Sydney Local Health District

Dementia Active Healthcare Framework and Roadmap 2024-30

Dementia is everyone's business

NSW GOVERNMENT

Sydney
Local Health District

Sydney Local Health District
Head Office

Street address:
Level 11, King George V Building
Missenden Road
Camperdown NSW 2050

slhd.health.nsw.gov.au

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Contents

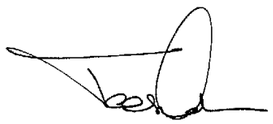
Foreword

Sydney Local Health District is a diverse and thriving community, with wide ranging health and social care needs. As the prevalence of dementia increases, it is a local and global challenge to determine how to provide the best quality dementia care. Dementia has likely affected us all: our loved ones' experience, our neighbour, the special patient we took care of, or the busy carer of someone with dementia that we know. We aim to ensure we can provide a positive healthcare experience, concentrating on the highest possible quality of life for everyone impacted.

The Sydney Local Health District Dementia Active Healthcare Framework and Roadmap 2024-30 considers the current landscape of dementia care, recognising the partnerships required and importance of offering a range of services to meet the diverse needs of each individual. This Framework is built on a review of current services and systems in the District, giving a voice to people with dementia, carers and our highly skilled and experienced staff, as to how to shape dementia care for the future.

While we provide the best quality dementia care, we also strive to enable our entire health system to be 'dementia-friendly' whether someone is involved with our health system for dementia specific care or more general health care. The Roadmap positions the District to rise to future challenges and supports our strategic vision of excellence in health and healthcare for all.

I would like to take this opportunity to thank everyone who has contributed to this Framework, including those with lived experience. I would also like to acknowledge those who will take the next steps required to ensure dementia care is individualised, responsive and flexible, as we recognise dementia is everyone's business.



Dr Teresa Anderson AM
Chief Executive
Sydney Local Health District

Executive Summary

Vision

Sydney Local Health District will provide timely, responsive, and flexible evidence-based healthcare to all people with dementia and their carers. Healthcare will always be continuous, tailored to meet the individual needs of the person with dementia and their broader social and cultural supports, and maximise quality of life for all.

Principles of Care

	Dementia Active Care Roadmap Summary	Timeframe
1	Establish Sydney Local Health District Dementia Roadmap Steering Group to oversee development and implementation	Short term (< 1 year)
2	Document and develop a repository for dementia specific service information in the District	Short term
3	Determine interventions within the District scope as a basis for a suite of dementia services, including a ‘Dementia Hub’	Short term
4	Develop and lead a sector-wide Dementia Community of Practice bringing together all stakeholders	Short term
5	Analyse equity and access to current District services and implement remedial actions	Medium term (2-4 years)
6	Conduct an environmental ‘dementia-friendly’ audit of Sydney Local Health District facilities	Medium term
7	Agree on standard activity data collection across the District, including identifying people with dementia and their carers	Medium term
8	Develop a dementia training pathway for staff, including Behavioural Psychological Symptoms of Dementia	Medium term
9	Analyse resources against expected population growth, effective clinical therapies, and necessary business cases	Long term (5 years+)
10	Evaluate the Dementia Active Healthcare Framework 2024-30 and further development of broad dementia research within Sydney Local Health District	Long term

Introduction

> Dementia refers to a collection of diseases that affect memory, thinking and the ability to perform daily activities[1].

It is a mostly progressive neurodegenerative illness with no effective disease modifying pharmacological treatments. It is a disabling and mortal condition that can have significant impacts on the person, carer and their family, their quality of life, life expectancy, economic and social wellbeing[2].

Dementia has profound and complex implications for the individual, family and carers. The type of information, support and care needed by people living with dementia and their carers varies due to the differences in the biological, psychological and social impact of dementia. The underlying philosophy of 'supportive dementia care' suggests that no single dementia care pathway or disease journey exists, but that individual needs will vary. A person living with dementia would be expected to have increased touch points with the health system throughout the duration of the disease due to their increased vulnerability, risk of healthcare complications and predisposition to delirium[3] [4]. However, individual preferences and the symptoms of the disease have a large influence on the patterns and requirements of care. A comprehensive Dementia Care Service has to be responsive to these needs.

