
Dr Harry Nespolon, President, RACGP
Via email StandardsforRACF@racgp.org.au

Dear Dr Nespolon

RE: Draft Standards for General Practice residential aged care

Dementia Australia welcomes the opportunity to provide feedback on the *draft Standards for General Practice residential aged care* (Standards for GPRAC).

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people of all ages with all types of dementia and their families and carers. We represent the more than 447,000 Australians living with dementia and the estimated 1.5 million Australians involved in their care.

Dementia Australia works with people impacted by dementia, all governments, and other key stakeholders to ensure that people with all forms of dementia, their families and carers are appropriately supported – at work, at home (including residential aged care) or in their local community.

In 2019 there is an estimated 447,000 Australians living with dementia and, without a significant medical breakthrough, we can expect there to be over one million people living with dementia in Australia by 2056.¹ People with dementia currently account for around 52% of all residents in residential aged care facilities.² It is therefore critical that general practitioners (GPs) are equipped to support aged care residents with dementia, who often have complex health and clinical care needs.

Dementia Australia supports the Royal Australian College of General Practitioners (RACGP) in this important endeavour. A key focus area of Dementia Australia's strategic direction is to clearly define what quality dementia care is and embed these principles consistently into practice across the aged care sector, including those parts of the healthcare system with which aged care intersects.

Dementia Australia looks forward to working collaboratively with the RACGP to ensure that people living with dementia in residential aged care receive quality care that meets their clinical, functional and lifestyle needs.

Dementia Australia has reviewed the draft Standards for GPRAC and, while broadly we are supportive of the approach and content included in the Standards, we have identified some areas for the RACGP to further consider, as outlined below.

¹ Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra

² The National Centre for Social and Economic Modelling NATSEM (2016) *Economic Cost of Dementia in Australia 2016-2056*

Standard 1: Resident care coordination

Dementia Australia commends the focus on resident care coordination in the draft Standards for GPRAC. However, we suggest the RACGP strengthen requirements for consultation with families and carers and work with providers to ensure that what is outlined in the standard is implemented in practice.

Care planning that involves people with dementia, where possible, as well as their families and carers, is critical to ensuring quality clinical care and preventing avoidable hospital admissions for residents with dementia. All too often we hear from families and carers of people living with dementia in residential aged care that they are not consulted in a timely manner, if at all. The role of families as advocates and substitute decision makers for people with advanced dementia must be recognised where those arrangements have been communicated – GPs and residential aged care staff must ensure that they include them in care planning, coordination and decision-making processes. This is especially important where medications are being prescribed and where informed consent to administer them must be obtained.

In addition, Dementia Australia suggests the RACGP give consideration to developing specific protocols for one-off doctor visits, or where locums are being called upon. In instances where the resident, family/carers and residential aged care staff do not have an existing relationship with a GP, and therefore, the GP does not have a thorough understanding of the resident's history and needs, it is especially important that carers and families are consulted and that follow-up reviews are undertaken by the regular GP.

Standard 2: Infrastructure, equipment, consultation spaces and treatment room

Dementia Australia recommends the RACGP include consideration of inclusive design principles in 2.1 to encourage residential aged care providers to create buildings, environments and spaces that are dementia-friendly and that enable and empower people with dementia.

More information about dementia friendly and inclusive design is available at www.dementia.org.au/files/helpsheets/Helpsheet-Environment03_HowToDesign_english.pdf or

Standard 3: Information management

Dementia Australia recommends the RACGP include criteria that residential aged care providers collect and record data on cognition and dementia consistently, and that the GP monitors this information for changes in a resident's condition.

Standard 4: Medication management

For indicator 4.1, Dementia Australia recommends that medication reviews are undertaken more than annually to ensure that residents with dementia are not on unnecessary or inappropriate medications. We also recommend that the Standards require residential aged care providers to include families, carers or advocates in the review process. We have heard multiple reports of families only finding out what medication the person with dementia is on when they receive the pharmacy bill. People with dementia (where they have the capacity), families and carers must provide informed consent to medications and be involved in the review process.

