

A roadmap for quality dementia care

Parliamentary Friends
of Dementia paper

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Introduction

Dementia Australia has a clear roadmap for quality dementia care. It is based on the views of people living with dementia, families and carers and addresses the gaps and possible solutions outlined in the Royal Commission into Aged Care Quality and Safety. Not only this, but the roadmap addresses the systemic failings in an aged care system in which dementia has not been core business.

The Government's response to the Royal Commission's findings is a rare opportunity to make a step-change difference to the experience of people impacted by dementia.

To that end, Dementia Australia has been working with people living with dementia, their families and carers, as well as some important sector partners, to develop an integrated "Roadmap for Quality Dementia Care." This collaborative vision, together with its key components, has been presented for careful consideration by the Government. .

In **2021**, the estimated number of Australians living with **dementia** is

472,000

Without a medical breakthrough, **by 2058** the number of people with dementia is expected to increase to

1,076,000

In **2021**, the estimated number of people with **younger onset dementia** is

28,300

By 2058 this is expected to rise to

41,250

Reference: Dementia Australia (2018). Dementia prevalence data 2018-2058, commissioned research undertaken by NATSEM, University Canberra.



Figure 1: The most significant system issues as identified by people living with dementia

The Royal Commission has brought focus to key themes for the aged care sector to better meet the needs of people living with dementia, their families and carers, including dementia support pathways; specialist dementia care services; workforce education; and dementia-friendly design of aged care accommodation.

Dementia Australia offers a roadmap for quality dementia care to translate these themes into practice.

Our vision for significantly improving the experiences of people living with dementia, their families and carers

Quality dementia care needs to become an intrinsic, core element of aged care in Australia. Dementia Australia believes that there are three key areas of transformation that collectively would make a substantial difference to the delivery of quality dementia care for people impacted by dementia:

- Dementia support pathways
- Building workforce capability
- Dementia-friendly design

We see these three focus areas, along with a set of underpinning principles such as integration, continuous improvement and ongoing consumer engagement, as combining to form a 'roadmap' for the future of dementia care and supports in Australia. We also recognise the power of effective partnerships and acknowledge the important role of Dementia Training Australia and Dementia Support Australia in bringing these initiatives to life.

The roadmap presents a connected, integrated dementia care system, where people living with dementia, their families and carers, and their care providers can access the information that they need and be supported to navigate the most appropriate services. In conjunction with this, the sector, and people working within it, will have the capacity and capability to consistently deliver quality care for people living with dementia, their families and carers, and the physical settings within which people receive care will also be fit for purpose.



There is ongoing consumer engagement and consultation.

People living with dementia, their families and carers are at the centre.

Research and evidence is used to inform decision-making.



Single dementia access point.

Organisations have a culture of continuous improvement.



Consumers are connected to information, services and supports that are appropriate, available, accessible and integrated.



The workforce is skilled, capable and focused on people living with dementia.



Built environments are fit for-purpose.

Focus areas

1

Dementia support pathways.

2

Building workforce capability.

3

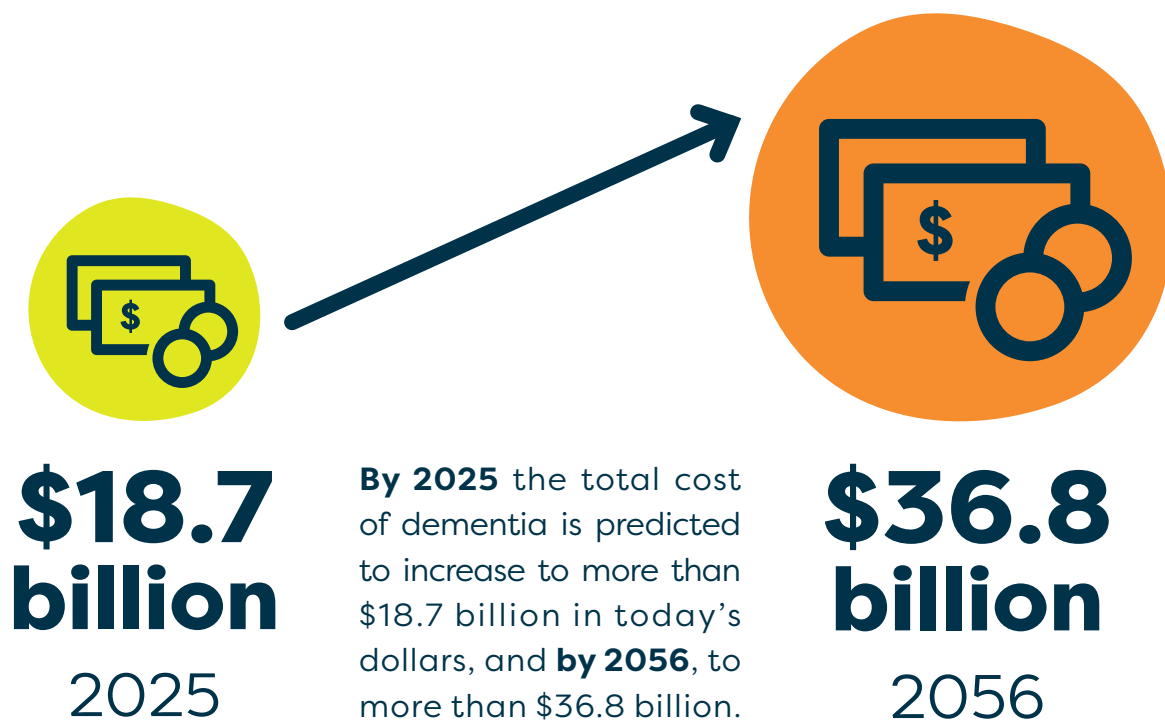
Dementia-friendly design.