5x

the length of hospital stay on average than the general population

3rd

leading cause of disease burden in Australia

$

$3 billion annually to manage disease burden of dementia

2nd

leading cause of death for Australians and leading cause of death for women

Between

386,200-472,000

people are living with dementia

Predicted to be over

849,000

people living with dementia by 2058

27,800

people under 65 are living with younger onset dementia

Younger onset dementia cases expected to rise

↗

39,000

by 2058

Source: National Dementia Action Plan Consultation Paper (November 2022)

Scope

There are many types of dementia, and there are many diseases that may cause dementia. This document will refer to dementia as an umbrella term for diseases causing dementia such as the most common Alzheimer's disease, through to an array of rare, inherited dementias. It does not extend to include acute cognitive impairment or delirium.

Sydney Local Health District provides dementia healthcare and support to people of any age, at any stage of the disease, across all settings, on a continuum and episodic basis, networked with external health and service providers.

This Framework has been developed and documented following a literature review, extensive internal and external consultation with staff, carers and other stakeholders. Over one hundred people were targeted to participate in the consultation including services, individuals and organisations. In addition input was provided by staff and consumers who sought the opportunity to be involved in the process. The response was substantial, with more than 140 people involved (More information, Appendix 14.1: Consultation Report).

The scope of this Framework includes:

- all dementia active healthcare offered by the District's Clinical Streams and Hospitals
- the general capabilities within the District to address the needs of those affected by dementia
- the needs of staff to provide professional and compassionate care for people with dementia
- the needs of priority populations
- Sydney Local Health District is one component of the wider service system supporting people with dementia. Integration of, and with, those components is critical to meeting an individual's needs.

This Roadmap outlines high level recommendations based on the consultation.

Facts about dementia

Both the direct and indirect costs of dementia are rising.

Dementia is the second leading cause of burden of disease in men aged 85+ years and the leading cause of disease burden in women aged 85+ years.

Costs rise as the disease progresses, so there is a need to address early intervention.

Source: Dementia Australia – The Economic Cost of Dementia in Australia 2016-56

Demographic Information

Over the next 40 years, the Australian population will continue to age. While not a normal part of ageing, age is the major risk factor for developing dementia [3]. The Australian Government Intergenerational Report 2023 at a Glance predicts a doubling of persons over 65 years, a tripling of those over 85 years, with a six-fold increase in people reaching 100 years.

In 2023 it was estimated there were more than 400,000 people in Australia and almost 135,000 people in New South Wales living with all forms of dementia. With ageing the major predictor of dementia, these figures are projected to increase to more than 800,000 and 260,000 by 2058 respectively [5].

In 2021, the Sydney Local Health District population was 697,781, and is predicted to increase by 11 per cent to 773,137 by 2031. Based on prevalence estimates of 15.1 cases per 1000 people [6], the District could have up to 10,500 people living with dementia, with approximately 140 receiving healthcare from the District's hospitals and services each day. An Australian Institute of Health and Welfare (AIHW) analysis indicates in 2021 the Central and Eastern Sydney Primary Health Network region (which includes Sydney and South Eastern Sydney Local Health Districts) had 22,299 people with dementia [6].

Modelling, regardless of methods used, shows a steady rise in the numbers of people with dementia due to an increase in overall life expectancy, better survival from cardiovascular diseases and cancer and the ageing of the population. The absolute number of people with moderate to advanced stages of dementia will increase. These people have greater health care needs, many of which are mostly provided by local health districts such as inpatient care, and associated services [7].

More than 53,000 unpaid carers provide support to people with various needs including dementia across the Sydney Local Health District [8]. The unique diversity of the District is outlined in the *Vulnerable Groups section*.

Current data identifies 4000 people living in residential aged care facilities. GEN Aged Care data indicates that within the Inner West Planning Region (which does not include City of Sydney) 62 per cent of those in permanent residential aged care facilities had a diagnosis of dementia in 2022 [9].

> To be a carer by yourself for someone with dementia is very different. There is not much to fall back on. People need to know what sole care is, what it looks like. I gave up my job. Financially it was expensive to care for mum. But money is not enough. I could not have met her needs without physical help. No amount of telehealth, phone counselling, internet reach-out would be able to share or ease the carer burden. I often stayed up all night to care for her.
>
> — David, Carer

Strategic Context

Literature at a national and international level unanimously identifies the need for a broad scope of services and interventions to address dementia: from legislation, partnerships, research and innovations across many organisations [10]. In addition to health, the World Health Organisation (WHO) identifies social services, education, employment, justice, and housing, as well as partnerships with relevant civil society and private sector entities as key contributors. Local planners, providers and researchers discuss 'optimal care pathways.'