This is especially important with regard to the prescription of antipsychotic medications which are regularly used to chemically restrain residential aged residents with dementia. Dementia Australia has heard from people with dementia, their families, carers, advocates and other stakeholders about the devastating impacts of the use of chemical restraint for people with dementia living in residential aged care facilities.

The overuse and inappropriate use of chemical restraint is all too common in residential aged care facilities. It is estimated that approximately 50% of people living in residential aged care are receiving antipsychotic medications, and about 80% of those people have dementia.³ International data suggests that only 20% of people with dementia derive any benefit from antipsychotic medications.⁴

Australian clinical guidelines recommend that antipsychotics are only prescribed after non-pharmacologic approaches have been attempted; yet we continue to see the over-prescription of these drugs. Antipsychotic medications have a range of serious side effects and are associated with an increased risk of stroke and mortality for people living with dementia. Despite overwhelming evidence that antipsychotics are not effective or safe, they are still being routinely prescribed and administered against clinical guidelines to people living with dementia often as the primary 'treatment' for 'managing' people with dementia.

A recent human rights inquiry into the *Quality of Care Amendment (Minimising the Use of Restraints)* identified considerable confusion with regard to the roles and responsibilities of approved providers, residential aged care staff, prescribers (GPs and other medical professionals), pharmacists, carers and advocates in the prescription, administration, application, and review of chemical restraints in residential aged care facilities.

Carers often report that when antipsychotics are prescribed for their loved one they are either not informed at all or that they are notified in a context in which the staff of the approved provider or the GP presents it as there is no choice and the medication must be administered. GPs report that they often do not have a full background of the individual and they are being brought in in an emergency situation to address a particular behaviour. Residential aged care staff say that they are just following the prescribing instructions of the GP or the specialist that has made an initial prescription. And in all too many instances, a medication review process does not seem to occur.

There are missed opportunities for more a collaborative and informed decision-making process that includes families and carers (and people with dementia, where possible).

In the creation of the Standards for GPRAC, the RACGP has the opportunity to respond to these concerns and confusion, and develop clear guidelines for GPs with regard to the prescription and regular review of medications for people with dementia.

Standard 5: Qualifications of the RAC care team

Dementia Australia commends the RACGP for addressing the qualifications of residential aged care staff. The draft standards currently state: "the care team members must consider what Continuing Professional Development and other training is relevant to their position and the specific needs of the resident population. This **may** include training related to...caring for and treating people with dementia" (our emphasis). Dementia Australia recommends that to

³ Peisah C. & Skladzien E. (2014) *The use of restraints and psychotropic medications in people with dementia*, Alzheimer's Australia Paper 38

⁴ Ibid.

meet the standard, residential aged care providers **must** provide dementia training to their staff.

It is critical that all aged care services are well equipped and motivated to provide safe, high quality care for people with dementia, as part of their core business. We need a well-trained and skilled aged care workforce that understands how to support people living with dementia and use psychosocial and non-pharmacological therapeutic approaches rather than physical or chemical restraint as a first measure to manage psychological and behavioural symptoms of dementia. These symptoms are, in a significant proportion of cases, an expression of unmet need, pain or distress.

A cohesive, structured and integrated national dementia training and education program for all aged care staff must be a priority to create better outcomes for people living with dementia and their families and carers. Through these standards, the RACGP is in a position to advocate for improved and mandatory dementia training for residential aged care staff.

Thank you again for the opportunity to review and provide feedback on the draft Standards for GPRAC.

Dementia Australia looks forward to the introduction of the Standards and to working collaboratively with the RACGP to ensure people with living with dementia in residential aged care facilities receive quality GP care.

We would welcome further conversation to identify opportunities for collaboration that will lead to tangible outcomes and systemic change.

Yours sincerely,



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