NATIONAL DEMENTIA ACTION PLAN

Response by: AGED CARE REFORM NOW (ACRN) 31-01-2023

ACRN is a non-partisan grassroots organisation, whose members all have lived experience and advocate for aged care reform that delivers improved benefits to all Australians receiving residential and in-home Aged Care services.

ACRN's vision is a transparent and effectively regulated aged care system that focuses on the human rights and quality of life of older people. We collaborate with other like-minded groups and organisations, to provide solutions and influence change. We would like to acknowledge Leonie M. Short, Seniors Dental Care Australia and Alwyn Blayse Allied Aged Care, for their input to the Oral Health and Allied Health components of this submission.

ACRN appreciates the opportunity to comment on the draft National Dementia Action Plan. We believe that there are some very worthwhile actions within the plan and that any plan requires a strong Vision Statement to guide the objectives of the plan.

While ACRN has focussed its attention mainly on adults with Dementia, we are aware that children with Dementia and their families would benefit from similar integrated assessment and treatment pathways that we have discussed in this submission.

VISION STATEMENT

The current vision statement:
"Australians understand dementia - people living with dementia and their carers have the best quality of life possible and no one walks the dementia journey alone."
We believe that it is difficult for all Australians to fully understand the many types of dementia unless they have personal experience. If people with dementia, their families and significant others have adequate support they will not be walking the journey alone.

Our proposed vision is:
People living with dementia and their carers are supported to have the best life possible, free from discrimination and harm.

OBJECTIVES

While we agree with many of the objectives and actions, we believe there are additional enabling components that should be included to support best practice Dementia care.

OBJECTIVE 1: Tackling stigma and discrimination

Intergenerational programmes

ACRN believes that intergenerational programmes are key to helping increase understanding of not just Dementia but other challenges related to ageing. We believe that educating children has a dual affect of not only impacting the children involved, but also their parents and other family members when they then go home and share the information. We believe that the 7-14 year age group would be the ideal group to be involved in these programmes. We are aware of some programmes that are currently running in New South Wales[1] but they appear to be on an ad hoc basis and should be run nationally. We believe that Dementia Australia is well placed to run these programmes.

We recommend having adult day centres being built alongside child care centres to further increase interaction between the generations.

Increased training

We support the action of providing more training to first responders including police, paramedics and firefighters. However, we also believe there needs to be more integrated dementia specific training to General Practitioners (GP's), Allied Health Professionals, Dental Health, Registered Nurses (RN's) and support workers. This is supported by recommendation 80 of the Royal Commission into Aged Care Quality and Safety (Royal Commission) dementia and palliative care training for workers and recommendation 82 review of health professionals' undergraduate curricula.[2]

[1] https://cheba.unsw.edu.au/kids4dementia
[2] Royal Commission into Aged Care Quality and Safety. (2021). *Final Report – List of Recommendations*. Government of Australia. https://agedcare.royalcommission.gov.au/publications/final-report-list-recommendations

Dementia Wellness Hubs

As dementia has multiple impacts on a person (including children with dementia) other than memory loss, we believe that the name Memory Clinics for people with dementia is misleading. We suggest instead the use of Dementia Wellness Hubs or clinics would be more appropriate.

OBJECTIVE 2: Minimising risk, delaying onset and progression

Oral Health

While the Action plan lists a number of risk factors, we are surprised that there is no discussion of risk factors related to Oral Health given increasing evidence that there are links between the two[3]. We support Recommendation 60 of the Royal Commission to establish a Seniors Dental Benefits Scheme for people who live in residential care or in the community.

Primary Health Networks

The use of Primary Health Networks (PHN) is vital in all aspects of improving dementia care. We support recommendation 15 of the Royal Commission - establishment of a dementia support pathway. This is especially important for people living alone or with few social supports who are experiencing cognitive decline. The use of the PHN could result in this being identified quicker. This would also be important for those who lack insight into their condition.