Figure 2: Quality Dementia Care Roadmap

Focus area one

Dementia support pathways

Dementia Australia proposes an integrated and specialist service response with a single access point through a centralised, national telephone and online service that complements My Aged Care, the Carers Gateway and the National Disability Insurance Scheme. By expanding on the existing National Dementia Helpline, Dementia Australia will offer a more comprehensive and integrated service pathway that includes the kind of service, social and psychological support that people need. This will ensure people of any age experiencing symptoms of dementia, living with dementia, and their carers and families have timely access to diagnosis and a direct and clear pathway to early and ongoing supports and treatment services.



Reference: The National Centre for Social and Economic Modelling NATSEM (2016) Economic Cost of Dementia in Australia 2016-2056.



Focus area two

Building workforce capability

Dementia Australia proposes a comprehensive approach to building the dementia capability of the aged care workforce to ensure the skills and knowledge to provide quality care and support to people living with dementia. This will focus on addressing the most immediate deficits in workforce capacity, along with implementing initiatives to support the sustainable transformation of dementia practice in the longer term. The education and training initiatives will address the needs of different vocational groups within and outside aged care settings and target both the current and the future workforce.



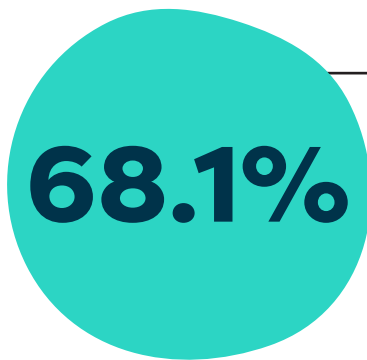
**Dementia education
is considered the
most needed training**

by both home care workforce
and service providers.

Reference: National Institute of Labour Studies (2017) The Aged Care Workforce, March 2016.

Together with Dementia Training Australia and Dementia Support Australia, we have identified two phases which would be implemented in parallel to address education and training needs and build the workforce dementia capability.

1. Uplift dementia capability of the workforce in the short-term.
2. Implement initiatives supporting in the sustainable transformation of dementia practice in the medium to long term.



More than two thirds of aged care residents have moderate to severe cognitive impairment.



80% of aged care residents with dementia **require high level care.**

This is almost double the amount of residents without dementia who have high care needs (80%).

Reference: National Institute of Labour Studies (2017) The Aged Care Workforce, March 2016.

Focus area three

Dementia-friendly design

Dementia Australia proposes developing and embedding a set of robust, evidence-based and practice-informed dementia-friendly standards. This will enable physical environments that support people living with dementia to be as independent as possible. Recognising that it is difficult and likely very costly to upgrade existing facilities to meet the needs of people living with dementia, Dementia Australia, Dementia Training Australia and Dementia Support Australia propose an approach in which incremental improvements are facilitated over time. At the same time, we recommend a specific focus on new builds to ensure that they comply with the existing guidelines relating to dementia friendly design and that over time these should form part of the building code requirements for building any new residential aged care facilities.

12% of Australian aged care residents have **no access to outside areas or gardens** (16% only 'sometimes')



Reference: South Australian Health and Medical Research Institute (SAHMRI) (2020) Inside the System: Aged care residents' perspectives.

The solution to sector transformation

Foundational steps are required to improve information and navigation processes so that people living with dementia, their families and carers can obtain a diagnosis and access a broad range of support services in an appropriate and timely manner. A key component of achieving this is building the capability of the aged care workforce in the short term and sustaining it over the medium to long term. This, alongside the physical environments for new aged care homes being dementia-friendly, will lead to improved care outcomes for people impacted by dementia. Dementia Australia would like to acknowledge Dementia Training Australia and Dementia Support Australia for their involvement and collaboration on these important initiatives and we look forward to continuing to work with them, as well as the Federal Government and people impacted by dementia to ensure their success.

