

Initiative of



ACT
Government

Evidence-based framework for dementia care

how the ACT health system cares for older
people living with dementia and experiencing
changed behaviours and supports their carers



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We respect the Aboriginal and Torres Strait Islander people, particularly our Aboriginal and Torres Strait Islander staff, and their continuing culture and contribution they make to the Canberra region and the life of our city.

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List of abbreviations

ACP	Advance Care Planning
ACT	Australian Capital Territory
ADACAS	ACT Disability, Aged and Carer Advocacy Service
ALOS	Average Length of Stay
AIN	Assistant In Nursing
BPSD	Behavioural and Psychological Symptoms of Dementia
CALD	Culturally and linguistically diverse
CARAT	Centre for Ageing Research and Translation, University of Canberra
CHS	Canberra Health Services
COPE	Care Of People with dementia in their Environments
CPOP	Clinical Placements with Older People
DA	Dementia Australia
DBMAS	Dementia Behaviour Management and Advisory Service
DRG	Diagnosis Related Groups
DSA	Dementia Support Australia
ED	Emergency Department
EMU	Emergency Medicine Unit
GANA	Gerontological Alliance of Nurses Australia
GNC	Gerontological Nursing Competencies
GRACE	Geriatric Rapid Acute Care Evaluation
GWAU	Group Weighted Activity Unit
HAC	Hospital Acquired Complications
HACDSP	The Hospital to Aged Care Dementia Support Program
HCCA	Health Care Consumers' Association
HCSO	ACT Health and Community Services Directorate
LaNS	Liaison and Navigation Service
NDIA	National Disability Insurance Agency
NP	Nurse Practitioners
OPMH	Older Persons Mental Health
PACER	Police, Ambulance, and Clinician Early Response
RADAR	Rapid Assessment of the Deteriorating Aged at Risk
RACH	Residential Aged Care Home
SDCU	Specialist Dementia Care Unit
SPICE	Sustainable Personalised Interventions for Cognitive, Care, and Engagement
UC	University of Canberra
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities

Foreword

With an ageing population, an increasing number of older Canberrans are living with dementia. Many experience symptoms like agitation, aggression and confusion which can escalate into crises, leading to prolonged hospital stays or repeated admissions while waiting for assessments or appropriate support.

Extended hospitalisations can harm independence, worsen physical and mental health, and increase the risk of complications. This situation is distressing not only for individuals with dementia but also for their carers, who face significant challenges and limited support in navigating complex and fragmented health and aged care systems which are the responsibility of different levels of government.

The health system struggles to manage care for older Canberrans with dementia who experience changed behaviours. Our current hospital infrastructure has not been designed to be dementia friendly, and many hospital staff have not been trained in dementia care. Delays in assessments, limited access to appropriate home care supports, and a lack of suitable residential care options leads to an over-reliance on hospital settings. This is inefficient and costly at a health system performance level. It is not the best outcome for patients with dementia and their carers nor for other patients whose access to and experience of care is affected. As part of the *Better care of older Canberrans* initiative, the then ACT Health Directorate assembled the Dementia Health Experts Network to develop evidence-based ideas on how to improve the ACT health system for older people living with dementia with a particular focus on those experiencing changed behaviours.

We were privileged to chair the Network and work with an expert and committed group of carers, clinicians, academic researchers, service providers and peak organisations who had a shared commitment to developing a more integrated, person-centred approach that reduces emergency department presentations, shortens hospital stays, and

enhances the health and wellbeing of older people with dementia and their carers.

We were grateful for the assistance of the ACT Health and Community Services Directorate (HCSD) who provided significant data analysis, policy input and meeting support. We thank the Health Care Consumers' Association, the Centre for Ageing Research and Translation at the University of Canberra and the Patient Experience Agency for their insightful research projects.

In particular, we thank those dedicated carers, service providers and health professionals who helped us to better understand the current state of dementia health care services in the ACT - at times this was painful for them, and we were privileged to bear witness to their experience. Their invaluable input has been front and centre of designing the recommended approach to improving future service delivery.

We have an opportunity to make the ACT a leader in caring for older people with dementia in the best environment for them and effectively supporting their carers. The Network has delivered a framework for the ACT to lead, enable and support the development of an inclusive and coordinated health and aged care systems that respond to the needs of older people living with dementia and experiencing changed behaviours and supports their carers.

Carolyn Smith, Consumer advocate representing Health Care Consumers' Association (HCCA)

Dr Mary Ann Kulh, Older Canberrans project clinical lead (Geriatrician), Health and Community Services Directorate.

Introduction

The population of the Australian Capital Territory (ACT) is growing and ageing, and demand for healthcare services is increasing. Dementia is the leading cause of death in Australia, and it is the leading cause of death for women [1]. It is a growing health issue with estimates of 6,100 people living with all forms of dementia in the ACT in 2025, with this number estimated to more than double by 2054 [2]. We know that two thirds of people living with dementia live in the community [3] with many experiencing changed behaviours.

Dementia encompasses a range of neurodegenerative diseases that primarily affect memory, cognitive abilities, emotions, physical functions, and behaviour. These conditions significantly impair a person's ability to perform daily activities independently, thereby requiring a supportive and enabling environment [4]. It results in an increased reliance on family, friends and health care providers for care and assistance [3, 5]. It has a substantial impact on the health and quality of life for people with the condition, as well as their carers, family and friends [5, 6]. The distinctions between various types of dementia are often unclear, and it is common for multiple forms to coexist simultaneously [4]. People living with dementia are at risk of experiencing stigma, discrimination, isolation and abuse.

A person with dementia will experience functional and cognitive decline which often includes emotional, perceptual and behavioural disturbances. These are also referred to as changed behaviours, responsive behaviours, behaviours of concern, neuropsychiatric symptoms, or behavioural and psychological symptoms of dementia (BPSD) [7]. These symptoms can be understood as expressions of unmet needs, reactions to lowered stress thresholds due to dementia, manifestations of brain pathology or changes in brain chemistry and/or a reaction to biological factors [7].

Brodaty, Draper and Low (2003) [8] developed a framework which describes seven tiers of services for managing BPSD, moving from services for mostly independent people who require primary care support (Tiers 2, 3) and progressing to services for those who require specialist support (Tiers 4, 5). At the tip of the triangle are people with dementia experiencing severe to extreme changed behaviours who require intensive specialist treatment and management (Tiers 6, 7) ([Appendix A](#)). The Bail et al Inverted Triangle supports the understanding that 'upstream' factors can be changed to influence 'downstream' outcomes [9]. It summarises key requirements relating to *services and settings and workforce*. There are no distinct boundaries between tiers, movement between tiers can be fluid and changeable [10] and may be affected by the way in which care is delivered and the nature of the care environments. The Network recommends the framework guides future planning and provision of services which have upstream/downstream health policy and service delivery approaches relevant to dementia care in the ACT.

The prevalence rates of changed behaviours amongst people living with dementia varies between 56 and 90 per cent, whether they reside in the community, residential aged care home (RACH) or are admitted to hospitals [7]. These symptoms can be episodic, fluctuate over time, and respond to various interventions and care strategies [11]. These changed behaviours are linked to early admissions to Residential Aged Care Home (RACH), higher rates of hospitalisation, increased distress for carers, and reduced functional abilities. This can significantly affect the quality of life, prognosis,

health outcomes, mortality risk and care needs of those living with dementia. The lack of support services to prevent challenging behaviours and respond appropriately as they happen can cause distress to both formal and informal carers [7, 8, 12].

A consumer centred, carer inclusive service model for the future that is supported by innovative solutions and enabling systems has been outlined in this framework. The service model for older people living with dementia and experiencing severe changed behaviours was co-designed with carers who prioritised the following four areas of need:

- A personalised navigation service connecting carers and patients with the right services at the right time, ensuring seamless access and ongoing support;
- Immediate access to respite services during challenging times, alleviating carer burden;
- Crisis support services in the community during challenging times;
- A hub for specialist dementia care, research and innovation providing support for the most complex cases.

Purpose

The purpose of this document is to propose evidence-based and human centred changes to the ACT health system, that will improve health services to better meet the needs of older Canberrans living with dementia and experiencing changed behaviours and better support their carers.

Scope

This work is informed by the lived experiences of Canberrans caring for older people living with dementia and experiencing changed behaviours. It proved challenging to consult directly with older people with dementia experiencing changed behaviours due to a range of factors including ethical challenges around obtaining consent and the inability for older people with advanced dementia symptoms to share their experiences and challenges. As such, a carer-led, co-designed, and human-centred approach was applied to understand the unique challenges and care needs faced by these people. This co-designed approach captured many common experiences but did not directly capture the experience of people living with dementia without a family or carer. More work is required to understand the needs of those older people without a carer to advocate for them.

This work focused on the needs of older Canberrans living with dementia and experiencing changed behaviours and their carers. It is estimated that seven per cent of people living with dementia are under the age of 65 years [3]. Further work will be required on how the ACT health system should respond to the needs of people with younger onset dementia.

Vision

Older Canberrans living with dementia and experiencing changed behaviours receive timely, compassionate, inclusive and effective care, in the best environment for them, while action is also taken to provide support for their carers

Mission

The ACT Dementia Health Experts Network calls for collective action to lead, enable and support the development of an inclusive and coordinated health care system that responds to the needs of older people living with dementia and experiencing changed behaviours and supports their carers. The ACT needs an approach that focuses on early identification, prevention and timely recognition of deterioration in behaviours and symptoms. This will in turn support the delivery of an integrated, evidence-informed care across the continuum from community and primary care to acute, residential, rehabilitation and palliative care settings. Workforce capability, service design, and system governance should prioritise dignity, inclusion and person-centred responses that uphold the rights and quality of life for older Canberrans living with dementia and experiencing changed behaviours and support their carers

ACT Framework

HCSD assembled the Dementia Health Experts Network to develop innovative, and evidence informed options for how to improve the ACT health system for older people living with dementia and experiencing changed behaviours as part of the *Better care of older Canberrans initiative*.

The Dementia Health Experts Network was co-chaired by Carolyn Smith, a former senior Federal government public servant with experience in aged care and consumer advocate nominated by the Health Care Consumers' Association and Dr Mary Ann Kulh, a geriatrician and physician with extensive clinical experience in adult medicine. Its membership included carers, clinicians, researchers, service providers and peak organisations. The members of the Dementia Health Experts Network and stakeholders are listed in [Appendix B](#) and [Appendix C](#).

This Framework is the outcome of a human-centred, carer led co-design approach, research and analysis undertaken for the Dementia Health Experts Network and engagement with health services, partner organisations in the community, consumers and carers. It draws on best practice and targeted consultation on recognised care options for older people living with dementia and experiencing changed behaviours in the ACT and is informed by the findings and recommendations arising from reviews relating to the former Oakden Older Persons Mental Health Service in South Australia [13] and the Royal Commission into Aged Care Quality and Safety [14].

This Framework integrates the co-designed work with ACT public hospital emergency department and admitted patient activity for people with documented dementia, and insights from health professionals' experiences. It considers existing nurse and allied health-led evidence-based models of transitional dementia care in Australia as key elements in designing systems to meet the needs of people living with dementia and experiencing changed behaviours in the ACT.

The Network drew on the following four pieces of research and analysis:

- Older Canberrans preliminary analysis to inform future health services planning of services for people experiencing severe to extreme Behavioural and Psychological Symptoms of Dementia (BPSD): A Carer's Perspective of the BPSD Journey [15]: Patient Experience Agency (PEA);
- Experiences of Older Adults with Dementia and BPSD: Understanding Healthcare Access in Residential Settings [16]: Health Care Consumers' Association;
- Scoping review of nurse or allied health led models of transitional dementia care [10]: CARAT, UC;
- Report on health professionals' experiences of and recommendations for providing care for people with dementia experiencing changed behaviours [17]: CARAT, UC.