Allied Health support

Allied Health Professional support as part of a multidisciplinary team approach is also vital, and we support Royal Commission recommendations 46 care at home to include Allied Health and 61 short term changes to the Medicare benefits scheme to improve access to medical and allied health services

[3] Qi X, Zhu Z, Plassman BL, Wu B. 2021. Dose-Response Meta-Analysis on Tooth Loss with the Risk of Cognitive Impairment and Dementia. J Am Med Dir Assoc. Oct;22(10):2039-2045. doi: 10.1016/j.jamda.2021.05.009. Epub 2021 Jul 8. PMID: 34579934; PMCID: PMC8479246.

Rochford, D. Alzheimer's and oral care. BDJ Team 8, 23 (2021). https://doi.org/10.1038/s41407-021-0681-1

Kanagasingam S, von Ruhland C, Welbury R, Singhrao S K. 2022a. Antimicrobial, polarizing light, and paired helical filament properties of fragmented tau peptides of selected putative gingipains. J Alzheimers Dis; doi: 10.3233/JAD-220486.

Kanagasingam S, von Ruhland C, Welbury R, Chukkapalli S S, Singhrao S K. 2022b. Porphyromonas gingivalis conditioned medium induces amyloidogenic processing of the amyloid-β Protein precursor upon in vitro infection of SH-SY5Y cells. J Alzheimers Dis Rep; doi: 10.3233/ADR-220029.

OBJECTIVE 3: Improving dementia diagnosis and post diagnostic care and support

Multi-disciplinary team

We need a consortium of professionals working as a multidisciplinary team. This would be best run through the PHN. It is important that individuals are able to access support in their communities and from individuals with whom they already have a relationship. While there are currently newly funded Care Navigators, these do not appear to be well known or well-co-ordinated and are run by different groups in different areas. We believe that Care Navigators should be managed through the PHN and should be available to all. The care navigators should be independent of providers.

Variant diagnosis should be covered under Medicare

While there are over 100 types of dementia, the most common causes of dementia include Alzheimer's disease, vascular dementia and dementia with Lewy bodies.[4] Currently the cost of variant diagnosis is borne by the individual unless they are part of a research group. We believe that knowing the variant can lead to better treatment, planning and understanding. Variant diagnosis for dementia should be covered under a Medicare item.

Cultural appropriate assessments

There needs to be greater access for diagnosis through GP's and greater awareness of cultural appropriateness of dementia assessments. Some of this is already happening through the development of the GPcog assessment and the Kimberley Indigenous Cognitive Assessment (KICA)tool.[5] These should be rolled out nation-wide.

Mandated Allied Health

Government funded numbers of sessions and direct care minutes to access allied health professionals for those living with dementia in either community or residential care should be legislated and mandated.

OBJECTIVE 4: Improved treatment, co-ordination and support along the dementia journey.

Equality in service delivery with national framework focusing on individual needs

There needs to be a national, harmonised, multi-disciplinary approach to dementia care. The care you receive should not be influenced by which state or region you live in or which cultural group you identify with. The best practice models in each state need to be looked at and a co-ordinated national framework needs to be developed from these.

[4] https://www.dementia.org.au/information/about-dementia/types-of-dementia
[5] https://www.dementia.org.au/resources/kimberley-indigenous-cognitive-assessment-tool-kica
http://gpcog.com.au/

Access to professionals should be based on individual needs and should focus on enablement and maintaining function, areas such as allied health, oral health and nutrition can assist with this and should be part of the individuals care.

One of these programmes that we believe should be rolled out Australia wide is the Safe and Found programme.[6]

Care should be delivered by the PHN with the care co-ordinated using Dementia Nurse practitioners. The Admiral Nurse program[7] in the UK is an example of this type of programme. WA has a small-scale programme funded by the McCusker foundation that supports two dementia nurses. However, this needs to be enhanced and more widely available.

Dementia specialist teams should be formed to travel to rural and regional areas as occurs with other specialties and specialist health needs e.g., Breast screening vans. These should again be co-ordinated with the PHN. Palliative care in WA has many of these features in its mobile palliative care service. [8]We have had feedback from people in regional areas stating that currently accessing specialist services is extremely difficult eg they have not seen a Geriatrician for 6 years or need to travel for 4 hours to see a neurologist.

