

Carers Australia response to the National Dementia Action Plan Consultation Paper 31 January 2023

Thank you for another opportunity to provide input to the National Dementia Action Plan (the Plan). We have appreciated involvement in the Plan's development as members of the Australian Government Department of Health and Ageing's Dementia Expert Advisory Group, as well as the facilitating consultations that involve people with lived experience of dementia and their carers.

We find the approach to the Plan accessible, well-structured and well-informed, as a high-level roadmap.

With respect to the consultations survey questions asked, Carers Australia agree with:

- the proposed vision.
- the objectives and the priority areas identified between 2023 and 2026.
- the broad actions identified under each objective, noting that it is intended these will be given more flesh in Implementation Blueprints on specific activities which will include funding, timeframes and responsibilities.

We would expect that further consultation will take place in relation to the Implementation Blueprints, and that this will involve carers of people living with dementia. As is always the case with these initiatives, the devil will be in the detail.

We also welcome that the proposed Plan is carer-inclusive throughout, that it identifies key supports that carers need for themselves, and reflects that carers are partners in care as per the *Carer Recognition Act (2010)*² and its State and Territory equivalents.

However, we note that while in most areas of the document the term 'carer' relates to family and friend carers, in others it relates to paid carers. We emphasise that the term 'carer' should not be used broadly and without context to describe a paid care worker, or a family member or friend who is not, in fact, a carer, as defined by the *Carer Recognition Act 2010*. In the consultation document the kind of carer being referred to may be inferred from the context, nevertheless, the failure to differentiate can create confusion.

Carers Australia strongly believes there is already enough unhelpful linguistic confusion between unpaid 'informal' carers and paid care workers, particularly within aged care and disability support. We request careful consideration of how the term 'carer' is used and when referring to paid care workers within the final Plan and any further documents, to avoid as far as possible adding another layer of complexity, confusion and impinging on the recognition of unpaid carers.

With reference to Objective 5 'Supporting people caring for those living with dementia', our responses are as follows.

Under Objective 5.1, recognising carers and assisting them in their caring role, we request a focus on building carers' capacity to advocate for the person with dementia and for the carer themselves.

In relation to 5.2, increasing access to carer respite services, the emphasis is on increasing access to diverse, flexible and innovative respite services, with which we concur. **However, with respect to the objective of ensuring emergency respite can be accessed from the community or hospital, we request that residential respite should be specifically identified.** In the vernacular, community respite is usually used to refer to respite programs which are normally provided under Commonwealth Home Support Program (CHSP) funding and is differentiated from residential care respite. The distinction should be made, along with the availability of both planned and emergency respite and improvements to the respite experience within residential care.

Equitable access and early referral to respite care, both planned and emergency, is critical to ensure sustainability of care relationships, and the health and wellbeing of carers. In many cases, lack of access to respite care can be the difference between maintaining the caring role or having no alternative but to seek other more costly government-subsidised care and accommodation options, cease or reduce employment, or risk further strain on carer and wider family relationships.

We are pleased that improving linkages between My Aged Care, the Carer Gateway and the National Dementia Helpline when making respite bookings is included as a Proposed Action. Feedback from our members, the peak advocacy organisations for carers in each State and Territory, is that there is an immediate need for improvement, especially in relation emergency respite and residential respite within the community. We also encourage improved linkages to the NDIS for people with younger onset dementia and their carers.

With respect to measurement of performance, we request that additional metrics are considered that not only measure increases in referrals and numbers accessing training and the like, but their satisfaction with services offered, and the impact on carer wellbeing.

The inclusion of a question addressing the impact of caring for a person with dementia in the ABS Survey of Disability, Ageing and Carers (SDAC) is identified as a metric for monitoring performance over the longer term. While we agree in principle, we highlight that the question does not need to be dementia-specific, since responses for carer of people with dementia can be identified using the SDAC Table Builder. **We caution that important data on the impact of caring for all carers in varying caring relationships and situations may be lost.** Data from the annual Carer Wellbeing Survey, funded by the Department of Social Services and commissioned by Carers Australia, may also be useful. The survey covers many questions relating to the quality of life carers have, how their caring obligations affect their quality of life, and the extent to which they have access to effective supports and their satisfaction with those supports.