As noted above, this work did not capture the experience of people living with dementia who did not have a carer. The needs of people with younger onset dementia were out of scope. Additional work will be required to ensure the unique needs of these people and other vulnerable groups are understood and addressed in the future.

Principles

The principles underpinning the National Dementia Action Plan have been adopted for the ACT. These principles were the result of extensive research, planning and consultation with people living with dementia, their carers and families, aged care providers and workers, advocates and peak industry bodies and organisations and include [3]:

- The human rights of people living with dementia and their carers are protected and upheld, aligning with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).
- The needs of priority populations at higher risk of developing dementia are explicitly considered in designing actions. The priority populations are listed in [Appendix D](#).
- Action on dementia is driven by people living with dementia and their carers, through equitable inclusion and expression of their lived experience.
- Action on dementia is collaborative, coordinated, integrated, planned and responsive to need.
- Services and supports for people living with dementia and their carers are:
 - **holistic and strengths-based**, supporting people living with dementia in all aspects of their life, including a focus on wellness, and maintaining independence
 - **person centred and relationship-based**, driven by the preferences of people living with dementia and their carers;
 - **evidence-based, outcomes focused and maximise quality of life** for people living with dementia and their carers;
 - **appropriate, trauma informed, accessible and culturally safe** for all people;
 - **co-designed and delivered in partnership with local communities and agencies** where possible, including Aboriginal and Torres Strait Islander people, Culturally and linguistically diverse (CALD) communities, women, people with disability and LGBTIQ+ communities and the National Disability Insurance Agency (NDIA).

The policy context

The Network acknowledges the ongoing commitment of the ACT government to improving health outcomes for older people in the ACT and those living with dementia. This Framework aligns with the policy directions outlined in the National Dementia Action Plan 2024-2034 [3] and is intended to support continued collaboration by the ACT Government and the Federal Government, to progress shared priorities:

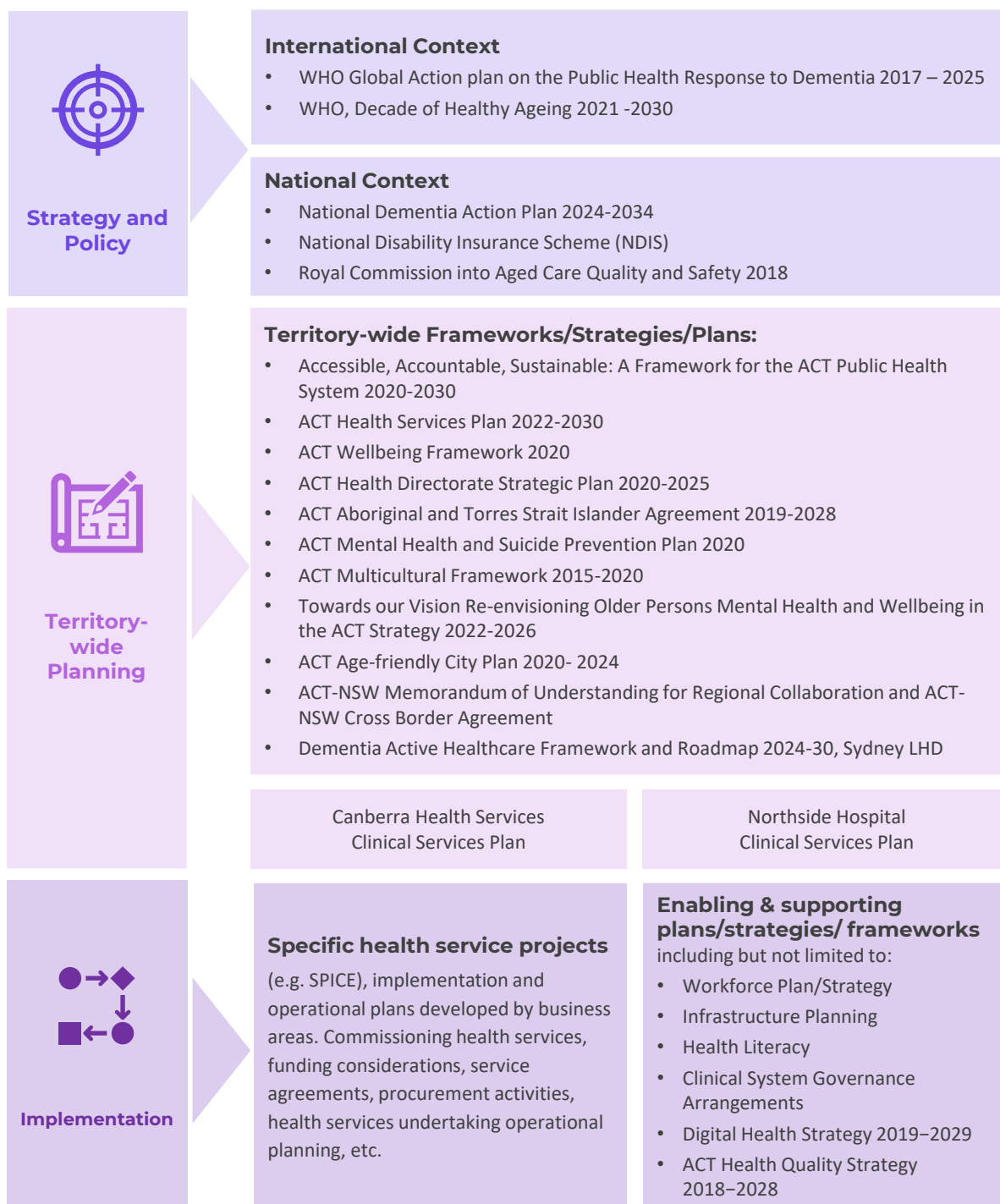


Figure 1: The policies, strategies and plans informing the Framework to improve the health system for older people living with dementia and experiencing changed behaviours and their carers

The Framework

The CARAT team developed an Inverted Triangle model (figure 2) which supports the understanding that 'upstream' factors can be changed to influence 'downstream' outcomes [9]. It summarised key recommendations relating to services and settings and workforce. This model emphasises, from the health professionals' view, the need for early intervention and generalised workforce responsiveness to decrease escalation to more intensive behaviours [17] thus demonstrating the positive flow down effect of community interventions upon health services, and early intervention for maximisation of function, cognition and independence and minimisation of dementia deterioration and symptom escalation [10].

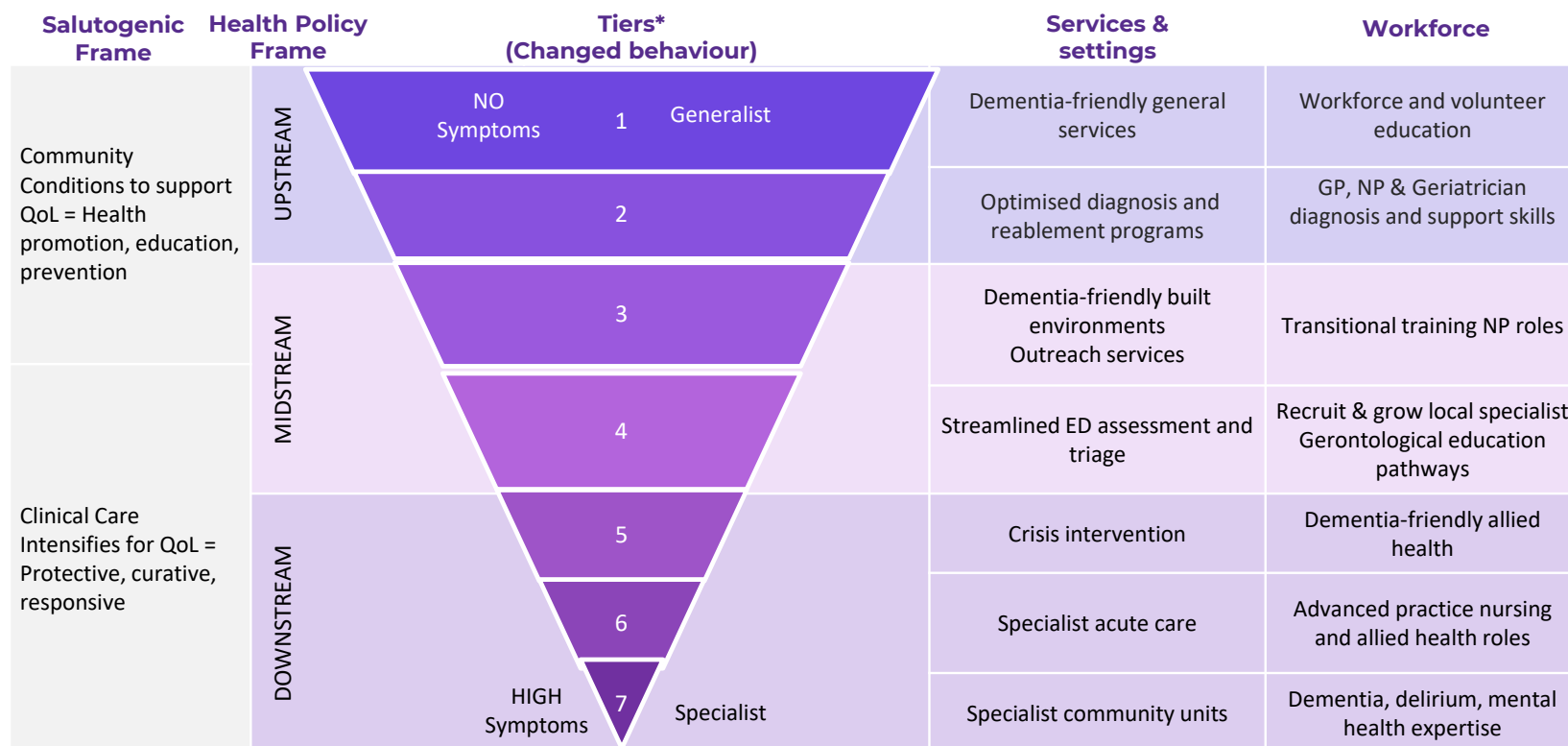
The framework emphasises the importance of prevention through focusing on healthy lifestyle and risk reduction behaviours. There is recognition of the need to provide support at times of deterioration in health, onset of dementia, changed behaviours and carer illness including burnout. At the extreme end, purpose-built environments with specialist trained health professionals and access to appropriate palliative care are essential.

Recommendation

The Network recommends the framework guides future planning and provision of services which have upstream/downstream health policy and service approaches relevant to dementia care in the ACT.

Bail et al Triangle (The Inverted Brodaty Triangle)

Mapping the 7 BPSD Tiers to salutogenic and upstream/downstream health policy and services approaches for dementia care



**Tiers refer to the range of changed behaviours experienced by people with dementia. They are not a static classification (people move between tiers) and may change within hours or days. Behaviour may be transient or more consistently experienced. Tier 7 displays extreme symptoms*

Figure 2: The Bail et al triangle [17]

People living with Dementia – a snapshot



Dementia is the **leading cause of death** in Australia accounting for **9.4%** of deaths. [2]



Dementia prevalence rates are **3 to 5 times higher** among Aboriginal and Torres Strait Islander people, nationally. [18]



The **prevalence of dementia** increases with age from less than 1 per cent in Australians under 60 years to:

- 4.1 % in 70–74 age group,
- 7.1 % in 75–79 age group,
- 12.3 % in 80–84 age group,
- 21 % in 85–89 age group and
- ~43 % in above 90 age group. [19]



Dementia prevalence rates are similar for men and women in younger age groups but quickly diverge with increasing age.

For the 90 years and above age group, the **rate of dementia among women is 1.4 times the rate among men** (479 per 1,000 women and 337 per 1,000 men). [19]



In 2026 there was an estimated **6,300** people living with all forms of dementia in the ACT.