Australia is a member state to the World Health Organization's Global Action Plan on the Public Health Response to Dementia 2017-25 [1]. In 2012 the Australian Government declared dementia as the ninth Australian National Health Priority Area, resulting in the National Framework for Action on Dementia 2015-19.

This highlighted the need for:

- increasing awareness and reducing risk
- timely diagnosis
- accessing care and support throughout including during hospital admissions and at the end of life

One outcome from the 2015-19 Framework was the National Health and Medical Research Council Clinical Practice Guidelines and Principles of Care for People with Dementia developed in 2016, although no funds for implementation were released.

The Australian Government is developing a new National Dementia Action Plan following on from the previous Australian Framework, expected to be released in 2024.

Studies have shown that the goals of people living with dementia and their carers may not be health related but relate to social inclusion and other key areas. The new National Dementia Action Plan will aim to address this, as it brings together multi-governmental agencies outside the health sphere to provide a holistic pathway. The NSW Health Agency for Clinical Innovation (ACI) is leading the NSW response to the National Dementia Action Plan and has set up a 'Dementia 100' working group to provide input and collaboration, with representation from Sydney Local Health District.

The 2019 Royal Commission into Aged Care Quality and Safety ("Aged Care Royal Commission") produced 148 recommendations, many specifically addressing dementia care, including capturing dementia data, which will inform the new National Dementia Action Plan. The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability is also relevant as it addressed the needs of the younger (under 65 years) population, with the Final Report and recommendations released in September 2023.

The National Safety and Quality Health Service (NSQHS) Standards provide a nationally consistent statement of the level of care consumers can expect from health service organisations. Sydney Local Health District provides person centred care at its core, in line with these standards. Person centred care is the central principle in best practice dementia care, with the Comprehensive Care Standard specifically relating to dementia, approaching all aspects of total health care from the new oral health principles, to follow up on discharge. The Clinical Care Standards include a Delirium Standard, and in development is a Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard, due to be released in 2024.

The Aged Care Quality Standards (Aged Care Quality & Safety Commission), which underpin the provision of Australian Government funded aged care services are currently under review following the Aged Care Royal Commission. A specific recommendation to urgently review the standards to reflect the needs of people with dementia, has led to an additional Aged Care Quality Standard – Clinical Care. Embedded in these standards is the provision of safe and inclusive services to people with diverse needs and life experiences [11]. The updated standards are expected to be implemented in 2024. Services in the District to which the Aged Care Quality Standards apply are likely to be assessed in 2024.

In line with the Aged Care Act 1997, 'people with special needs' are specifically addressed within the Aged Care Quality Standards, and are to be considered in all aged care service planning. The Aged Care Diversity Framework 2017 recognises people living with dementia among the identified groups with diverse characteristics and life experiences, and provides guidance on appropriate care within the aged care system. Other strategic documents addressing specific vulnerable population needs are listed in the *Key Documents section.*

Facts about dementia

- 47 per cent of hospital admissions for patients with dementia do not have dementia recorded as a principal or additional diagnosis
- The average cost of hospital care for people with dementia is higher than for people without dementia ($7720 compared with $5010 per episode)
- People with dementia have a longer length of stay in hospital
- Hospital discharge destination to a different place of residence, for example from home to a Residential Aged Care Facility, is higher for people with dementia
- The majority, 71 per cent of hospitalisations for people with dementia were of the highest clinical complexity. Combined highest and second highest clinical complexity accounted for 97 per cent of dementia hospitalisations. Only 16 per cent of hospitalisations without a diagnosis of dementia are of the highest clinical complexity

47%

hospital admissions for patients with dementia do not have dementia recorded as a principal or additional diagnosis

62.1%

of people using permanent residential care in the Inner West on 30 June 2022 had a diagnosis of dementia*

In 2021-22, the most commonly used home support service in the Inner West was:

Allied Health and Therapy Services

Source 1: The Australian Institute of Health and Welfare Report Dementia Care in Hospitals 2016-17
Source 2: AIHW GEN Aged Care Data, 2023 (9)

Service Context

The health system is a complex system to map for a disease such as dementia, where there is no single disease pattern. Every person living with dementia has a unique health and care need trajectory which can change frequently. People with dementia who live in the District may interact with a variety of health professionals for diagnosis and ongoing care including their Doctor, or General Practitioner (GP), hospital and private medical specialists, Sydney Local Health District Aged Health, Mental Health and Neurology Clinical Streams and many non-medical clinicians [12]. They are also likely to access public or private mainstream health services for non-dementia health care such as inpatient or ambulatory care services, podiatry or optometry. Referral requirements and pathways, age and geographic criteria are varied and not documented in a single location.