We can map this transformative process over a ten-year period, with most of the activity taking place in the first three years.



Almost two thirds (63%) of residential aged care facilities report skill shortages. Regional facilities are more likely to report skills shortages.

Reference: National Institute of Labour Studies (2017) The aged care workforce 2016.

Immediate action

In essence, the elements of the Roadmap that can be **rolled out right now** include:

Building workforce capability

- A revised dementia unit of competency for the Certificate III in Individual Support.
- Targeted delivery of Dementia Essentials¹ to deliver foundational dementia education to the workforces in greatest need.
- Establish and implement a national network of dementia communities of practice.
- Roll out of a comprehensive assessment of current workforce dementia capability to understand where best to target future education in residential care.
- Roll out advanced dementia education to a range of health professionals across health and aged care.
- Expansion of the National Dementia Support Program where gaps exist.

Medium term action

Across the **next three years**, we can achieve:

Dementia support pathways

- Short-term implementation of a single access point for people impacted by dementia by focusing on back-end infrastructure to more effectively link people to Dementia Australia and facilitate ‘warm’ referrals to and from My Aged Care, NDIS and the Carer Gateway.
- The creation of new social support and peer support programs to complement the NDSP.

1 Dementia Essentials is underpinned by a nationally accredited unit of competency.

Building workforce capability

- Roll out of comprehensive assessments of the current workforce dementia capability to understand where best to target future education in home care.
- Delivery of Certificate IV in Dementia Practice.
- Start to develop and implement dementia practice leaders in every aged care organisation.
- Developing and implementing a national dementia education standards framework supported by learning pathways and career development.

Dementia-friendly design

- Developing physical design standards and review panel.
- Implementing approval processes for new-build or renovated services that assesses dementia-inclusive design.

Long term action

In the **longer term** we can achieve:

Dementia support pathways

- A single Dementia Helpline number for dementia information, services and support, that facilitates access to key services such as Dementia Behaviour Advisory Service and Carer Gateway.
- Building workforce capability.
- Ongoing review cycles for dementia education standards and courses/content.
- Embedding a network of dementia practice leaders, supported through communities of practice as key features of knowledge translation, practice improvement and systemic change.
- Building the focus on dementia competencies across a range of tertiary education programs for relevant professional groups.

Dementia-friendly design

- Legislative changes to building codes.
- Ongoing accreditation/quality standard review that focuses on the physical environment.

While we have provided a solid vision to improve the quality of dementia care, changing the culture of aged care will take time. Ongoing actions such as re-auditing services, embedding continuous improvement processes specific to dementia, transforming the regulatory environment of aged care services, as well as changing legislative and policy contexts and building education and workforce pathways and communities of practice, are all important components of the sector transformation that is needed.

The prevalence of dementia in our community continues to grow exponentially. Those impacted by dementia across Australia are seeking decisive action to ensure that the outcomes for people living with dementia, their families and carers are adequately considered in the context of more generalised health, disability and aged care reforms, with targeted, translatable action.

Investing in initiatives that define the pathway to and through services, developing education mechanisms to embed quality dementia care, focusing on the impact of the physical environment and capturing the reform actions in a Roadmap to Quality Dementia Care will demonstrate that the Federal Government is serious about making dementia core business in Australia.



Dementia prevalence estimates 2021-2058

Australian Commonwealth Electoral Divisions (CED) alphabetically

CED	2021	2058
Adelaide	3,715	7,686
Aston	2,839	7,041
Ballarat	3,394	7,000
Banks	3,104	7,578
Barker	3,854	5,474
Barton	3,441	8,701
Bass	2,376	3,276
Batman	3,101	7,874
Bendigo	3,511	6,433
Bennelong	3,096	8,012
Berowra	3,393	12,611
Blair	2,500	7,493
Blaxland	2,990	7,319
Bonner	2,353	5,558
Boothby	3,553	6,397
Bowman	3,418	8,722
Braddon	2,577	3,025
Bradfiel	3,854	10,685
Brand	2,425	7,151
Brisbane	2,760	6,520
Bruce	3,337	7,357
Burt	2,536	7,755
Calare	3,673	5,598
Calwell	2,530	9,368
Canberra	3,565	9,672
Canning	3,470	8,296

CED	2021	2058
Capricornia	2,676	4,739
Casey	2,817	6,616
Chifley	2,269	7,364
Chisholm	3,843	7,327
Clark	2,187	3,579
Cook	3,065	6,631
Corangamite	3,548	7,436
Corio	3,627	8,491
Cowan	2,098	7,494
Cowper	4,817	5,893
Cunningham	3,580	6,274
Curtin	3,124	6,183
Dawson	2,763	4,993
Deakin	3,264	6,996
Dickson	2,981	8,180
Dobell	4,043	8,132
Dunkley	3,397	7,994
Durack	2,277	6,808
Eden-Monaro	3,380	6,165
Fadden	3,434	8,629
Fairfax	3,825	8,704
Farrer	4,099	5,236
Fenner	2,792	9,180
Fisher	3,795	8,636
Flinders	4,604	11,800
Flynn	2,578	4,650