This figure is estimated to increase to **12,300** people by 2054 with a projected percentage change of 102%. [2]



Nationally, more than **50%** of people living in **Residential Aged Care Homes** have dementia [3].

52% (1,657) people had dementia in the RACHs in ACT in 2021. [20]



In 2022, **67%** of people living with dementia in Australia lived in the **community**. [19]



People living with dementia stay in hospitals **5 times longer** than the average of all hospitalisations, nationally. [3]



Majority of people with dementia will develop at least one kind of **changed behaviour** over the disease journey [8]



CALD people living with dementia are underrepresented in RACHs (21% versus 25% of all Australians nationally) but over-represented in the ACT public hospital system (27–33%). [20]

Figure 3: Snapshot of people living with dementia

ACT public hospitals service activity and trends for people with documented dementia between 2018-19 and 2022-23



Figure 4: Dementia related ACT public hospitals service activity and trends [20]

Journey of the person experiencing changed behaviours and their carer

Dementia is a disease that is characterised by progressive loss of cognitive function. For older people living with dementia and experiencing changed behaviours, carers recognised six critical stages of the journey, including pre-diagnosis, diagnosis, decline, escalation, transition and palliative. Each stage presents distinct challenges to both the individuals and their carers. The complexity and fragmentation of the journey is illustrated by current state of the service system presented below in Figure 5. The figure 7 and appendix E further depict the current service navigation and pain points identified by carers.

The Current state Services Flow:

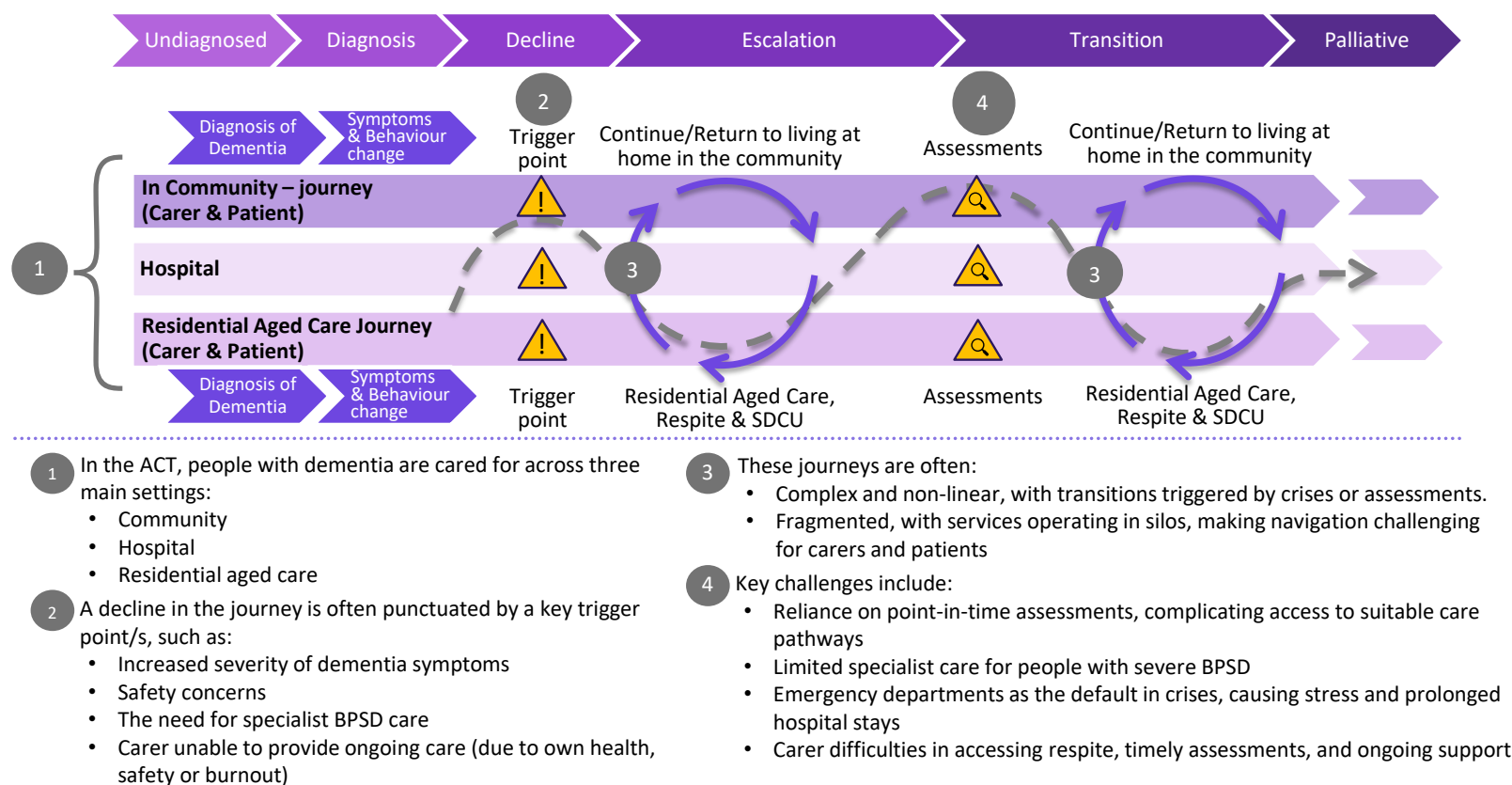


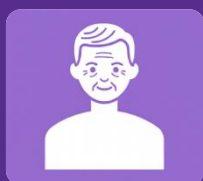
Figure 5: Current services flow in ACT [15]

Experiences of older Canberrans living with dementia and experiencing changed behaviours and their carers

A co-designed approach recognises the importance of developing a health system that reflects the lived experiences of people who interact with its services. A human-centred, carer-led design approach was adopted by the Network enabling people with lived experience to lead key aspects of the Framework through the development process. To capture these perspectives, a series of co-design workshops, one-on-one interviews with carers and health professionals and surveys were conducted. This process captured first-hand insights into the challenges and gaps within the current healthcare system for older people living with dementia and their carers – particularly when an older person living with dementia is experiencing changed behaviours. Mapping the current dementia care pathway in the ACT highlighted key pain points and daily barriers that are encountered by older people living with dementia and their carers. This informed the development of design options for future service delivery.

A key theme that emerged from this work was the co-dependent journey of older people living with dementia and their carers. The journeys of older people with dementia and their carers were interconnected and their shared experience gave rise to emotional and practical complexities. Two dominant personas emerged from the diverse input received from the workshops and surveys - a “Partners persona pair” and a “Parent-Child Persona pair”. An insight into the complexities experienced by the persona pairs is as follows:

Partner persona pair: Insights into Robert and Helen’s dementia care pathway



Robert, 72
Husband
Living with dementia



Helen, 68
Wife
Transitioning to carer

Robert lives with dementia and experiences severe changed behaviours. He is cared for by his wife Helen who struggles with the physical and emotional demands of caregiving when Robert’s needs escalate. Helen’s main goal is to maintain Robert’s dignity and stability while protecting her own health. She requires crisis support and smooth transitions to specialist care for Robert.

When Robert’s dementia symptoms worsened, Helen was determined to keep Robert at home for as long as possible however, his escalating behavioural symptoms begin to impact her health and safety resulting in frequent ED visits and longer hospital stays. Robert’s health practitioners recommend that Robert transition to a Specialist Dementia Care unit (SDCU) or memory support area of a RACH. Helen gets frustrated with the arduous assessment and application process to secure a place. When Robert is accepted into the RACH, she visits him daily, providing him comfort and familiarity while adjusting to her new role as a supportive visitor rather than a full-time carer.

“ [I would just like to see] Information provided up front after diagnosis. Information provided simply and logically. Better linkages between services. Referrals to services in a timely manner. -Carer, ACT (Source: Project Carer’s Survey) ”

Parent-Child Persona Pair: Insights into Evelyn and Priya's dementia care pathway



Evelyn, 82
Mother
Living with dementia



Priya, 57
Daughter
The carer

Evelyn is an older woman living with dementia and experiencing changed behaviours. Priya, her daughter supports her whilst juggling work and raising her own family. Priya's main goal is to keep her mother safe and comfortable while managing her own wellbeing and responsibilities. She seeks reliable respite options and proactive support to navigate each stage of Evelyn's care.

When Evelyn's dementia progressed and she required more support, her daughter, Priya, became her primary carer. Priya balances Evelyn's care needs with her own family's needs and other responsibilities. Initially, in-home care providers through an aged care package enabled Evelyn to remain at home; however, as her health declined, she had a fall requiring a hospital visit. Priya realised her mother's needs had increased, and she needed more supported care.

Evelyn moved into Priya's home while she undertook the lengthy process of getting her a place in a residential aged care home. Now, Priya and her family try to visit Evelyn regularly, providing her mother with familiarity and comfort in this new environment while navigating the evolving challenges of their relationship.

“My mother became quite isolated and depressed, and I am now aware that there are many support groups we could have tapped into, but it was left to me as her carer to seek these out. We could possibly have delayed her going into an aged care facility if we had engaged more in the groups and the activities they ran. -Carer, ACT (Source: Project Carer's Survey)”

Figure 6: Partner Persona Pair and Parent-child Persona Pairs [15]

Key pain points at each stage of dementia journey in the ACT

Each persona pair above, highlights the individual experiences of disease progression in Robert and Evelyn and their carers Helen and Priya respectively. Figure 7 below highlights the key pain points in the six critical stages of the dementia journey for both the persona pairs from a carer's perspective highlighting their respective stressors from pre-diagnosis, diagnosis, decline, escalation, transition all the way to palliative care.

Stage/ Persona Pair	Robert and Helen (Partner persona pair)	Evelyn and Priya (Parent-Child Persona Pair)
Diagnosis	• Slow to get a diagnosis • Gender bias – fighting to be heard as a wife/partner with some male GPs/practitioners • Person with dementia refusing to cooperate with getting a diagnosis (masking symptoms) • Hard to know where to go to get help	• Slow to get a diagnosis • Person with dementia refusing to cooperate with getting a diagnosis (masking symptoms) • Not knowing how to navigate the system on behalf of parents • Lack of knowledge amongst GPs on what services to access
Decline	• Long waits for specialists and ACAT assessments • Lack of proactive services – have to wait until something bad happens to get help • Caring and health administration becoming a full-time job • Escalating costs • Difficult to navigate system • Trying to balance patient and carer wellbeing • Becoming socially isolated	• Long waits for specialists and ACAT assessments • Hard to find or keep in-home carers once symptoms escalate • Balancing carer role and raising own family • Difficult to navigate system • Bouncing between services, hospital, RACH, respite, SDCU and home – 86% transferred between 1-3 times • Lack of respite options
Escalation/ Deterioration	• Lack of specialist services to support escalating symptoms, so 100% have at least one ED visit • Difficult to find places in RACH with specialist dementia support • Carer own health and/or wellbeing deterioration • Long waits to see specialists or get assessments resulting in long hospital stays • Being rejected from RACH due to changed behaviours • Fears for own safety	• Lack of specialist services to support people living with dementia with changed behaviours in-home or RACH • Difficult to find places in RACH • Poor communication between services and practitioners • Growing caring and administration burden • Long waits for assessments • Lack of respite options • Distress caused by unfamiliar carers or emergency services visiting home or in ED

Stage/ Persona Pair	Robert and Helen (Partner persona pair)	Evelyn and Priya (Parent-Child Persona Pair)
Transition	• Difficulty navigating systems • Lack of continuity across services and practitioners • Waits for ACAT and RACH/Specialist Dementia Care unit assessments • Paperwork to apply for RACH • Lack of staff trained to support people living with dementia and experiencing changed behaviours • Distress caused by move to new facility or service • Finding the right facility • Changing role as a carer (from carer to 'visitor') • Carer burnout	• Wait times for ACAT and access to RACH places • Low staff ratios in RACH to suitably support complex needs • Lack of in-home care options to support people living with dementia with changed behaviours • Changing roster of staff in services makes familiarity and consistency of care difficult • Ensuring safety in home or RACH for people living with dementia and experiencing changed behaviours
Palliative	• Accessing specialist palliative services for older people with changed behaviour • Care plan often not covering this stage • Not always understanding the care plan and palliative approach • Medication management decision not clear • Managing the change to a different environment • Lack of grief counselling and support, particularly for carers post-death of loved one	• Palliative conversations being had too late – lack of care planning for this stage • Lack of continuity of care in RACH settings • Lack of psychological support for carers post-death of loved one • Unfamiliar environments or people in palliative stage • Not understanding palliative process fully • Lack of in-home palliative options for people living with dementia and experiencing changed behaviours

Figure 7: Key pain points at each stage of dementia journey of two persona pairs [15]

Appendix E provides a more detailed description of the current service navigation and pain points in dementia care services.