The Central and Eastern Sydney Primary Health Network (CESPHN) aims to increase efficiency and effectiveness of medical services for individuals, particularly those at risk of poor health outcomes such as people living with dementia. The Network also aims to improve coordination of care to ensure people receive the right care in the right place at the right time. Support and training is offered to primary health care professionals in the area. CESPHN has a particular focus on dementia care and works closely with Sydney Local Health District and the Service Sector.

The aged care and disability service sectors are equally complex. Unfortunately, Australian Government planning regions do not line up with local health district boundaries, creating artificial boundaries to care. Key providers of care for those over the age of 65 years, include Australian Government funded programs via My Aged Care, of which Sydney Local Health District is both an assessment service and one of many service providers. Access to aged care services is described as confusing, requiring interaction with the My Aged Care call centre and/or website, before a formalised assessment, which often delays access to services. This My Aged Care structure, introduced in 2015, providing social and daily care supports has had numerous iterations since this time, with major redesign planned for 2024, 2025 and 2027.

Allied Health support is central to dementia care. Within the aged care system the most frequently used support for those living at home in the Inner West region is Allied Health [9]. This is a significant consideration for the District as at the time of writing, it is the only provider of Australian Government subsidised Allied Health - Occupational Therapy, Physiotherapy, Dietetics and Speech Pathology - in the Inner West.

The Residential Aged Care industry is prominent in the Inner West, with 54 facilities totalling 4000 beds in 2023. Structures are in place to facilitate collaboration, led by the District's Aged Health Residential Aged Care Facility (RACF) Outreach Service. At this stage, a Specialist Dementia Care Unit has not been established as per the Australian Government Specialist Dementia Care Program framework to meet the needs of people within our district with severe Behavioural and Psychological Symptoms of Dementia. There are many types of models of residential care, with increasing interest in providing specific dementia care, including small group home environments. There is not currently a Specialist Dementia Care Unit within our district.

The introduction of the National Disability Insurance Scheme (NDIS) in 2017 to provide social participation and support services to people under the age of 65 years living with a disability including those with Younger Onset Dementia (YOD), has altered the provision and roles of health care professionals, with an open market for providers to move in and out of the district. Some providers target dementia specific populations and are often both NDIS and Aged Care providers.

The aged care and NDIS schemes offer different levels of care, and therefore equity in service provision across the ages varies considerably. NDIS plans can reach in excess of $1 million per annum including accommodation, while a Home Care Package Level 4, being the top level of community care, is valued at approximately $60,000 per annum or Residential Aged Care being $100,000 per annum. A person who develops dementia after 65 years of age will therefore have markedly fewer support options including less access to government funded community services, than someone who is diagnosed with dementia before turning 65.

Other providers and organisations offer targeted, disease-specific services, to large scale population initiatives. Local councils provide programs to support social participation in the dementia and aged care sector as well as leading dementia-friendly community initiatives. The Inner West Dementia Alliance and Canterbury-Bankstown Dementia Alliance are initiatives to make the local communities more dementia friendly. Sydney Local Health District has current representation on the Inner West Alliance.

The Australian Government funds a range of dementia initiatives and programs. The Carer Gateway and Dementia Australia offer resources, training, information and services. Both sit independently outside the healthcare system with no formal relationships between the organisations and the District. Dementia Support Australia is a centralised referral point to the Australian Government funded Dementia Behaviour Management Advisory Service (DBMAS) and Severe Behaviour Response Teams (SBRT). These Services have dedicated resources to support understanding behaviours and to develop behaviour support plans.

The Australian Government funds a specialist Dementia Advisory Service through the Commonwealth Home Support Program (CHSP). This funding is currently allocated to Baptist Care in the Inner West, with the service providing education and capacity building.