In response to what improvements might be seen in the dementia journey in ten years' time if the identified improvements are operationalised (question 9), we provide that:

- When people go to their GPs with concerns that they might have dementia they will be referred for diagnosis rather than having their concerns dismissed on the grounds they are paranoid, or that their symptoms are a normal outcome of ageing, or they can be attributed to some other condition or circumstance.

- When people are diagnosed with dementia, a carer is also identified, as many carers do not consider themselves in this role – we often hear ‘I’m just the wife/husband/partner’ or ‘I’m just the son/daughter’. This would assist in early recognition of the implications of caring and referral to support services to prevent this occurring during crisis situations.
- When people are diagnosed, GPs have available information within their practices that assist them and their carers to understand what kind of supports are available to them and how they can be accessed.
- Dementia and the behaviours which accompany it along the journey do not immediately elicit reactions of embarrassment, lack of respect and avoidance from family members, friends or the general community; attitudes which so often contribute to the social isolation of people with dementia and those who care for them.
- Carers are regarded as partners in care by the medical profession and other health providers and by aged care providers and their staff whether they are caring for someone in a residential facility or are being cared for at home.
- The medical and treatment costs associated with dementia are appropriately recompensed through Medicare or the PBS, with other supports in place to reduce out of pocket costs and provide a safety net for those particularly vulnerable due to low income.
- Carers have ready access to educational advice and the support they need to manage the changes that occur along the dementia journey, recognising that no one caring situation is alike, just as no one dementia journey is the same.
- People with dementia and their carers have enough information at hand to know their rights and entitlements in relation to the supports available to them, and can advocate effectively for these rights through different service systems.
- Medical professionals, care workers and volunteers who deal with people with dementia have the training they need to provide best practice care and emotional support to people with dementia.
- Carers have the access they need to diverse respite services that accommodate the needs and wishes of themselves and the person they care for.
- Investment in research has improved both the clinical outcomes and other wellbeing outcomes for people with dementia and their carers.
- That a diagnosis of dementia is also understood to be one that leads to reduced life expectancy, noting that dementia is the leading cause of death for women in Australia,

and the second leading cause overall³, and that palliative care can occur concurrently with ongoing treatment, for many years, dependent on an individual's illness trajectory.

- That the importance of support for the person with dementia and their carer in appropriate planning is identified early, and there is assistance to navigate issues related to powers of attorney and advance care planning.
- When people with dementia are at the end of life, they have access to high-quality palliative care, including within palliative care facilities, where we have had representations that palliative care facilities/hospice care won't 'take them because they cause disruption to other patients'.

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About Carers Australia

Carers Australia is the national peak body representing the diversity of the 2.65 million Australians who provide unpaid care and support to family members and friends with a disability, chronic condition, mental illness or disorder, drug or alcohol problem, terminal illness, or who are frail aged.

In collaboration with our members, the peak carer organisations in each state and territory, we collectively form the National Carer Network and are an established infrastructure that represent the views of carers at the national level.

Our vision is an Australia that values and supports all carers, where all carers should have the same rights, choices, and opportunities as other Australians to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment, and education.

This includes carers:

- Who have their own care needs
- Who are in multiple care relationships
- Who have employment and/or education commitments
- Aged under 25 years (young carers)
- Aged over 65 years, including 'grandparent carers'
- From culturally and linguistically diverse backgrounds
- Who identify as Aboriginal and Torres Strait Islander
- Who identify as lesbian, gay, bisexual, transgender, intersex (LGBTI+)
- Who are living in rural and remote Australia, and
- Who are no longer in a caring role (former carers).

Carers Australia acknowledges Aboriginal and/or Torres Strait Islander peoples and communities as the traditional custodians of the land we work on and pay our respects to Elders past, present and emerging.

As an inclusive organisation we celebrate people of all backgrounds, genders, sexualities, cultures, bodies, and abilities.