Towards the end of dementia journey

Currently, dementia is an irreversible disease and can be defined as a terminal condition. The disease trajectory of everyone is different and people often live with other comorbidities. In figure 8, the illness trajectories of cancer and organ failure were described in trajectory 1 and trajectory 2. Unlike cancer and organ failure, the illness trajectory of people with dementia is characterised by gradual deterioration, from an already low baseline of cognitive or physical functioning, as in trajectory 3. The illness trajectory of dementia can be

unpredictable leading to the difficulties in determining the life-stage of individuals with dementia and when to commence palliative and end-of-life care [21]. One of the pain points, suggested in figure 7, was palliative conversations being held too late which hinders effective planning. Dementia trajectories may be exacerbated by acute or chronic conditions. The trajectory can be more unpredictable after an acute event such as a fall or more gradual generalised deterioration of multiple body systems [21].

People with dementia are more likely to access end of life care in hospital settings, but there is an opportunity for advance care planning at early stages and increased palliative care planning for end-of-life care in community and residential settings [22].

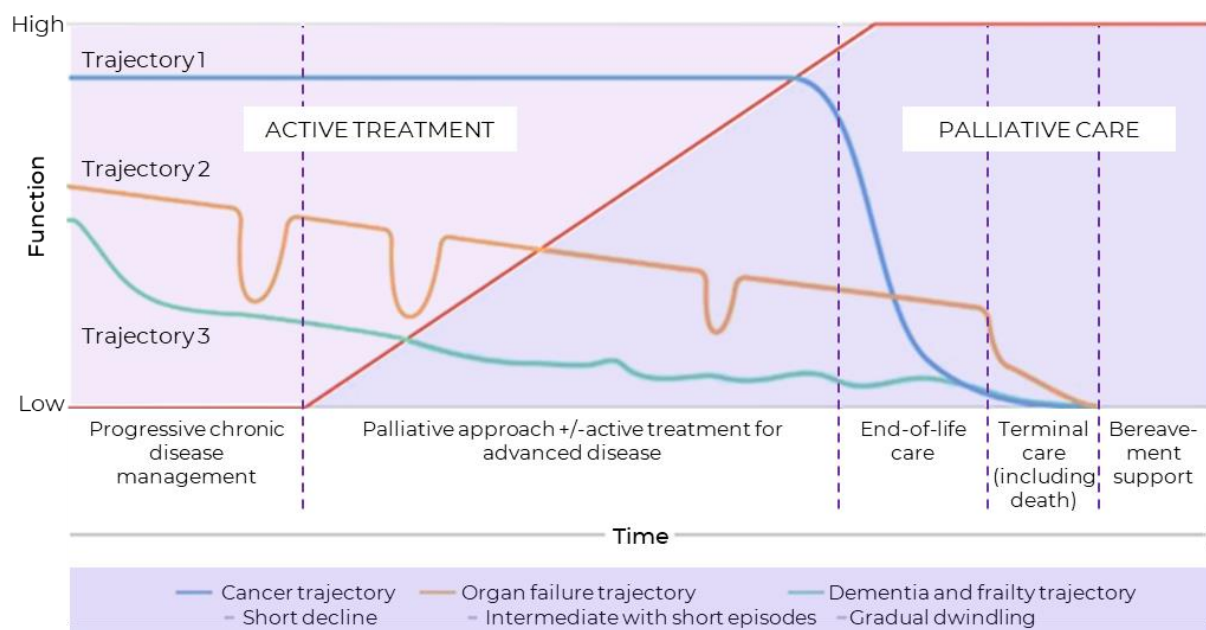


Figure 8: Typical illness trajectories and palliative care phases towards the end of life [22]

Priority concepts co-designed with carers

The future health system co-designed with carers for older people living with dementia and experiencing changed behaviours centres on a carer inclusive service model supported by innovative solutions and enabling systems. Carers with lived experience prioritised four areas of need which are outlined below:

Priority concept 1:

A personalised navigation service connecting carers and patients with the right services at the right time, ensuring seamless access and ongoing support.

Priority concept 2:

Immediate access to respite services during challenging times, alleviating carer burden.



Priority concept 3:

Crisis support services in the community during challenging times.

Priority concept 4:

A hub for specialist dementia care, research, and innovation, providing support for the most complex cases.

Figure 9: Four priority concepts co-designed with carers [15]

Consumer Priority Concept 1

Carer and Patient Desired Outcomes:

- Reduced burden of caring, and social isolation.
- A need to tell their story once (single point of contact).
- Easy access to right care at the right time inclusive of carer support.
- Carers understand the progression of dementia symptoms before they occur.

Dementia Navigator

Navigating the systems to support older people with dementia can be overwhelming – health and aged care services are fragmented and confusing, the transitions are difficult, and the communication is poor between care settings. Carers describe the need for navigator support that transforms this experience by serving as a single, trusted point of contact through the dementia journey.

Through the eyes of the carer, this role provides clarity and guidance while streamlining access to appropriate services to ensure continuity of care. When carers need to transition the person with dementia from home to a respite facility, the journey is coordinated every step of the way, from referrals to booking services, and thereby eliminating the burden of repetitive forms and phone calls.

Carers of people living with dementia and experiencing severe changed behaviours, highlight the need for a single point of contact, coordinating services and assisting smooth transitions to required services such as a specialist dementia RACH or facility. This personalised, proactive approach saves time and ensures carers feel supported, confident and empowered to make the best decisions. This approach initiates care planning, provides education and prepares carers for what may happen during the different stages of dementia progression, providing support at time of stress, assisting carers and people with dementia in accessing resources, funding and services.

The University of Canberra (UC)'s Centre for Ageing Research and Translation (CARAT) proposes that, to be effective, the role needs to be delivered or heavily informed by a health professional with specialised gerontological education who can triage health issues, identify assessment needs, including complex presentations of delirium superimposed on dementia. This role will likely need hands-on support from a specially trained health professional who can provide care, rather than a position limited to administrative tasks such as completing paperwork or coordinating service linkages.

The proposed service could function as an early intervention, post-diagnostic multidisciplinary service designed to co-ordinate dementia care. The service would need to establish strong referral pathways and shared responsibilities for care with existing services at Canberra Health Services (CHS), Dementia Australia (DA), Dementia Support Australia (DSA), Carers ACT and private geriatricians.

Care provision should be closely integrated with the Geriatric Rapid Acute Care Evaluation (GRACE) Service, Rapid Assessment of the Deteriorating Aged at Risk (RADAR), Liaison and Navigation Service (LaNS), Residential Aged Care Liaison Nurse, Police Ambulance and Clinician Early Response (PACER) team and the Sustainable Personalised Interventions for Cognition, Care, and Engagement (SPICE) program. It should maintain clear escalation pathways for specialist clinical support and/or advice and rapid hospital admissions when required.

Recommendation

The Network recommends the design of a localised ACT navigator service for older people living with dementia and experiencing changed behaviours that requires specialist support. This service should bring together and build on existing navigator services in the ACT, including those operated by CHS, ACT Disability, Aged and Carer Advocacy Service, and Carers ACT. The aim is to strengthen coordination and relationships with existing programs and services like RADAR, GRACE, LaNS, PACER and SPICE, ensuring these services are adequately resourced to manage any additional specialist support needs arising from referrals.

The model should be co-designed with older people with dementia and their carers to ensure it addresses current navigation challenges such as delayed assessments, limited respite access, and complex service pathways and provides them with timely, coordinated, and specialist support [17].

Consumer Priority Concept 2

Carer and Patient Desired Outcomes:

- Reduced carer burnout and enable sustained ability to care for their loved one at home.
- Improved emotional resilience and carer wellbeing.
- Reduced distress for people living with dementia.
- Avoid unnecessary Emergency Department presentation and/or hospitalisation.

Planned Respite and Respite on demand

Planned respite is a preventative measure to reduce carer burnout and improve wellbeing. A centralised shared booking system to enable providers to coordinate availability and efficiently match individual needs with the right setting and resources, improving accessibility for carers and older people with dementia. In this model, respite services are integrated as part of the care continuum.

In extension to planned respite, respite on demand or emergency respite would offer immediate, flexible access to specialist respite care for older people with dementia experiencing severe changed behaviours and provided in dementia friendly settings. Carers need to be able to rely on this service to step in and provide high-quality support, reducing stress and burnout. Knowing their loved ones are in safe, expert care enables carers to rest and recharge, ensuring they can continue their caregiving roles with confidence.

With this service, whether at home or other dementia-friendly settings, older people with dementia would receive support from a trained workforce of general practitioners and primary care providers, skilled in managing complex symptoms and ensuring continuity of care without the distress of an ED visit and/or hospitalisation. This solution would enhance quality of life for both carers and older people with dementia, offering peace of mind, reduced stress, and improved well-being.

Recommendation

The Network recommends improved access to planned respite and immediate access to flexible (emergency) respite with day and overnight options for older people with dementia experiencing escalating changed behaviours. This would provide carers the support and essential respite from their caring duties to recharge, maintain their wellbeing and remain safe.

Consumer Priority Concept 3

Carer and Patient Desired Outcomes:

- Access to emergency and crisis support services as needed.
- Increased carer and patient management of safety.
- Avoiding ED presentation and subsequent hospitalisations.

Dementia specific crisis support

Crisis support providing immediate, tailored assistance during moments of overwhelming stress or escalating changed behaviours that could impact the carer and/or the safety and wellbeing of the older person with dementia. It would deliver at-home assessment and management, helping carers to manage challenging situations without resorting to the hospital setting.

Offering real-time, at-home support, that is trauma informed and culturally sensitive to de-escalate situations early could alleviate carers' emotional burden, reduce feelings of isolation, and avoid unnecessary emergency department presentations. This model would leverage a skilled workforce that is trained in managing dementia with changed behaviours, delivering emotional and practical support to carers while also assessing individual needs. The integration with priority two, respite when needed, ensures smooth transitions to more intensive care when necessary, maintaining continuity of care and minimising disruption.

The Dementia Health Experts Network supports the need for crisis support options for older people with dementia and their carers and recommend enhancing existing services. A Police, Ambulance, and Clinician Early Response (PACER) like service to complement Dementia Support Australia's Dementia Behaviour Management and Advisory Service (DBMAS) and carer response service is recommended.

To be effective, crisis support needs a multidisciplinary team that comprises dementia-trained paramedics, registered nurses and mental health workforce, trained to deescalate behaviours. The crisis support service should have links with existing Canberra Health Services (CHS) the Rapid Assessment of the Deteriorating Aged at Risk (RADAR) and Geriatric Rapid Acute Care Evaluation (GRACE) services, with police backup in case of escalation to physically aggressive behaviours.

Recommendation

The Network recommends the establishment of a specialist service or bolstering existing CHS programs like PACER, RADAR and GRACE, to provide crisis support during critical moments to de-escalate unsafe situations, keeping people living with dementia and carers safe at home or in the community, which in turn will avoid unnecessary ED presentations and subsequent hospitalisations.