Dementia prevalence estimates 2021-2058

Australian Commonwealth Electoral Divisions (CED) alphabetically (continued)

CED	2021	2058
Forde	2,706	7,377
Forrest	3,039	5,648
Fowler	2,890	7,664
Franklin	2,329	3,793
Fremantle	2,716	7,306
Gellibrand	2,886	8,007
Gilmore	4,988	8,403
Gippsland	3,841	5,302
Goldstein	3,520	8,499
Gorton	2,588	11,480
Grayndler	2,454	7,212
Greenway	2,292	7,380
Grey	3,739	4,880
Griffith	2,509	5,927
Groom	3,342	6,042
Hasluck	2,540	6,211
Herbert	2,400	5,277
Higgins	3,220	7,724
Hindmarsh	3,837	7,391
Hinkler	4,237	6,869
Holt	2,879	11,405
Hotham	3,240	7,581
Hughes	2,943	6,549
Hume	2,919	8,425

CED	2021	2058
Hunter	3,519	6,217
Indi	3,591	5,016
Isaacs	3,338	8,112
Jagajaga	3,011	6,876
Kennedy	3,597	6,179
Kingsford Smith	3,254	8,242
Kingston	3,180	6,222
Kooyong	3,176	7,034
La Trobe	2,562	8,952
Lalor	2,620	14,215
Leichhardt	2,549	6,527
Lilley	2,432	5,746
Lindsay	2,444	6,609
Lingiari	966	3,241
Longman	3,245	8,937
Lyne	4,981	7,891
Lyons	2,342	3,071
Macarthur	2,414	8,587
Mackellar	3,300	7,880
Macquarie	2,999	7,413
Makin	3,113	6,701
Mallee	3,710	4,496
Maranoa	3,223	4,939
Maribyrnong	3,178	8,234
Mayo	3,795	6,279
McEwen	3,394	12,664

Dementia prevalence estimates 2021-2058

Australian Commonwealth Electoral Divisions (CED) alphabetically (continued)

CED	2021	2058
McMahon	2,689	7,209
McMillan	3,924	10,843
McPherson	3,206	8,057
Melbourne	2,602	9,515
Melbourne Ports	2,491	8,459
Menzies	3,728	6,908
Mitchell	2,565	8,114
Moncrieff	3,705	9,310
Moore	2,490	5,882
Moreton	2,614	6,176
Murray	3,869	5,021
New England	3,794	4,678
Newcastle	3,135	5,119
North Sydney	3,154	9,796
O'Connor	3,159	5,125
Oxley	2,442	6,480
Page	4,394	5,727
Parkes	3,591	4,415
Parramatta	2,749	6,094
Paterson	3,506	7,022
Pearce	2,746	8,535
Perth	2,729	6,474
Petrie	3,108	8,283
Port Adelaide	3,470	8,221

CED	2021	2058
Rankin	2,687	7,256
Reid	3,357	9,006
Richmond	4,613	8,327
Riverina	3,811	4,731
Robertson	3,864	7,772
Ryan	2,447	5,781
Scullin	2,905	10,972
Shortland	3,827	6,645
Solomon	1,024	3,216
Stirling	2,951	6,152
Sturt	3,832	7,032
Swan	3,092	7,192
Sydney	2,316	8,959
Tangney	2,891	5,453
Wakefield	3,151	6,757
Wannon	3,610	4,407
Warringah	3,256	7,956
Watson	3,167	7,400
Wentworth	2,778	7,169
Werriwa	2,474	7,872
Whitlam	3,688	6,698
Wide Bay	4,066	7,645
Wills	3,232	7,412
Wright	3,022	7,492

For methodology: bit.ly/3puhvcu



About Dementia Australia

Dementia Australia is the source of trusted information, education and services for the estimated half a million Australians living with dementia, and the almost 1.6 million people involved in their care. We advocate for positive change and support vital research.

We are here to support people impacted by dementia, and to enable them to live as well as possible. Founded by carers more than 35 years ago, today we are the national peak body for people living with dementia, their families and carers.

We involve people impacted by dementia and their experiences in our activities and decision-making, to make sure we are representative of the diverse range of dementia experiences.

We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

No matter how you are impacted by dementia or who you are, we are here for you.

National Dementia Helpline

1800 100 500



For language assistance
call **131 450**

Find us online
dementia.org.au