Specialised processes for people with Dementia in the hospital system

When a person with dementia needs hospital or emergency treatment, this can be extremely distressing for both them and their carers. There needs to be greater awareness and understanding by staff in tertiary hospitals of the challenges facing people with dementia and what issues can occur when they are not in a familiar environment. The use of a separate stream of admission for people with dementia especially in emergency care would be extremely beneficial. Again, the Primary Health Networks could be used to assist with this.

Advanced Care Planning

Part of the process of support for people diagnosed with dementia should include advanced care planning. We need to encourage Australians to plan for the time they may not have legal capacity to act for themselves. That is, once someone receives a diagnosis from a health professional of diminished capacity, they may not be able to make independent decisions regarding their finances, medical support, and lifestyle. Whilst they have capacity, a detailed plan of the people they would like to appoint to make decisions on their behalf, for a variety of issues and details of their wishes related to lifestyle are important to ensure they are appropriately supported.

[6] https://www.safeandfound.org.au/
[7] https://www.dementiauk.org/get-support/what-is-an-admiral-nurse/
[8] https://www.bethesda.org.au/facilities-services/mpaccs/

Harmonised mediation and supported decision-making legislation

There has to be a mediation system to deal with family and other disputes related to the care of people with diminished capacity. Increasingly we are seeing the Public Trustee being involved in the event of family disputes. We understand the Public Trustee is not appropriate in aged care settings as they do not have day to day involvement with the person they are supporting, and they are relying on the aged care facility to provide health and other information. A person with diminished capacity needs an advocate to support their care needs, and this requires a person independent of the aged care facility that has some understanding of that person, and some continuity of interaction with that person to ensure their needs are met, and foresee any changes to emotional and physical support. Supported decision making and substitute decision-maker legislation needs to be standardised Australia wide.

Smaller alternate models of accommodation

We support the Royal Commission recommendation 46 capital grants for small households' models of accommodation.[9] We believe that alternate models of residential care need to be investigated. Blended funding models should allow for more community small scale residential care. There are examples of these models overseas and also beginning in Australia[10]

Best practice models of integrated care

ACRN believe we can look to other models that are currently working well to deliver integrated care and these can be adapted to aid the design and implementation of the Action Plan. The Headspace model is one that we believe would work well in this area[11]

This would include:

- Increased access through a hub and spoke national model, which involves an enhanced PHN. These would be Dementia Wellness Hubs. We envisage four core streams– psychosocial, physical/medical (which includes Oral Health), Allied Health and advocacy with consent planning including advanced care planning linked to palliative care. In rural areas there may need to be regional hubs with travelling teams.
- Multi-disciplinary workforce –the workers required from a range of disciplines and backgrounds – with the right knowledge, skills and expertise – who work together to holistically meet the health and wellbeing needs of people with dementia, and their families and friends, within the local community.

[9] Royal Commission into Aged Care Quality and Safety. (2021). Final Report – List of Recommendations. Government of Australia. https://agedcare.royalcommission.gov.au/publications/final-report-list-recommendations

[10] https://newdirectioncare.com.au/
https://communityhomeaustralia.org/first-home/
https://www.kyloring.coop/about/

[11] https://www.health.gov.au/resources/publications/evaluation-of-the-national-headspace-program?language=en

- Continuous involvement of the individual, family and friends in the care of the person with dementia, and in the governance, design, development, delivery, evaluation and continuous improvement of dementia services.
- Evidence informed practice to guide service development, delivery, evaluation and continuous improvement. This should lead to the most appropriate care for each individual with dementia by matching their treatment plan to their presenting needs.
- Blended funding – the use of multiple funding streams and in-kind contributions to increase income diversity, flexibility and the sustainability of the service in accordance with the needs of the people with dementia and the community to ensure access to appropriate services.