Consumer Priority Concept 4

Carer and Patient Desired Outcomes:

- Reduced carer burnout, and increased carer wellbeing.
- Improved quality of life for patients (engagement, wellbeing and peaceful palliative experience) and carers.
- Integrated and consistent care, with less transitions as care needs increase.
- Reduced emergency department presentations and hospital admissions.

The dementia integrated hub

An integrated hub (Hub) with specialist expertise in complex dementia care offers multidisciplinary clinical care, research, innovation and a compassionate approach to dementia care. This service would build on existing work and provide services from diagnosis to specialist care, ensuring carers no longer need to navigate a fragmented system. Specialist dementia care providers in the hub would have strong links to education and research institutions within the ACT.

Over time, carers and older people with dementia would build strong relationships with familiar staff, creating a sense of trust and stability. The environment would be dementia-friendly and support the emotional well-being of carers and older people with dementia alike. With education, training, and peer support programs integrated into the hub, carers would feel empowered, informed, and supported throughout the journey, reducing stress and enhancing their ability to care.

Recommendation

The Network has brought together research, co-design and expertise to consolidate best practice recommendations for dementia care in the ACT. The Network's recommendation is to translate the Hub from a conceptual model into a physical and operational model – one that provides seamless multidisciplinary specialist dementia care for complex people living with dementia and experiencing changed behaviours. The Network recommends a Specialist Dementia Hub within the new Northside Hospital precinct.

The established Specialist Dementia Hub will continue to drive the work of the Network and centralise clinical care in addition to research, innovation, and impactful best practice outcomes for ACT. It would serve as a hub for workforce training and knowledge translation as well as case management.

Enablers

The Network recognises that improving the health system in the ACT requires collaboration with older people living with dementia, their carers and families in conjunction with service providers, the community, non-government sector, ACT Government and the Federal Government.

To ensure responsiveness to emerging needs, the Framework is designed to adapt alongside advancements in research, diagnostic methods and treatment. It aims to strengthen the settings, services and workforce required to support older people living with dementia and their carers by fostering a health system focused on prevention, early intervention and healthy lifestyle promotion including risk reduction strategies.

As such, support needs to be tailored across the entire dementia journey and care continuum, including during times of distress and behavioural change, as well as addressing issues such as carer burnout. Dementia friendly facilities, re-enablement and rehabilitation services with a dementia trained generalist health workforce are central to this approach. Access to ongoing education for staff, volunteers and carers is essential in recognising and appropriately responding to behavioural changes as they develop.

The Framework emphasises the importance of access to transitional supports such as home-visits by specialists, guidance at the point of entry into emergency, crisis support and response units as well as access to respite care. At the more complex end of the dementia spectrum, timely and suitable access to purpose-built environments, specialist trained health professionals and appropriate palliative care and end-of-life care are critical in improving the quality of life for both the older person with dementia and their carers.

Effective dementia care relies on both well-designed care services and settings along with a dementia trained generalist and specialist workforce. Carers are a vital part of the care journey and must be equipped with the knowledge and skills to meet the unique and ever evolving needs of those they support.

Reducing stigma, improving access to diagnosis and evidence-based care, and ensuring culturally appropriate evidence-based interventions are available at every part of the dementia journey are priorities of this Framework.

These evidence-based interventions for people living with dementia and their carers are comprehensively outlined in figure F1 in [Appendix F](#).

Successful implementation of this Framework will rely on the following enablers (figure 10):

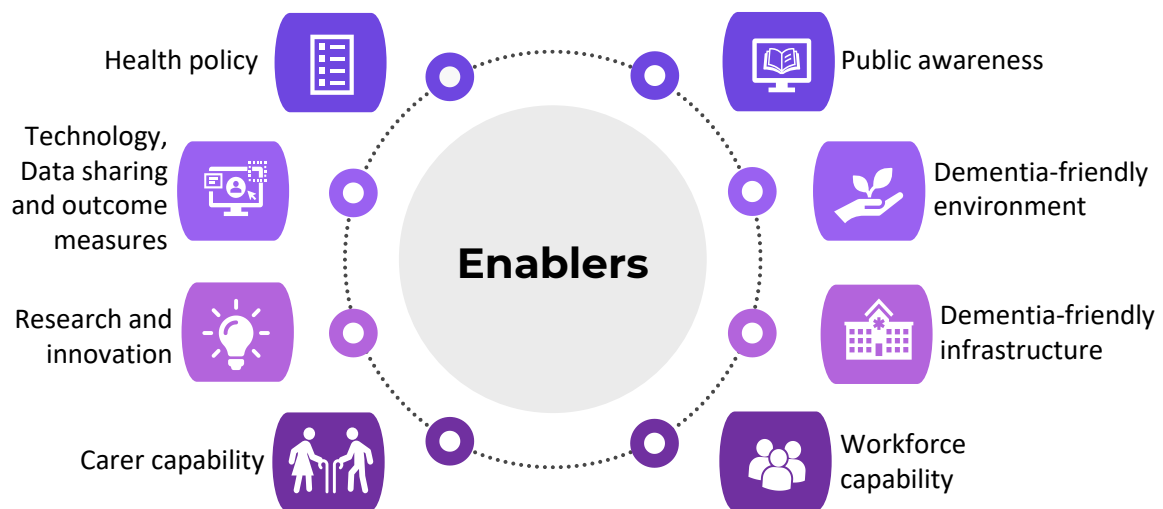


Figure 10: Enablers outlined in the ACT Health Services Plan [23] with carer focus [15].

The eight enablers are further described in [Appendix G](#).

Conclusion

Through a values-based health care approach, the Network tried to move beyond traditional clinical metrics to measure and act on what mattered to people living with dementia and experiencing changed behaviours and their carers. These outcomes were described by carers when developing the priority concepts.

Co-designed Priority Concepts	Carer and Patient Desired Outcomes
A personalised Dementia Navigation service connecting carers and patients with the right services at the right time, ensuring seamless access and ongoing support.	• Reduced burden of caring, and social isolation; • A need to tell their story once (single point of contact); • Easy access to right care at the right time inclusive of carer support; • Carers understand the progression of dementia symptoms before they occur.
BPSD-Specific Respite and Crisis Support providing immediate access to essential services during challenging times.	• Access to planned respite support; • Access to emergency and crisis support services at home when needed; • The carer and patient/person are safe; • Reduced carer burnout and sustained ability to care for their loved one at home; • Improved emotional resilience and carer wellbeing; • Reduced distress for person living with dementia; • Avoid unnecessary Emergency Department presentation and/or hospitalisation
Dementia Centre of Excellence: A hub for advanced care, research, and innovation, providing support for the most complex cases.	• Reduced carer burnout and increased carer wellbeing; • Improved quality of life for patients (engagement, wellbeing and peaceful palliative experience) and carers during the dementia journey; • Integrated and consistent care, less transitions as care needs increase; • Reduced hospital presentations and/or hospitalisations.

Figure 11: Desired Outcomes of Carers' Priority Concepts

This approach is designed to ensure every element of the service model from navigation to crisis support and specialist care works together to improve quality of life, dignity, and emotional wellbeing. The Network's outcomes working group identified a list of indicators to align with the Framework priority concepts enclosed in Appendix I for monitoring and continuous improvement evaluation of the future health system when caring for people living with dementia and experiencing changed behaviours and their carers.

Successful implementation of each priority concept together with concrete action on the underpinning enablers will position the ACT to deliver a compassionate, coordinated, and sustainable dementia care system that empowers carers as partners in care, supports people living with dementia to maintain dignity and engagement while delivering measurable improvements in their health and wellbeing.

Appendices

Appendix A: Brodaty, Draper, Low Triangle

Brodaty *et al* developed a seven-tiered model of service delivery to assist with the planning of services for managing the people experiencing behavioural and psychological symptoms of dementia (BPSD) or changed behaviour [8]. The model is shaped as a triangle of seven tiers with increasing severity of symptoms as the tiers ascend but the prevalence of people decreases with tier. There are no distinct boundaries between tiers, movement between tiers can be fluid and changeable [10] and may be affected by the way in which care is delivered and the nature of the care environments. However, people experiencing severe to extreme (Tier 5-7) changed behaviour often are highly vulnerable group requiring the highest level of intervention, resources and support.

Seven-tiered model of management of behavioural and psychological symptoms of dementia

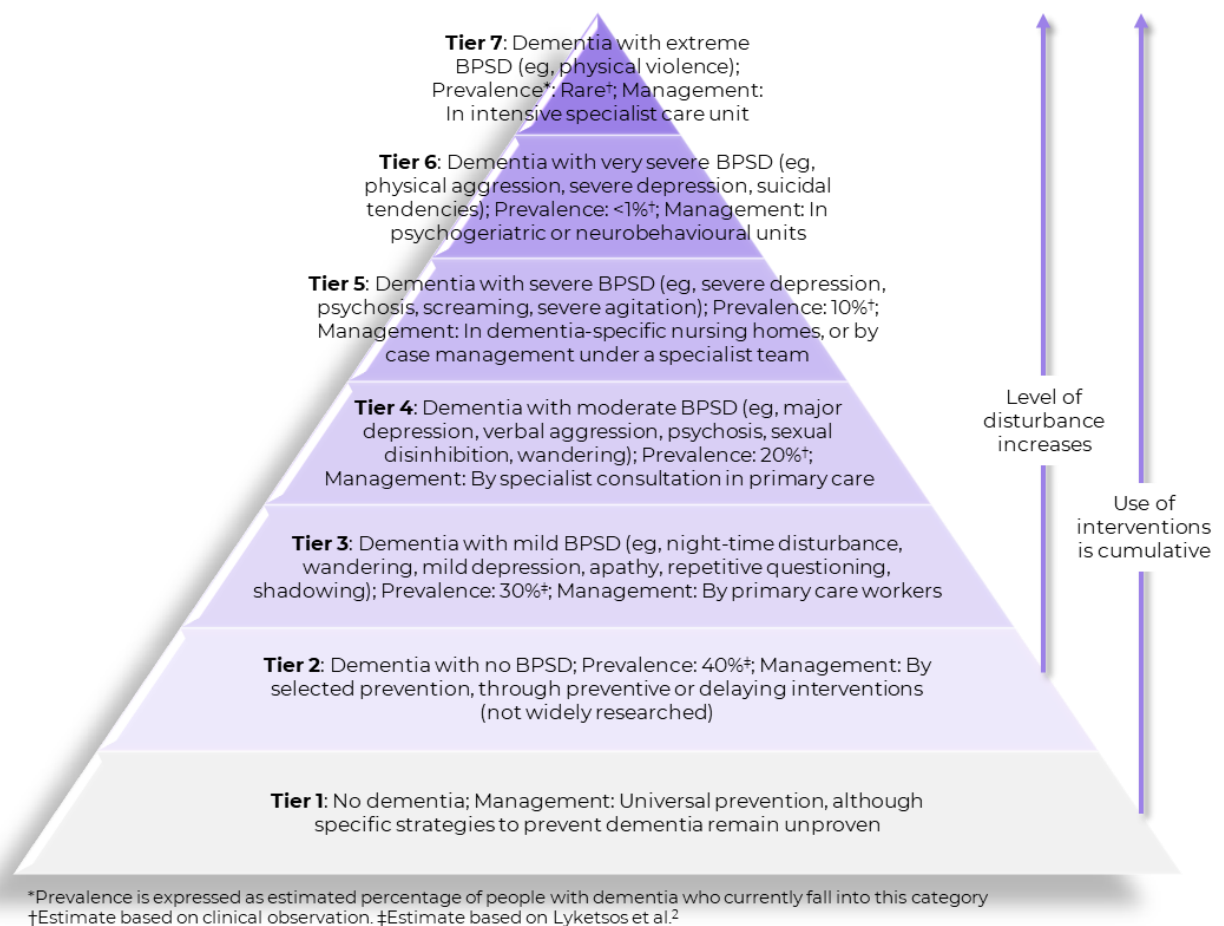


Figure A1: Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery [8]

Appendix B: Members of Dementia Health Experts Network

The Dementia Health Experts Network was formed in 2024 and co-chaired by Carolyn Smith, a former senior Federal government public servant with experience in aged care and consumer advocate nominated by the Health Care Consumers' Association and Dr Mary Ann Kulh, a senior geriatrician and physician with extensive clinical experience in adult medicine. Its membership included carers, clinicians, researchers, service providers and peak organisations.

