

10 January 2020

Prof Danielle Mazza
Royal Australian College of General Practitioners
Chair, Red book Expert Committee
Via email qualitycare@racgp.org.au

Dear Prof Mazza,

Re: Guidelines for preventive activities in general practice 10th edition

Thank you for inviting Dementia Australia to participate in the consultation process to inform the development of the 10th edition of the *Guidelines for preventive activities in general practice (the Red book)*.

Dementia Australia is the peak, non-profit organisation for people of all ages living with all types of dementia, their families and carers. We work with individuals, families, communities, all levels of government, and other key stakeholders to ensure that people with dementia, their families and carers are appropriately supported. Our close engagement with people who have a lived experience of dementia means that we are an important advocate for those impacted by the condition and we are also well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders.

Dementia is one of the largest health and social challenges facing Australia and the world. Dementia is a terminal condition and there is currently no cure. It is the leading cause of death of women in Australia, the second leading cause of death in this country and it is predicted to become the leading cause of death within the next five years.¹ Dementia is not a natural part of ageing. It is more common in older people but it can affect people in their 40s, 50s and even their 30s.

In 2020 there are more than 452,000 Australians living with dementia and, without a significant medical breakthrough, we can expect there to be over 1.1 million people living with dementia in Australia by 2058.² There are currently an estimated 1.5 million people involved in the care of people with dementia.³

¹ Australian Bureau of Statistics (2018) *Causes of Death, Australia, 2017* (cat. no. 3303.0)

² Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra

³ Based on Dementia Australia's analysis of the following publications – M.Kostas et al. (2017) *National Aged Care Workforce Census and Survey – The Aged Care Workforce*, 2016, Department of Health; Dementia Australia (2018) *Dementia Prevalence Data 2018–2058*, commissioned research undertaken by NATSEM, University of Canberra; Alzheimer's Disease International and Karolinska Institute (2018) *Global estimates of informal care*, Alzheimer's Disease International; Access Economics (2010) *Caring Places: planning for aged care and dementia 2010–2050*

Comments on preventive activities in older age

As per your invitation, we have reviewed the 9th edition of the Red book, with a particular focus on *Chapter 5 – Preventive activities in older age*. Dementia Australia is largely satisfied with the existing content. In particular, we are pleased that it is recommended that GPs conduct medication reviews for people with dementia, as polypharmacy places people living with dementia at greater risk of medicine-related harm, medication errors, inappropriate use, side effects and adverse interactions.

However, we recommend the following additions to the forthcoming 10th edition:

- ***Acknowledgement of younger onset dementia.***

Younger onset dementia describes any form of dementia diagnosed in people under the age of 65, and can impact people in the 50s, 40s and 30s. The misconception that dementia is a condition of old age contributes to, and exacerbates, multiple challenges experienced by people with younger onset dementia. Although dementia is most commonly diagnosed in people over the age of 65, the prevalence of dementia in younger people is significant. There are currently more than 27,000 Australians living with younger onset dementia. The experience for people with younger onset dementia – who often receive a diagnosis when they are in full-time employment and actively raising and financially supporting a family – is different from those diagnosed with dementia at a later stage of life. Loss of income, self-esteem and perceived future purpose can pose multiple physical and psychological challenges for people with younger onset dementia and their families. They are also more likely to experience misdiagnosis and delayed diagnosis which can impede opportunities for early intervention and timely support services.

- ***Greater emphasis on potential modifiable risk factors for dementia.***

Although the biggest risk factor for developing dementia is age, risk reduction measures have a strong role to play at a population level and are the most effective approach to reduce the prevalence of dementia. There is a growing body of evidence that there are seven modifiable risk factors for Alzheimer's disease in particular. These are: diabetes; midlife obesity; smoking; depression; cognitive inactivity or low educational attainment; midlife hypertension, and; physical inactivity.⁴ Dementia Australia is therefore supportive of efforts to improve the availability of evidence-based preventive information and activities in primary care. Dementia Australia would also welcome opportunities to collaborate with the RACGP to deliver dementia risk reduction education to GPs to enhance their ability to support patients at risk of developing dementia.

⁴ Barnes, D. E. & Yaffe, K. (2011) The projected effect of risk factor reduction on Alzheimer's disease prevalence, *Lancet Neurology*, 10: 819-828; Norton, S., Matthews, F. E., Barnes, D. E., Yaffe, K. & Brayne, C. (2014) *Potential for primary prevention of Alzheimer's disease: an analysis of population-based data*, *Lancet Neurology*, 13: 788- 794

- ***A referral pathway to support services for patients diagnosed with dementia.***
Dementia Australia notes that on page 51 of the Red book it states: *“When a person has dementia, adequate support is required for the person, carer and family. Counselling and education are important. Management priorities will vary from patient to patient, but there may be a need to consider medical management of dementia, behaviour and comorbidity, legal and financial planning, current work situation, driving, and advance care planning”*. Too often, people with dementia and their carers report to Dementia Australia that they did not experience a comprehensive referral pathway following their diagnosis of dementia. There is therefore a need for a structured diagnostic pathway that supports post-diagnosis referral to early intervention supports, including those offered by Dementia Australia. As such, we argue that it is appropriate that referral to additional support is addressed in greater depth in the Red book.

Dementia training for GPs

People with dementia and carers often experience challenges when presenting with cognitive concerns and possible symptoms of dementia to GPs, including receiving timely diagnosis and referral to support services.

It is not known how many GP have a thorough understanding of dementia, given dementia is only a small component of GP training, and there is no mandatory professional development in dementia. Given the increasing number of Australians with dementia, greater consistency in the training of GP and primary care professionals will improve the quality of care and support provided to people at risk of dementia and people living with dementia, as well as their families and carers.

Thank you again for the invitation to participate in the consultation for the 10th edition of the Red book. We hope our comments are considered and look forward to the opportunity to provide more detailed feedback later this year when the chapter content has been drafted. We would also welcome further discussions with the RACGP to discuss preventive activities for dementia risk reduction and how our two organisations can work together to improve the quality of care and support provided to people at risk of developing dementia as well as people living with dementia, their families and carers.

Yours sincerely



Kaele Stokes
Executive Director, Advocacy and Research
Dementia Australia