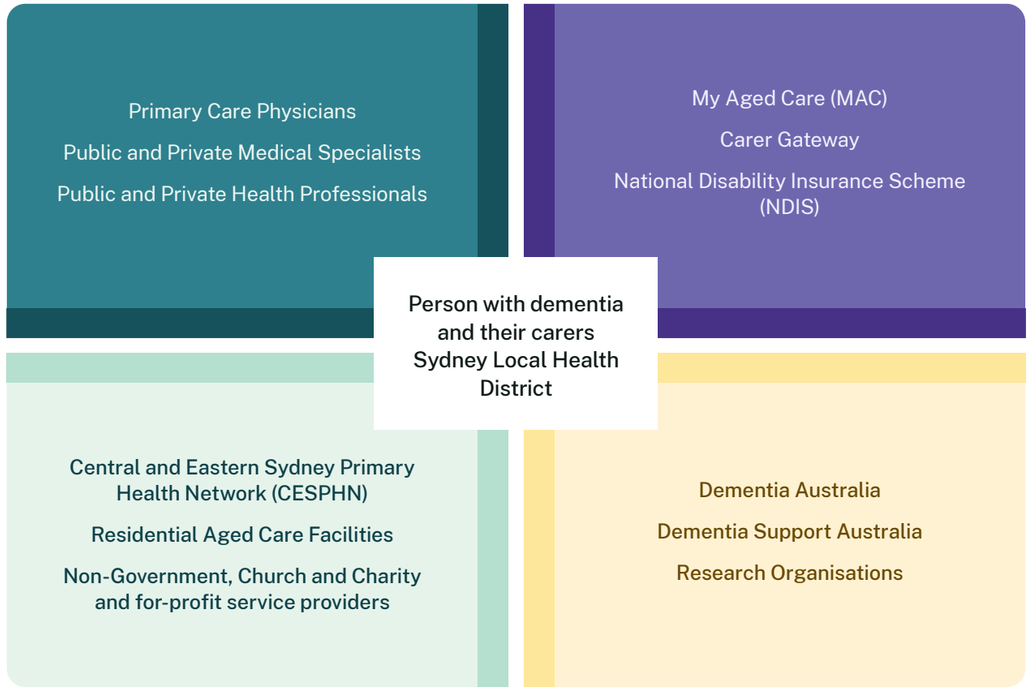


Figure 1: Dementia 'Service Sector'

Sydney Local Health District is one of several dementia respite providers in the region supporting carers and people with dementia to remain supported and living at home. As this program of funding is due to cease in June 2027 with the Australian Government moving to a new program, the future of these services is unclear.

Various research-based organisations and universities have a clinical and services "arm" but their main focus is on research. There are limits to the ability of these organisations to directly provide ongoing clinical care and support. In Sydney Local Health District these organisations are especially important for some specific dementias such as frontotemporal dementia.

Within the Inner West service sector there are multiple providers of community based and residential care, a Dementia Alliance formed in 2021, and regular interagency meetings. The Sydney Local Health District Aged Health Service is strongly positioned within this service sector.

With such a variety of funded organisations contributing to the service sector, interaction and clear communication between all providers, whether public or private, health or service sector based is critical to the provision of person-centred care for a person with dementia.

> We have some private, some government services. There is lots of information, services are available but nothing is centralised. There isn't a clear pattern of what you can do or what services there are.
>
> — Peter, Carer

Services

There is no single dementia model of care in Sydney Local Health District, with varied experiences of dementia care depending on the entry point or mode of delivery. Care is available to all regardless of where they reside, that is, independent or assisted living, homeless or at risk of homelessness, in residential aged care or supported living care.

The District has services for people with dementia and their carers that operate under different Clinical Streams. These services address different aspects of dementia care. Whenever present the dementia is usually an important factor in the clinical course and management. A person may access healthcare with dementia, or due to dementia, and may engage with services at any stage in the disease's progression for preventative, acute or chronic care [7].

> With the rates of dementia growing, all dementia specific services will face an increase in demand. All main-stream services will also experience an increase of people with dementia as either a co-morbidity or primary diagnosis.
>
> *Dementia is everyone's business.*

Dementia develops in a person with inherent variability, and the District provides care in a range of settings, with the aim of providing care in the most appropriate location.