- ACT Discrimination, Health Services & Disability and Community Services Commissioner
- ACT Human Rights Commission
- Australian Government Department of Health and Aged Care
- Australian Institute of Health and Welfare
- Canberra Health Services
- Capital Health Network
- Carers ACT
- Council of the Ageing ACT (COTA ACT)
- Centre for Ageing Research and Translation (CARAT), University of Canberra
- Dementia Australia
- Health Care Consumers' Association
- Patient Experience Agency
- North Canberra Hospital
- Senior Practitioner, Community Services Directorate, ACT
- ACT Health and Community Services Directorate, Health System Innovation and Performance Division
- ACT Health and Community Services Directorate, Policy, Partnerships and Programs Division
- ACT Health and Community Services Directorate, Office of Professional Leadership and Education

Appendix C: Stakeholder consultation

During the co-design process, the Network consulted with a broad range of stakeholders including:

Carers

Up to 60 current and previous carers caring for people living with BPSD participated throughout the project.

Service Representatives

- ACT Ambulance Service
- ACT Health Directorate, Health Services Planning
- ACT Health Directorate, Application Support, Digital Solutions
- ACT Health Directorate, Office of the Chief Medical Officer
- ACT Human Rights Commission
- ACT Policing
- Calvary Haydon Residential Aged Care
- Canberra Health Services, Acute Geriatrics
- Canberra Health Services, Allied Health
- Canberra Health Services, Community Care Services
- Canberra Health Services, Nursing
- Canberra Health Services, Mental Health, Justice Health and Alcohol and Drug Services (MHJHADS)
- Canberra Hospital, Ward 11A
- Canberra Hospital, Emergency Department
- Capital Health Network
- Capital Chemist
- Carers ACT
- Clare Holland House
- Dementia Australia
- Dementia Support Australia
- Goodwin Residential Aged Care
- Jindalee Aged Care Residence
- Health Care Consumer Association (HCCA)
- GRACE (Geriatric Rapid Acute Care Evaluation)
- More Than Medicine geriatrician practice
- Next Practice General Practice
- North Canberra Hospital, Emergency Department
- North Canberra Hospital, Social Work and Psychology
- North Canberra Hospital, INSPIRED Clinical Team
- North Canberra Hospital, Geriatrics
- Older Persons' Mental Health, inpatient and community services
- PEACE (Palliative Aged Care Specialists)
- RADAR (Rapid Assessment of the Deteriorating Aged at Risk)
- Uniting Care Eabrai, Weston (Specialist Dementia Care Unit)
- University of Canberra Hospital, Older Person Mental Health
- University of Canberra Hospital, Transitional Therapy Care Program
- Villaggio Sant' Antonio (VSA) Residential Aged Care
- Wakefield Gardens General Practice

Appendix D: Priority Populations List

According to the National Dementia Action Plan, the following groups are at a higher risk of developing dementia or facing barriers to equitable access [3]:

- Older People
- Women
- People from culturally and linguistically diverse backgrounds
- People living in regional, rural and remote areas
- People with disability
- People living with younger onset dementia
- Children living with dementia
- People living with dementia who identify as LGBTIQ+
- Veterans living with dementia
- People at higher risk of repeated head injuries
- People living with dementia who are experiencing, or at risk of homelessness
- First Nations people living with dementia

Appendix E: Current Service Navigation and Pain Points in Dementia Care Services, from carer's perspective

Through co-design workshops, interviews, surveys and stakeholder engagement, carers provided their living experience and insights of service navigation and pain points when accessing dementia care services in ACT.

Current service navigation and pain points in dementia care services, from the carer's perspective

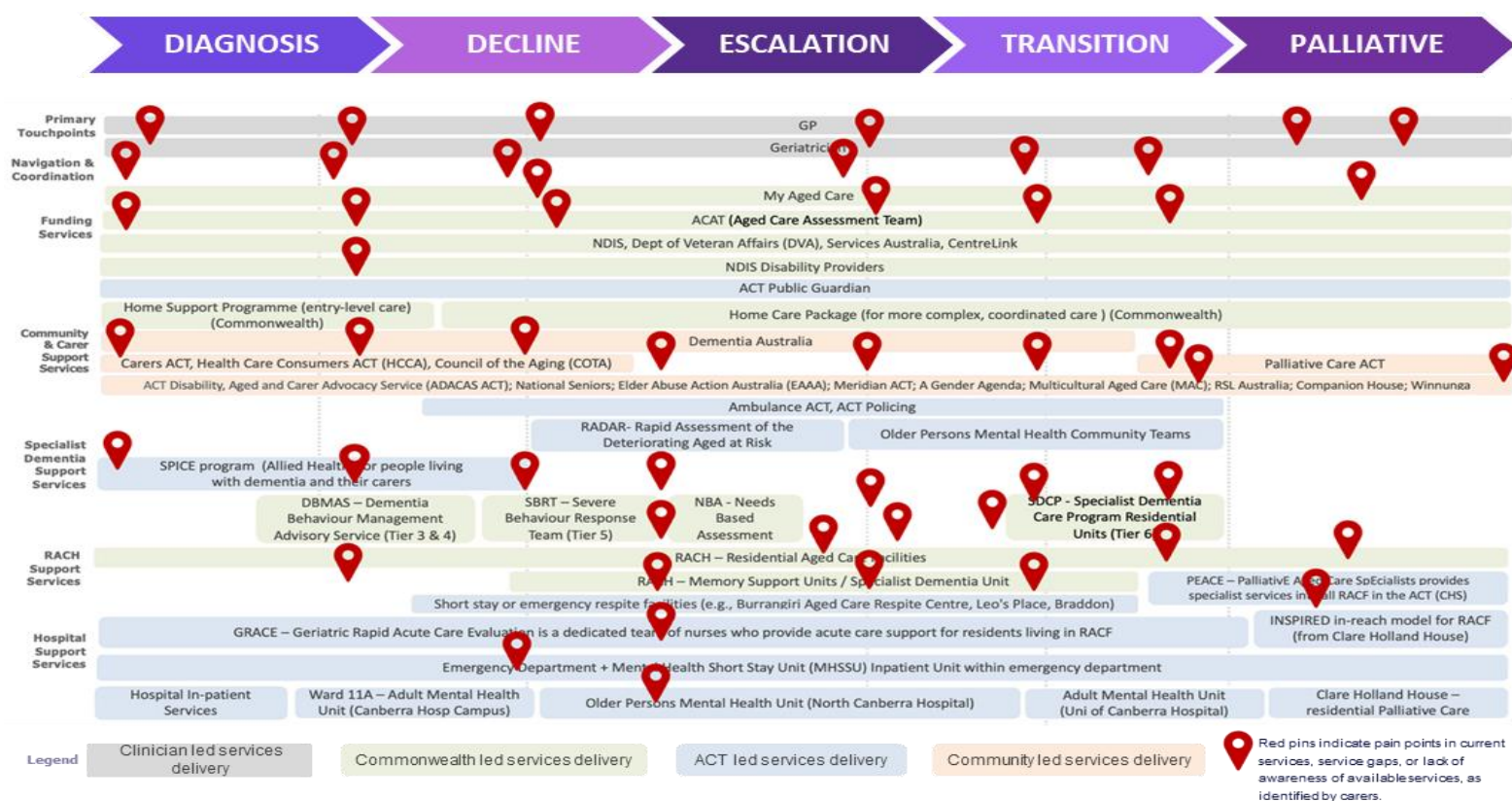


Figure E1: Current service navigation and pain points in dementia care services, from carer's perspective [15]



Appendix F: Evidence-based Interventions for People with Dementia and their care partners

This evidence-based framework outlines the ACT's model of care for people living with dementia with different levels of changed behaviours including the unique safety and functional needs of people experiencing changed behaviours when in hospital and in the community. It has been designed with carers and experts from the ACT health and aged care systems.

The model supports an evidence based human rights approach to enablement for people living with dementia to reduce decline and promote quality of life.

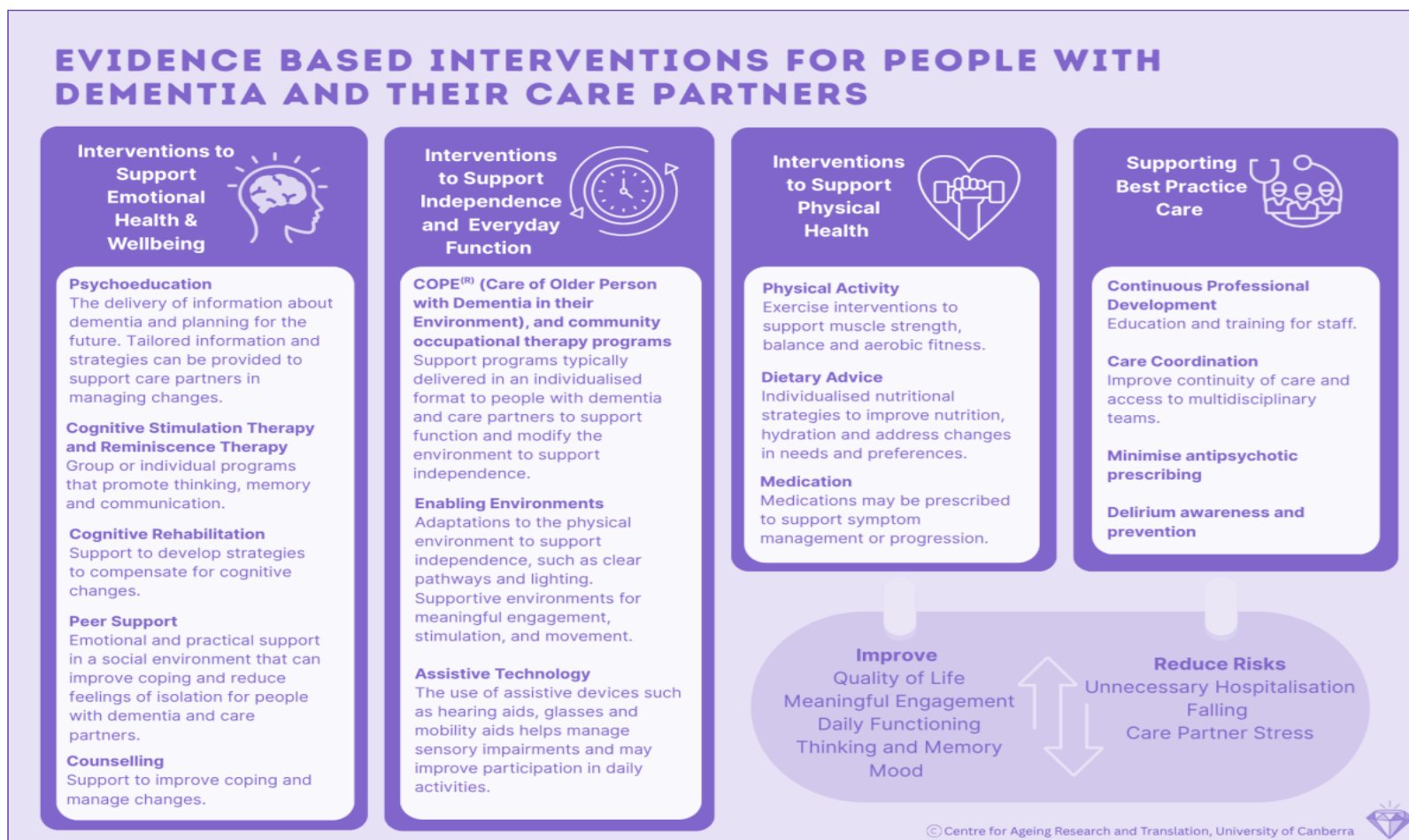


Figure F1: Evidence-based interventions for people living with dementia and their carers [24, 25, 26, 27, 28, 29, 30, 31, 32, 33] [34, 35, 36, 37, 38, 39, 40, 41, 42, 43] [44]

Appendix G: Enablers

The Network recognises that improving the health system in the ACT requires collaboration with older people living with dementia, their carers and families in conjunction with service providers, the community, non-government sector, ACT Government and the Federal Government. The Network identified eight system enablers that are crucial to support the future ACT health system to better care for older people living with dementia and experiencing changed behaviour and their carers

Health Policy

Health services planning is a continual process. The successful implementation of this Framework would require integration of dementia specific health policy at all levels of government, territory and federal. All levels of Government play a role in providing the services and supports needed for people living with dementia, their carers and families.