OBJECTIVE 5: Supporting people caring for those living with dementia

Increasing respite availability

We support recommendation 16 of the Royal Commission[12]- specialist dementia care includes respite. There is need for specialist dementia respite centres as well as the need for emergency respite, in home respite care and day respite. Our membership inform us that the reality is respite does not happen, especially emergency respite, causing extreme stress and burnout on many unpaid carers

ACRN has been told that residential care facilities are often reluctant to take on people for respite especially if there are behavioural challenges. Carers have stated they were unable to get respite for their loved one, until they stated they were seeking respite with a view to placement. This makes it more feasible for a facility. Dedicated respite centres would eliminate this issue.

It is important that when a person is receiving residential respite – wherever that is – that they are able to continue to access the support worker and allied health sessions that they were accessing in the community, using their home care package, to provide familiarity and continuity of care.

Improvements to support for Carers

In our joint Carers leave submission to the Productivity Commission we discussed the impact of caring for both formal and informal carers.[13] We believe that National Employment Standards should be changed to separate personal/carer leave from sick leave and there should be additional unpaid carers leave available. There should be greater access to telehealth as well as GP, geriatrician and other specialist home visits.

[12] Royal Commission into Aged Care Quality and Safety. (2021). *Final Report – List of Recommendations*. Government of Australia. https://agedcare.royalcommission.gov.au/publications/final-report-list-recommendations

[13] https://agedcarereformnow.com.au/submissions/

ACRN recommends that there be a review of carers payments and allowances as these are currently inadequate to reflect the true cost of caring for a person with dementia. We also recommend a review of carers gateway.

It needs to be recognised that when a person goes into residential care that while the carers' role may change, it does not cease. They often need to become a greater advocate for their loved one. This is especially true for those from a CALD background.

OBJECTIVE 6: Building dementia capability in the workforce.

Increased minimum standard of training

We have previously acknowledged that there needs to be dementia specific training for first responders as well as GP's, allied health, RN's, EENs and support workers. This should be at undergraduate level as well as at specialist level.

We support the Royal Commission recommendation 82 review of undergraduate curriculum.to ensure it meets the needs of older people[14] for nurses, medicine, psychology, social work, physiotherapists, occupational therapists, osteopaths, dental practice, audiology, optometry, dietetics, speech therapy.

We also urge the Government to accept Recommendation 78 of the Royal Commission mandatory minimum qualifications for personal care workers. We believe that Certificate III should be the minimum required pre-employment. If this is not possible then workplace training needs to be national TAFE directed training with the worker given paid time for training. Traineeships should be considered including school-based traineeships. Fees for Certificate courses in aged care and support should be waived.

We support Recommendations 114: Immediate funding for education and training to improve the quality of care, including oral health and Recommendation 79: Review Certificate III and IV courses to consider including oral health as a core competency. This is especially true for those working in residential care.Along with increased education and knowledge it is also important for there to be continuity of carers/ medical professionals for people living with dementia.

Palliative care training should be mandatory for all direct care staff working in residential care and there should be universal access to community palliative care services for those living in the community.

Attitudes around dementia

The assessment and treatment of someone who has dementia requires appropriately skilled and trained staff, present in adequate numbers and with enough mandated time for them to be able to work together in a multidisciplinary team to meet the individuals needs. Involvement of family members and advocates as part of that team is crucial also in providing feedback on non-verbal signs of pain in particular. Attitudes to treating those with dementia need to be

[14] Royal Commission into Aged Care Quality and Safety. (2021). Final Report – List of Recommendations. Government of Australia. https://agedcare.royalcommission.gov.au/publications/final-report-list-recommendations

improved, with less judgement of the individual and condition than currently occurs, and more knowledge and skill in effective treatment. [15]

Physical issues relating to dementia

It is often neglected to mention in discussions around dementia, that dementia also has a significant physical manifestation. Those persons living with dementia have significantly greater likelihood of having poorer physical outcomes than someone who does not have dementia, whether they live in the community or in residential aged care

For example someone living with dementia is twice as likely to fall (2X rates of someone without dementia at a similar age). This can be contributed to a number of physical factors of dementia itself, such as having more physical pain, altered sensation, and spatial awareness.