Emergency Departments	• Aged Health Services in Emergency Team (ASET) • Medical consultations
Inpatient Care	• Acute and subacute care • Care coordination • Behavioural and Psychological Symptoms of Dementia management • End of life care
Outpatient or Ambulatory Care	• Medical and multidisciplinary clinics • Memory and cognition clinics • Allied health including Strength Training, Rehabilitation and Outreach Needs in Geriatric Medicine (STRONG) clinics • Future planning • End of life care
Community Based Care	• Assessment • In-home nursing and Allied Health • Transition care • Respite • Carer support groups • End of life care
Outreach	• Residential Aged Care Facilities • Geriatric medicine outreach • Regional, rural and remote communities • Cognition and Aged Care Clinic Redfern Aboriginal Medical Service

Figure 2: Delivery of Dementia Care in Sydney Local Health District

Flexible care options including face to face, home visits, virtual and telehealth services exist within these services.

Activity data collection is problematic and is mostly modelled on population projections and estimated prevalence of dementia. Individual services often keep their own data that is not standardised or comparable. Some Sydney Local Health District dementia data is presented in Appendix 14.2: Dementia Data.

Fact highlight

Concord Hospital Performance Unit Data:

1/7/2021 – 30/6/2023 discharges from Concord Hospital

2897 of total discharges from Concord Hospital (including mental health services) in this two year period were coded with one or more of the 56 unique dementia codes. Multiple codes are possible and some individuals had several.

The following applied to these patients:

- Age range = 28–106 years
- Average age = 84 years
- Length of stay range = 0-722 days
- Average length of stay = 19 days
- 7 patients had a length of stay > 1 year,
  3 x JARA, 3 x Ward 17, 1 x Ward 2B
  Age range 53-77 years
- 3% of discharges were people <65 years
- Average length of stay for those with dementia aged <65 years = 59 days

Concord hospital had a total of 99,995 discharges in this 2 year period.

Focus areas of dementia care

Dementia care is not linear but includes key focus areas which may occur and recur throughout the person with dementia's experience. Carer support must occur simultaneously throughout the process. These key focus areas are:

- Dementia awareness
- Dementia diagnosis and assessment
- Ongoing clinical and medical management
- Behaviours and psychological symptoms of dementia
- Residential care
- End of life care

Dementia Awareness

Dementia as a disease is generally misunderstood. Negative associations surround it, creating stigma and reluctance to seek care. This stigma is well documented among the general and vulnerable populations, an identified issue clearly expressed by those impacted by dementia [13]. Stigma can influence people's willingness to obtain a diagnosis, reveal their diagnosis to others, and seek supportive care and/or to participate in daily life [1].

The Inner West and Canterbury-Bankstown Dementia Alliances run programs of dementia awareness and community development activities to make communities 'dementia-friendly', reducing stigma. Representation on the Inner West Alliance brings a health lens to these activities.

Sydney Local Health District celebrates Dementia Action Week each September with community stalls and educational activities, with other dementia-focused events throughout the year. These events allow safe opportunities for members of the community to ask questions, share frustrations regarding family scenarios and seek advice as to next steps.

The Sydney Local Health District Population Health Strategic Plan 2019-24 outlines the strategies and programs that focus on health prevention, including multicultural strategies targeting healthy ageing and the modifiable dementia risk factors such as hypertension, type 2 diabetes management and obesity which are outlined in the report Understanding Dementia: what puts someone at risk of developing dementia and Risk Reduction of Cognitive Decline and Dementia: WHO Guidelines. The 2020 Lancet Commission report found risk factors for dementia change over the life course. By targeting strategies throughout the life course, it could be possible to reduce the global burden of dementia by 40 per cent [4]. Australian studies estimate even higher values.

Addressing modifiable risk factors throughout the life course in conjunction with highlighting the relationship with dementia can bring about awareness and understanding of the disease. There are various Clinical Streams, programs and specialty services within the District which address these risk factors such as the diabetes centre, metabolism and obesity service, the chronic disease rehabilitation programs and drug health among many. Including dementia risk and prevention in service planning and community messaging can strengthen the approach to dementia care.

There is evidence that exercise may prevent dementia. Preventative health programs such as the Strength Training, Rehabilitation and Outreach Needs in Geriatric Medicine (STRONG) Program operating at Balmain and Concord Hospitals aim to improve strength and balance in the older people they see.

Framework Consultations continually reported that access to diagnosis and services is the single most difficult step for a carer. Some carers reported delays of four years while seeking a diagnosis, reflective of literature estimates, reinforcing the need for very transparent, easily accessible, understandable information regarding dementia, dementia diagnosis and available care.

There are no targeted strategies or mandatory training to increase staff awareness and understanding of dementia within NSW Health.