The principles underpinning this Framework are modelled on the National Dementia Health Action Plan, and Figure G1 provides examples of the roles and responsibilities of different levels of government [3]. Integration of this complex care system for dementia almost always requires that territory and federal government share responsibility for a support or service system.

Australian Government	State and territory governments	Responsibility is shared
Medicare Benefits Schedule, Pharmaceutical Benefits Scheme	Managing and administering public hospitals and memory clinics	Funding public hospitals
		Preventive health services
Funding community controlled Aboriginal and Torres Strait Islander primary healthcare services		Transition care services
		Palliative care
Aged care regulation and funding	Multipurpose services	Older adult mental health services
Dementia programs		
NDIS administration	N/A	NDIS funding and governance
	Accessible buildings and urban planning and design by local government	Community infrastructure

Figure G1: Examples of roles and responsibilities at different levels of government for supporting older people living with dementia [3]

As new local and national policies are endorsed or new evidence and technologies emerge, flexibility would be needed to respond to changing practices to ensure government priorities are aligned with best practice models as well as the changing needs of the community and that the outcomes remain relevant.

The potentially modifiable risk factors identified will serve as the foundation for the development of the outcome measures. Local management would be required to adjust these indicators as priorities change, and services develop but with the expectation that this Framework continues to shape and deliver improved health care for older people living with dementia and their carers.

Effective implementation of this Framework would require alignment across health policy levers, including ACT Government's annual budget priorities, operational plans, workforce planning and infrastructure planning. The Network recommends that the ACT Government work collaboratively with system leaders, peak bodies, and relevant stakeholders to embed the Framework's priorities within existing and future planning cycles to ensure sustainable and coordinated action.

A critical component of the recommended approach is the promotion of early diagnosis. Timely diagnosis and identification of dementia or changed behaviours empowers carers, individuals living with dementia, their families and health professionals to make informed decisions about their future treatment, care and support preferences via advance care planning [3] [45]. Policies should support health professionals to engage in these conversations early, revisit them as needed, and provide guidance to individuals and carers throughout the progression of dementia.

Equally important is ensuring access to quality palliative and end-of-life care. Dementia has been recognised as a life limiting condition, and policy needs to ensure that older people with dementia receive compassionate, person-centred care that upholds their comfort, quality of life, and dignity. Support for carers is essential, including access to resources, respite care and practical guidance. Timely provision of palliative care has been shown to reduce unnecessary hospitalisation. For example, when specialist palliative care needs rounds were led by Nurse Practitioners (NPs) it was found to have led to decreased length of stay and reduced hospitalisations from residential care [46]. However, dementia's unpredictable progression means referral criteria in ACT for specialist palliative care and end-of-life care in dementia must be clear, and consensus must be established around criteria for accessing palliative and end-of-life care.

Ultimately, empowering carers and professionals to engage in advance care planning and understand the supports available will help ensure that care provided aligns with the values and preferences of the individual. A health policy that integrates the elements of early diagnosis, care planning, and palliative care will be essential to delivering better outcomes for people living with dementia and those who support them.

Public Awareness

Raising public awareness about dementia is a critical component of creating a dementia-friendly community. Increased understanding of dementia and changed behaviours can reduce stigma, shift behaviours and encourage earlier diagnosis and planning.

Public health campaigns should aim to normalise conversations around dementia and remove the stigma associated with cognitive decline, including discussions about palliative care and end-of-life preferences. Despite the benefits of Advance Care Planning (ACP), it remains significantly underutilised, with around 68 per cent of people living with dementia not having an ACP in place [45] [46]. This limits the ability of the older person living with dementia to have their values and wishes respected as the disease progresses, particularly when they may no longer have capacity to make decisions. There is a pressing need to raise awareness of the importance of ACP as a tool for preserving autonomy and dignity, while also promoting equity and human rights within the community.

Action 1 of the National Dementia Action Plan 2024-2034 [3] is to promote equity and human rights and as such health promotion efforts should be targeted, accessible, and culturally responsive enabling individuals, families, and carers to engage with dementia-related information early and meaningfully. A multidisciplinary approach is essential to improve identification and management of behavioural and psychological symptoms, reduce stigma, and support informed decision-making. Importantly, these efforts should align with broader goals of healthy ageing, a key priority of the ACT Preventive Health Action Plan 2023–2025 [47]. By embedding dementia awareness and ACP into healthy ageing initiatives, public health policy can empower communities to better support older people living with dementia and contribute to a more dementia inclusive, respectful, and prepared society.

Dementia-friendly environment

Positioning the ACT as an age friendly and dementia-friendly city would support the health, independence and dignity of older Canberrans living with dementia, their families, community members and carers. Creating dementia-friendly communities that are safe, respectful, supportive, and empowering not only reduces the risk of social isolation for older people living with dementia and their carers but also promotes earlier identification and diagnosis, timely access to care, and sustained engagement in post-diagnostic support.

Empowered communities play a strong and important role in dementia prevention and care by reducing stigma, supporting wellness-focused approaches, and promoting early intervention. A ‘no wrong door’ approach to accessing services should be embedded, ensuring that older people living with dementia and their carers can find the support they need—when and where they need it. Community-based services should prioritise inclusion and resilience, increasing access to in-home and therapeutic supports and ensuring care is responsive to individual needs.

This aligns with the ACT Government’s Age-Friendly City Plan [48], particularly Focus Area 3: Information, Services and Support, which aims to embrace diversity, respond to individual circumstances, and empower all Canberrans to exercise choice and control over their lives. The Network supports the actions included in Focus Area 3 which are to include the designation of dementia-friendly spaces, the integration of inclusive design across public buildings, and the hosting of dementia-friendly events within ACT Government service centres and at major community events throughout Canberra [48]. These actions will foster a more inclusive society, reduce stigma, and ensure that people living with dementia and their carers feel visible, supported, and respected in every part of the ACT community.

Dementia-friendly infrastructure, inpatient settings and services

Dementia-friendly infrastructure and inpatient care services are essential to improving experiences for older people with dementia, carers, and staff, while also reducing complications, hospital stays, and avoidable readmissions. The use of dementia-friendly and dementia-inclusive design principles, including those from the National Aged Care Design Principles [49] should inform the development and refurbishment of public health infrastructure maximising independence, safety, and wellbeing through physical environments that enable rather than restrict. Features such as clear signage, familiar surroundings, access to natural light, and calming sensory cues can significantly improve patient, carer, and staff experiences while reducing complications and length of stay.

System-wide service improvements ensure access to multidisciplinary care, early intervention, and therapeutic supports for individuals living with dementia. Embedding comprehensive geriatric assessments in emergency departments, expanding transitional care services, and identifying behavioural changes earlier can reduce unnecessary hospitalisations and support better outcomes. A “no wrong door” approach should underpin access to dementia-related care, ensuring people and their carers can navigate services effectively across community, hospital, and residential care settings.

Inpatient and residential services should be supported with appropriate models of care, workforce training, and infrastructure investment to meet the needs of people with complex dementia. These initiatives must extend beyond hospital settings to aged care and community-based environments, ensuring consistency in the quality and experience of care across the ACT.

In particular, the development of the new Northside Hospital presents a critical opportunity to embed dementia-friendly principles into hospital design and service delivery. The National Aged Care Design Principles [49] and this Framework should inform the development of inpatient and behaviour support services at the new Northside Hospital, including the establishment of a dedicated unit to support people with BPSD experiencing severe or complex behavioural changes. The unit should work in collaboration with the Older Persons Mental Health Service to provide avenues for staff training and professional development. It would meet the needs of people with co-existing dementia and mental health conditions.

However, opportunities for the adoption of dementia-friendly design principles should be grasped as wards are redeveloped at Canberra Hospital. Priority should be given to those wards which are heavily utilised by older patients including but not limited to orthopaedic, cardiac, geriatrics and respiratory units.

The Network has brought together consumers, carers, clinicians, researchers, and health system leaders to co-design this evidence-based Framework for older people living with dementia and experiencing severe to extreme changed behaviours using a learning health system approach. This should transition from a conceptual model into a physical and operational service that is integrated within the Northside Hospital as a key innovation and research partner. Its ongoing role would further the work of the Network and identify opportunities for clinical service translation and improvement. Establishment of a Dementia hub would foster innovation and reduce strain on the public hospital system through fewer preventable admissions, lower non-acute occupancy, and reduced emergency department presentations for older Canberrans.

Workforce capability

Effective dementia care relies on not only well-designed care services and settings, but also the capacity and capability of the workforce. High quality care for older people living with dementia experiencing changed behaviours requires the generalist workforce to be trained in dementia as well as a specialist workforce. This capability must be recognised, supported, and strategically developed across all levels of the care continuum.

The Bail et al Triangle [17] shows as a person’s behaviours increase in severity, care needs become increasingly complex. In the initial stages, a generalist workforce, trained in dementia care can provide appropriate, person-centred support. However, when a person is exhibiting severe changed behaviours there is a need for a specialised trained workforce.

The Network emphasises that an investment in a sustainable and skilled workforce is required to meet this growing need. In alignment with the ACT Health Workforce strategy [50], ACT Government has an opportunity to attract, support and retain the ‘best and brightest’ gerontological specialists and expand psychogeriatric medicine as a specialty in the ACT public health system. In addition to strengthening specialists’ capacity, the Network recommends investing in postgraduate education and specialist training, including supporting geriatric medicine training for post-graduate medical officers as ‘first choice’ to increase workforce capability. Providing targeted education opportunities for current and emerging leaders in gerontological nursing and encouraging clinical placements and mentoring in dementia care settings will also bolster dementia care provision.

In addition, the Network recommends that gerontological expertise be supported and embedded across all levels of the health system – in hospitals, community settings and RACHs. To further this, the Network suggests that ACT Government continues to work in partnership with the Federal government to promote and implement their programs:

- Clinical Placements with Older People, is a federally funded program to extend awareness of evidence-based dementia care, the specialised area of gerontological nursing, and the fact that ‘older people are everywhere’ for nursing students, nursing teachers and clinical facilitators;
- Cognitive Impairment Clinical Care Coordinator role in RACH promotes postgraduate study and succession planning. This position is highly valued by staff with the risk being that it is very person-dependent and will need coordinated efforts to sustain the role as well as the person;
- Gerontological Nursing Competencies Transition to Practice program for new graduate nurses (up to 2 years), recently transferred from acute or community nursing (up to 2 years) helps to build specialist knowledge and skills, self-reflective capacity and mentored support to be educated and trained in key aspects of dementia care.

