National Mental Health Commission
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Feedback on the draft National Dementia Action Plan

Australian Government
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About the National Mental Health Commission

The National Mental Health Commission (the Commission) provides cross-sectoral leadership on policy, programs, services and systems that support better mental health and social and emotional wellbeing in Australia. There are three main strands to the Commission's work: monitoring and reporting on Australia's mental health and suicide prevention system; providing independent advice to government and the community; and acting as a catalyst for change.

The Commission's underpinning principle is the Contributing Life Framework. This framework acknowledges that a fulfilling life requires more than just access to health care services. It means that people who experience mental ill-health can expect the same rights, opportunities, physical and mental health outcomes as the wider community.

Noting that dementia is more common in older people, it is of note to recognise that the Commission first recommended an Older People's Mental Health and Wellbeing Strategy be developed as part of its 2020 National Report, which detailed the expansive gap in the current health system around identifying and supporting mental ill-health for older people. Key questions the Commission would look to address in the development of a national strategy include:

- The continuum of experience, including wellbeing, flourishing and active ageing
- What mental health support, prevention, and promotion looks like through strategies and systems.

The Commission has undertaken a scoping study on the mental health of older people, including current gaps in systems and policies (delivered by the National Ageing Research Institute). This research highlighted that:

- There are large gaps in research on older people's experiences. Most studies focusing on older people with diagnosed mental illness, as opposed to mental health and wellbeing.
- Older people experience high amounts of stigma which is impacting their mental health, particularly within the health system and health workforce
- The prevalence of stigma emphasises the need for targeted training around identifying and supporting older people's mental health.

The Commission also worked with the Council for the Ageing (COTA) to assess the impact of COVID-19 on those aged 75 years and over, as part of the Pandemic Plan Priority Populations Research Grants. Findings indicate that:

- The impact of COVID-19 has been profound, manifesting through loneliness, fear and worsening mental health.
- The pandemic highlighted the importance of clear and targeted communication in times of national emergencies. Many felt they were better connected and united during the bushfires compared to during the pandemic.
- Older people relate to and identify with language around "coping" more than "mental illness" or diagnostic language (for example, depression). Framing around "mental illness" can be a barrier for accessing support.
- Other barriers to accessing support include a lack of appropriate and affordable mental health services; ageism by service providers who presume older people will be resilient and will not need support; the stoicism of this group not wanting to use services that others may need; and a lack of awareness that mental health services were available, particularly for people who were living in residential aged care.
- When support was accessed it tended to be through GPs and community-based services.
- Protective factors for those that fared better during COVID-19 included having strong social connections, financial security, being physically well and having space to isolate safety.

Feedback on the draft National Dementia Action Plan

The Commission welcomes the opportunity to respond to the draft National Dementia Action Plan (Action Plan). Our response has been structured around key themes the Commission considers pertinent to strengthening the Action Plan in relation to supporting the mental health and wellbeing of people living with dementia and their carers.

Should you wish to discuss this feedback in further detail, please contact Rachel Earl, Director Priority Populations, rachel.earl@mentalhealthcommission.gov.au.

General feedback

The Commission welcomes the Action Plan vision centring carers alongside people living with dementia. While the focus on carers is warranted, this language could be expanded to include "Carers, family and kin" recognising that family can take various forms across cultures but also that 'carers' may not see themselves through this language. Put fundamentally, they may see themselves as family supporting family. The Commission notes that mental health carers also face similar challenges to those outlined in the Action Plan for carers of people living with dementia.

In addition, the Commission appreciates how each Objective is written with an Objective Statement, accompanied by a "Statement for people living with dementia." This centres the voice of lived experience.