Pain in older people is poorly managed in general, but more so for those with dementia. The Australian Pain Society estimates that 60-80% of all of those in nursing homes have under-diagnosed and under-reported pain. This is a frightening statistic already but it is even worse when you consider pain is much more likely to occur for residents of nursing homes who have moderate-to-severe cognitive difficulties (68% of nursing home population) . Multiple studies of those with dementia or impaired cognition has shown that they are much more likely to have poor assessment of their pain, and be given less analgesia than others due to difficulty communicating pain.[16]

In Vascular Dementia, individuals most likely have more pain, because of white matter lesions that may stimulate Central Pain. [17]

Poorly managed pain has a dramatic effect on decreasing an older person's quality of life. It leads to depression, reduced participation in activities, anxiety and decreased mobility. This in turn causes loss of muscle mass, range of motion, bone density, pressure areas, swelling and difficulty transferring and increased likelihood of musculoskeletal injury. Individuals with poorly managed pain are more likely to be prescribed inadequate or inappropriate medication, such as psychotropics which also causes side effects such as falls.

Physiotherapy in particular has good evidence that targeted interventions can reduce falls by as much as 55%. Falls are the leading cause of death in older adults, some 5100 people per a year. Those with dementia therefore are twice as likely to die from falls as another older adult, this is a further indication for preventative physiotherapy.

We support the recommendation of Dementia Australia, that pain in an older person be managed with the same approach of ongoing and regular non-medication-based approaches used with other individuals. The person with pain should be believed that their pain is real and recognised. A multidisciplinary assessment must be made of that person's pain including its likely causes, severity and effects on function, emotions and mental / spiritual well-being. Along with the allied health team RN's, EN's and PCA's must have the appropriate training and expertise to be able to manage a person's pain issues including an understanding of nonverbal / behavioural cues that pain is present, what therapy including analgesia is

[15] Zwakhalen S, Docking RE, Gnass I, Sirsch E, Stewart C, Allcock N, Schofield P. Pain in older adults with dementia : A survey across Europe on current practices, use of assessment tools, guidelines and policies. Schmerz. 2018 Jun 21. doi:

[16]] Achterberg WP, Pieper MJ, van Dalen-Kok AH, de Waal MW, Husebo BS, Lautenbacher S, Kunz M, Scherder EJ, Corbett A. Pain management in patients with dementia. Clin Interv Aging. 2013;8:1471-82.

[17] 2 Achterberg and Busedo, "Pain in Dementia" International Association for the Study of Pain 2019 Fact Sheet

effective, what the side effects might be, how to manage and report those issues both in documentation and consultation with the wider team including doctors. This should lead to the development of a treatment plan along with the individual and their family to ensure it relates to their clinical needs and goals of care.

ACRN supports the Royal Commission recommendation 38, Residential aged care to include allied health.

OBJECTIVE 7: Improving dementia data and maximising the impact of dementia research and innovation.

Increased funding and expanded scope of the Australia Dementia Network

Dementia is currently the seventh leading cause of death among all diseases and one of the major causes of disability and dependency among older people world-wide[18].

It is vital that adequate funding goes into research, education, diagnosis and treatment.

We believe that funding variant diagnosis through Medicare would provide important data on prevalence and outcomes for different types of dementia.

The Australia Dementia Network (ADNet)[19] needs to be broadened to include diagnosis by GP's this will allow the gathering of more data and provide information on what pathways/trajectories are being followed. This would be possible with the hub and spoke model we are suggesting.

CONCLUSION

ACRN would like to see dementia care become integrated and harmonised nationally. We envisage Dementia Wellness Hubs run through the Primary Health Network where the individual can receive treatment and support in their community from a well-trained multi-disciplinary team.

We believe this will facilitate early diagnosis, improve initial support for the person and their carers/family, promote enablement and provide ongoing support including advocacy.

We hope this will lead to people living with and alongside dementia, thriving in compassionate inclusive communities free of stigma and discrimination.

[18] https://www.who.int/news-room/fact-sheets/detail/dementia
[19] https://www.australiandementianetwork.org.au/