Through initiatives such as those above, the aim is to create a sustainable, specialised workforce that has expertise in dementia care, including the care of people with changed behaviours across inpatient, community and RACHs. It also ensures dementia care being provided by the workforce is grounded in best practice that is evidence-based and responds to the needs of the community and makes gerontological expertise a core standard of care for all staff working with the health system who are caring for older people. This supports all health professionals to develop the skills and confidence especially in the early stages of dementia to lead conversations on advanced care planning and end-of-life care, including legal and ethical considerations.

Carer capability

The Network recognises the commitment of the ACT Government to supporting carers’ rights, choices and opportunities to participate fully in all aspects of life in line with the ACT Carers Strategy First Action Plan [51]. This Framework recognises the essential role of carers as partners in care and considers that prioritising the development of carer capability is a key enabler of high-quality, sustainable dementia care. Carers play a critical role in the wellbeing of people living with dementia who experience changed behaviours and they must be equipped with the knowledge, skills, and emotional resilience to navigate the increasing complexity of care.

To build a carer-inclusive future health system, this Framework has been co-designed with carers via the Network, including Carers ACT, HCCA and DA, ensuring that the emotional and psychosocial needs of carers are clearly articulated as core priorities. The proposed service model is grounded in co-design with carers and supported by innovative, enabling systems and identified four key priorities for carers of older people living with dementia and experiencing changed behaviours:

- Personalised navigation support connecting carers and people with dementia to the right services at the right time;
- Immediate access to respite options during periods of crisis or high stress to alleviate carer burden;
- Community-based crisis support services to provide timely intervention and avoid unnecessary hospital presentations;
- A central hub for specialist dementia care, research, and innovation, supporting complex cases and fostering collaboration across different service settings.

Aligned with these priorities, carers should have access to tailored education and training opportunities, including comprehensive online learning modules focused on dementia care, behaviour changes, system navigation and practical day to day support to manage their complex caring responsibilities. It also reinforces the importance of inclusive and trauma-informed approaches that respect the diverse needs and lived experiences of carers across all settings.

Opportunities for carers to be trained in dementia care to build community awareness of people living with dementia and reduce stigmatisation should be prioritised. CHS programs like the volunteer initiative on Ward 11a of the Canberra Hospital - Acute Care for the Elderly Unit [52] demonstrate how community participation can improve outcomes for people living with dementia and reduce stigma.

The Network advises the ACT Government to continue working in partnership with these stakeholders to strengthen access to appropriate supports such as peer-led networks, group counselling, respite, mindfulness programs, and other wellbeing resources that help carers maintain their own health and resilience.

Evidence-based initiatives such as the Sustainable Personalised Interventions for Cognitive, Care, and Engagement (SPICE) which is a post-diagnostic allied health led rehabilitation program co-designed by the UC and CHS, supported by DA further demonstrate the value of embedding structured support for carers. Recent outcomes show statistically significant improvements in quality of life for both people with dementia and their care partners, reduced neuropsychiatric symptoms and related distress, and enhanced physical function outcomes, including dynamic balance and mobility [53]. High levels of program satisfaction, particularly from care partners, further highlight the effectiveness of models that include carers as active participants in cognitive engagement and rehabilitation. By the end of 2024, UC aimed to deliver a total of 14 group programs reaching up to a 100 people with dementia and their care partners [53]. As the program continues to grow including efforts to establish a student-led clinic at the UC Health Hub, lessons from SPICE should continue to inform scalable approaches to carer engagement.

Through these combined efforts the Network hopes to ensure carers receive the information, training and emotional support they need to confidently undertake and sustain their caring roles. This approach should foster a system where carers are partners in care and not just support people and are empowered to make informed decisions, navigate transitions effectively and access appropriate support and respite as needed.

Technology, data sharing and outcome measures

The Network recognises the critical role of digital innovation, data sharing and performance measurement in enabling a sustainable world class dementia care system for the ACT. Building on the foundations already established through the ACT Government's Digital Health Strategy 2019-2029 [54] whose strategic goals are underpinned on access, accountability and sustainability, the Network supports continued progress to build on the digital foundations already available in the ACT to deliver more integrated and efficient digital solutions for all healthcare providers, health consumers, families and carers.

In the future of dementia care, technology must be embedded not as an add on but as a foundation for providing timely, personalised, and coordinated care across settings via the development of a dynamic dementia database and digital care plans.

Integrated platforms would enhance service navigation, virtual support, and access to timely information for carers and healthcare teams. Systematic outcomes measurement and data analysis would ensure care models remain effective and responsive, while empowering older people with dementia and changed behaviours and their carers to make informed decisions throughout their care journey. The aim is to monitor the lived experience of older people with dementia and their carers and provide necessary intervention and support.

System-wide data collection and outcomes measurement would ensure that care models remain effective, responsive, and aligned with the needs of the community.

Research and Innovation

Improving dementia care requires a sustained commitment to research, innovation and evidence informed policy from diagnosis through to end-of-life. The Network has not only championed this principle but actively demonstrated it through the development of this Framework. This process has built on ACT Government's commitment to enhancing the health and wellbeing of the community through a strong and continuous focus on excellence in policy, research, innovation, and academic partnership and embedded it in the delivery of this Framework.

The establishment of the Network and the development of this Framework are consistent with the priorities set out in the Strategic Plan for Research in the ACT health system 2022–2030 [55]. This is particularly so for Priority 4 of this Framework, the Dementia Hub, which is intended to work as a hub for consistent, compassionate and evidence-based dementia care. A Dementia Hub integrates clinical care with research, innovation, workforce training and knowledge translation to drive best practice outcomes while supporting older people living with dementia, including those experiencing changed behaviours, and their carers across the full continuum of care.

In developing this Framework, the Network has drawn on partners from UC, reflecting our shared commitment to evidence-informed policy development. This collaboration shows the value of bringing academic rigour, clinical expertise and lived experience together to shape systematic change.

Looking ahead, the Network supports the continued advancement of research partnerships between ACT Government and universities, hospitals and service providers with a focus on integrating research into practice. In addition, ACT Government should continue to play a key role in sharing research insights across the aged care and community sectors and in return, learning from those with lived experience, their carers, and trusted support services [55]. This two-way exchange will help build a culture of collaboration, innovation, and continuous improvement across the dementia care system.

Appendix H: Potentially modifiable risk factors for dementia

The Lancet Commission on dementia provides evidence about dementia prevention, intervention and care. In the 2024 update, the Commission added untreated vision loss and high LDL cholesterol to previously modelled risk factors for developing dementia including less education, hearing loss, hypertension, smoking, obesity, depression, physical inactivity, diabetes, excessive alcohol consumption, traumatic brain injury [TBI], air pollution, and social isolation) [31]. The government should consider minimising or addressing risk factors in future health and environmental policies and legislation to prevent and delay dementia in the population.

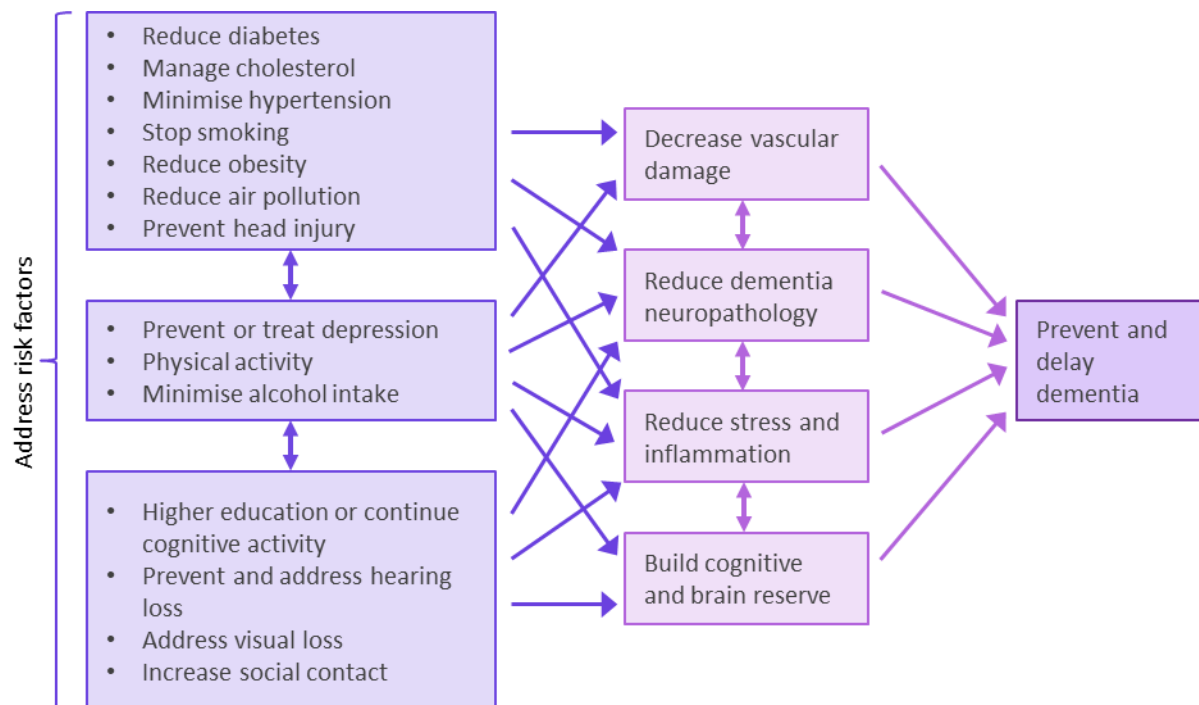


Figure H1: Possible brain mechanisms for enhancing or maintaining cognitive reserve and risk reduction of potentially modifiable risk factors in dementia [31]

Appendix I: Potential Outcome Indicators

The proposed list was agreed by the Dementia Health Experts Network working group.

Indicator	Scale
Number of specialist Dementia Care Programs	ACT
Avg Hospital Length of Stay (LOS) for people dementia diagnosis	ACT
Proportion of EOC for dementia-related episodes of care of older persons with documented dementia vs total number EOC for older people in APC	ACT
Proportion of total number of older people with documented dementia vs total number of older people in ACT	ACT
Number of deaths of people with documented dementia in ACT public hospitals	ACT
Number of people with a primary diagnosis of dementia who died in the emergency department.	ACT
Percentage of ED presentations by people with documented dementia against ED visits by older persons	ACT
Benchmarked HAC for EOCs of people living with dementia	ACT
30-day readmission rates for dementia-related hospitalisations	ACT
Medicare items 141, 143 processed from July 2023 to June 2024 (for dementia related services - geriatric assessment)	ACT
Medicare items 61650 (FDG pet scan for Alzheimer's) processed from July 2023 to June 2024	ACT
Proportion of Cost of admissions due to dementia (Primary diagnosis) vs Total cost of admitted dementia-related care in ACT public hospitals	ACT
All Dementia (derived) Public Hospitals - Avg Funding per episode	ACT
Percentage of CALD that have dementia-related episodes	ACT
Percentage of First nations individuals that have dementia-related episodes	ACT
Percentage of Older people (non-indigenous 65+, First Nations 50+) that have dementia-related episodes	ACT
Percentage of Younger people (age <65) that have dementia-related episodes	ACT
Percentage of Sex that have dementia-related episodes	ACT
Number of approved NDIS plans for people living with younger onset dementia.	National
Number of people living with younger onset dementia referred to Dementia Support Australia (DSA).	National
Proportion of aged care workers who completed dementia care training in the previous 12 months.	National
Total Vet students that completed a vocational training subject about dementia	ACT
Number of occasions of dementia training completed through Dementia Training Australia.	National
SPICE Program - Waiting list, ED presentations, Completion rates, Functional and outcome measures, Carer outcome measures	ACT
GRACE Program- Number of clients, Length of service, waiting lists	ACT
RADAR Program- Number of clients, Length of service, waiting lists	ACT

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