Current Strategies: Dementia Awareness in Sydney Local Health District

- Programs, plans and services targeting chronic disease and modifiable risk factors
- Healthy ageing strategies
- Representation on community groups and associations
- Community stalls and celebrations for Dementia Action Week

Dementia diagnosis and assessment

Literature estimates the time between onset of dementia symptoms and formal diagnosis of dementia can be up to four years [14]. It often takes several visits to make a definitive diagnosis partially due to the varying severity and evolving nature of the presentation and similarity of the presentation of multiple types of dementia (15). Enabling timely diagnosis and intervention is recommended by the World Health Organisation, the Australian National Dementia Action Plan Consultation Paper 2022 and the Australian Clinical Practice Guidelines [16].

There can be a reluctance to seek or provide timely diagnosis of dementia due to the lack of preventative or curative treatments. There is a valid ethical question of "does it help to know?". The arguments for the timely diagnosis include it may improve longer term planning, reduce carer stress and increase quality of life for the person with dementia and their carer [14]. People with dementia and their carers often get comfort in finally being provided with an explanation for symptoms, functional and other problems that have been affecting their everyday lives due to dementia. As new and emerging disease modifying therapies are developed and become available, they are likely to be more effective in people with mild cognitive impairment and early dementia, this may become an additional reason for the value of making a timely diagnosis. This may indicate a need for different and expanded structures and resources to identify and intervene for the pre-symptomatic and minimally symptomatic person. It should be noted that some services/clinics are funded only as a diagnostic service with no ongoing care. However a diagnosis delivered in isolation is potentially harmful, and there is a central need for ongoing support and management [14].

The timeliness of a dementia diagnosis will differ for different people and different settings. Identifying the type and/or mix of dementia present can take time for some individuals, yet significantly improve the outcome for the individual and support structure. Enabling responsive and flexible district services to support accurate and appropriate diagnosis so the most current best practice recommendations can be applied.

> Knowing the dementia diagnosis of Dementia with Lewy Bodies changed the game for me. It saved my mum's life. It was very important as I was able to be explained in relevance, not generalism. It was important to me.
>
> — David, Carer

The diagnosis of dementia is clinical, with primary care GPs, public, and private medical specialists able to diagnose dementia [17]. There is no data or information on the number of GPs within the District who diagnose or specialise in dementia. The 2023 Federal budget permits a larger Medicare rebate to allow General Practitioners to book longer consultations for people with chronic or complex needs. The over 75 year health check incentivises General Practitioners to complete a thorough and holistic review to identify risk factors or persistent symptoms. The Central and Eastern Sydney Primary Health Network supports General Practitioners with training and education regarding dementia diagnosis. The joint Health Pathways Portal (Central and Eastern Sydney Primary Health Network and Sydney Local Health District) provides information and resources to guide a dementia diagnosis, and includes the District's specialist service information, but there is no shared care pathway in place.

Private Geriatricians, Neurologists and Psychogeriatricians also diagnose dementia, and sometimes offer ongoing consultation. Memory Clinics in Australia are open to consumers from any geographic location depending on the individual service. Consumers can seek specific clinics if they are seeking specific clinical trials, specialist teams or other key features. There is a register of some of these clinics on the Australian Dementia Network (ADNeT) website, with several being within the District.

Diagnosis in Sydney Local Health District occurs across several Clinical Streams and medical specialists including Geriatricians, Neurologists and Psychogeriatricans. The Concord Hospital Cognitive Disorders Clinic and the Royal Prince Alfred Hospital (RPA) Memory and Cognition Clinic provide a multidisciplinary assessment and management service. Dementia may also be diagnosed in people seen in general Geriatric Medicine, Psychogeriatrics and Neurology clinics or when an inpatient under these teams. These people may also be referred to dementia services and other services within the District. Outreach services provide specialised care to targeted groups such as the Cognition and Aged Health Clinic at Redfern Aboriginal Medical Service, and the regional, rural and remote Geriatrician Outreach Service. It should be noted that the District's services are not only diagnostic, and develop an ongoing care plan and remain engaged in the management of the person with dementia and their carers.