Key themes for consideration in relation to mental health and wellbeing

Groups at higher risk of developing dementia or facing barriers to equitable access

The Commission welcomes the focus on groups at higher risk of developing dementia in the Action Plan, and suggests the current list of groups could be further expanded. Evidence suggests that people living with schizophrenia are at higher risk of developing dementia.[1,2,3,4] The latest prevalence data estimates that 2.4 per 1,000 people in Australia are living with schizophrenia.[5] While the nature of the relationship between schizophrenia and subsequent risk of developing dementia remains contested, this is nonetheless a significant group at higher risk of developing dementia, currently excluded in the Action Plan.

In addition, the number of older people in prison is increasing, causing a corresponding increase in the number of people in prison with dementia.[6,7] In Australia, the prison population aged 65 and over increased by 143% over a 10 year period to 2019, while the proportion of prisoners aged 45 and over increased from 18% of the total prison population to 22% over the same period.[8] People involved with the justice system already typically experience higher rates of physical and mental ill-health[9] and prisons are not designed to care for or support people with dementia or cognitive impairment. Further, being incarcerated increases the likelihood of diagnosis of dementia in the later stages of the disorder, reducing opportunities for early intervention for this population.[6]

The Action Plan could benefit from inclusion of these additional populations as well as specific detail around how the plan will support groups at higher risk in general. For example, incorporating actions that increase dementia awareness and education for staff who work closely with groups at higher risk to encourage earlier intervention.

Strengthening the approach to tackle stigma and discrimination

The Commission has been tasked with the development of a National Stigma and Discrimination Reduction Strategy to be finalised in 2023. This national strategy outlines a vision for an Australian community where people with lived experience are treated with equal dignity and respect and where mental health related stigma is not a barrier to living a life of meaning and purpose. It will:

- Reduce self-stigma amongst those who experience mental ill-health and those who support them.
- Reduce public stigma by changing attitudes and behaviours in the general community and amongst identified target audiences.
- Take steps towards eliminating structural stigma and discrimination towards those affected by mental ill-health in identified settings.

The Commission notes that some of the activities proposed in the Action Plan (for example, awareness raising through campaigns, a dementia ribbon, and a reliance on changing public attitudes) are not necessarily aligned with the latest evidence on stigma reduction (for example, focussing on structural levers for change and measuring experiences and behaviours rather than attitudes). The Commission suggests reviewing the research report on the National Survey of Mental Health-Related Stigma and Discrimination conducted by the Behavioural Economics Team of the Australian Government, in partnership with the Commission to inform the Strategy's development. In addition, there has been some significant work conducted overseas on understanding dementia related stigma worth reviewing. The Commission is well placed to work with the Department of Health and Aged Care to strengthen the approach outlined in 'Objective 1: Tackling stigma and discrimination' of the Action Plan, and is interested to further discuss collaboration on this.

Minimising identified risks for dementia that relate to mental health and wellbeing

Given that depression is identified as a potentially modifiable risk factor for dementia and "taking care of mental health" is identified as a proven way to reduce and/or delay the onset of dementia (page 24), the Commission suggests the proposed action under focus area 2.2 be expanded to include: "Increasing focus on brain health **and mental health** alongside physical health in regular health checks." It may also be worth highlighting that several of the proven ways to reduce risk and/or delay the onset of dementia are also conducive to taking care of your mental health, such as regular physical activity, good sleep, maintaining social connections and eating healthy meals. This means that mental health promotion and prevention should be recognised as contributing to dementia prevention.

The association between depression and dementia, beyond depression as a risk factor, is worth noting. The Lancet Commission also states that later life dementia may cause depression. Put differently, depression in late life is often part of the early symptoms of dementia.[10] People with a history of dementia are also more likely to be diagnosed with Alzheimer's Disease later in life.[11] It is important to recognise this relationship and ensure service and care provision addresses this intersection, such as the example noted above to support earlier intervention for groups at higher risk of developing dementia.

In addition, there seems to be an opportunity to highlight actions that are relatively unique to dementia prevention highlighted on page 24 such as keeping an active brain, protecting your head, and looking after your hearing. These are actions that may stretch beyond what is understood to be a "healthy lifestyle".

Improving diagnosis and conflation of symptoms of dementia and mental health conditions

For many older people, deteriorating mental health can be overlooked as dementia or general cognitive decline, with low visibility of the underlying causes of depression and mental ill-health. On the contrary, conflating symptoms of dementia for mental health symptoms has the potential to lead to missed or delayed diagnosis of dementia.

This is of particular concern for the Commission, with an increased emphasis on mental health and wellbeing throughout the dementia journey being one way to mitigate this. The Commission welcomes the proposed actions for increased focus on dementia in professional training across the health and aged care workforce (focus area 6.1) and suggests the addition of training components that specifically address and reduce conflation of symptoms of dementia and mental health conditions, including education on the effects of ageing with regard to the mental health needs of older people, suicide prevention, and the behavioural and psychological symptoms of dementia, from mild to severe.

Greater support for mental health and wellbeing throughout the dementia journey

There are certain points throughout the dementia journey that are likely to be particularly distressing for people living with dementia and their carers, families and friends that warrant additional mental health support. For example, receiving a diagnosis of dementia and during the transition to residential aged care. The Commission would like to see greater emphasis on supporting mental health and wellbeing during these critical periods. This could involve encouraging greater uptake of existing counselling support available through Dementia Australia. GPs, hospitals, residential aged care facilities and other critical touchpoints are particularly well placed to encourage this uptake. A focus on the mental health and wellbeing of people living with dementia and their carers should also be a core component of the proposed care coordinator role, linking people in with appropriate mental health and wellbeing supports. Increasing mental health and

wellbeing support during critical periods could also reduce the 'self-imposed' stigma (highlighted on page 19 of the Action Plan) which can be experienced by people living with dementia and their carers.

This focus on mental health and wellbeing should also be extended to health and aged care workforces who provide crucial care for people living with dementia. Available evidence suggests that issues of job satisfaction such as workloads, rostering and supervision are related to burnout levels among workers in dementia care.[12] These issues have been raised more broadly as quality and safety concerns in aged care during the Royal Commission into Aged Care Quality and Safety, including actions to address these concerns which the Action Plan could consider. Supporting the mental health and wellbeing of workers who provide care to people living with dementia will have flow on effects to the mental health and wellbeing of the people they care for.

Reducing suicide risk

Recent research indicates adults over the age of 65 diagnosed with dementia are more than twice as likely to die by suicide compared to older adults who are not living with dementia[13], with suicide risk particularly increasing following a recent diagnosis of dementia[13,14] and for people with psychiatric comorbidity.[14] Noting however, other studies have shown increased risk for adults diagnosed with dementia before age 65.[14] These findings further support the need for targeted mental health and wellbeing support immediately following a diagnosis of dementia, and the importance of integrated dementia and mental health care supports. Further, research has also highlighted an increased risk of suicidal ideation in carers of someone with dementia,[15] suggesting support should be extended to carers of people living with dementia. The Commission strongly suggests the addition of targeted mental health and wellbeing support (as described earlier) immediately following a diagnosis of dementia.

Greater emphasis on a strengths-based approach

The Commission welcomes the person-centred focus on quality of life evident throughout the Action Plan, however suggests the need to incorporate more of a strengths-based approach. While the challenges associated with dementia are significant, it is important to reinforce that quality of life is nonetheless possible, particularly when moving beyond a focus on deficits in cognitive and physical functioning associated with the disorder. For example, focussing on relatedness, shared moments, feelings and what remains rather than what has been lost. Taking such a strengths-based approach to dementia care has been shown to increase wellbeing.[16,17]

The Commission therefore suggests a greater emphasis on strengths-based aspects and approaches as a vital addition to the Action Plan. This includes ensuring a range of nonpharmacological interventions[18] such as music, sensory stimulation and other creative therapies are considered in 'Objective 4: Improving treatment, coordination and support along the dementia journey' of the Action Plan.

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