The NHMRC Clinical Practice Guidelines and Principles of Care for People with Dementia, and its consumer companion guide provide best practice recommendations for assessment and care. The Australian Dementia Network National Memory and Cognition Clinic Guidelines outline recommended ideal standards for assessment and post-diagnostic support to be provided by Australian memory and cognition clinics. They provide advice on the referral processes, assessment procedures, effective communication and post-diagnostic support and seek to enable timely diagnosis and quality early support for people diagnosed with dementia. The Guidelines are currently under review, updates will include additional aspects such as dementia and intellectual disability, and some levels of best practice, to acknowledge differing inputs into funding this model of practice. No clinics currently have a documented model of care or set of clinical guidelines specific to their service but use these documents as a reference.

Timely access to relevant imaging and other investigations facilitates appropriate dementia diagnosis [15]. Working with existing and innovative technology such as telehealth is vital to support vulnerable groups such as regional, rural and remote assessment and diagnostic practices. Disease modifying medications if and when available will result in a shift in focus and expansion of dementia diagnosis and management services.

Current Strategies: Assessment and diagnosis in Sydney Local Health District

- Provide a range of services in various settings to facilitate appropriate diagnosis
- Multidisciplinary team approaches

Ongoing clinical and medical management

Following a dementia diagnosis, development of a coordinated, ongoing plan is critical with each person living with dementia and their family/carers having a varying spectrum of needs. Future planning should account for changing needs and include:

- a healthcare plan that is managed mostly in primary care with an agreement of when specialist follow-up and involvement is needed
- scheduled ongoing medical reviews via outpatient clinic appointments
- education on the expectations of anticipated disease progression and management of symptoms
- providing direct support and strategies and/or referral to appropriate services to help improve and maintain quality of life for the person living with dementia and their family/carers
- the management of other acute and chronic health conditions including oral care, hearing and vision, foot and skin care, nutrition and fitness
- social support and carer support including advice and considerations for transition to retirement, driving cessation, change in accommodation
- planning for the future, for example, wills, advanced care directives, enduring guardian, enduring power of attorney, accommodation etc. [1] [4]
- planning for optimal environmental design

Emerging dementia prevalence and improved management of chronic conditions in Australia means people living with dementia will present to more district facilities and services.

Most recommended models of dementia care include or recommend a coordinated approach across the service sector.

> *Dementia is everyone's business.*

Coordination and communication needs to occur between the health services involved, the aged care or disability care services, the person with dementia and their carers. Since the introduction of the aged care reforms in 2012, Australian aged care services have moved away from the case management model, towards consumer-directed care [12]. This approach presents challenges to some people with dementia and is a common gap in service delivery cited by people with dementia, carers, district staff and others.

> There is a difficulty in getting in touch with people. You leave messages, send an email. You use the precious spare time between care to contact people, and it was too hard to do these communications. Call backs came at difficult times when I was busy caring, and from private numbers. I would need to keep calling back, and if I missed a call they didn't try again.
>
> — David, Carer

Within Sydney Local Health District there is no single model of care. Aged Health, Mental Health and Neurology services, across the Emergency Department, inpatient, outpatient/ambulatory, community and outreach settings participate in care. The Sydney Local Health District Cognition and Falls Committee provides oversight in the inpatient setting.

For some people with dementia, a hospital admission may be the first entry to a dementia pathway. For others it may be a repeating pattern or part of coordinated care provision. There is ad hoc identification of dementia on admission into hospitals, making bed usage and activity analysis challenging. Acute care inpatient episodes have been shown to have poorer outcomes for people with dementia, with longer lengths of stay [4] [18]. Programs to prevent unnecessary hospital presentations exist however people with dementia are expected to require hospital admission, and dementia-friendly care and support in all inpatient settings must be provided. Dementia-friendly care has the potential to reduce the risk of incidents in the inpatient setting, while maximising positive outcomes for patients. The 'TOP 5' or 'My Story' tool, which identifies strategies to provide supportive inpatient care to a person with dementia, is used inconsistently, and may be difficult to locate in electronic and hard copy medical records. Key elements of this type of care include meaningful activities, appropriate building design and supportive decision-making based on the person with dementia's wishes. With deafness being recognised as a risk factor for dementia, maximising coherent sensory input by addressing hearing and vision impairment is paramount. Oral health, adequate nutrition and time reorientation strategies are vital strategies for delirium prevention. Various standards include the need for appropriate inpatient care and support for people with cognitive impairment, including dementia. The Sydney Local Health District Disability Inclusion Action Plan facilitates supportive environments for all people including people with dementia. All new District facility developments should include consultation with, and consideration of the needs of people with dementia.

Providing dementia care in any setting is most effective when provided by an integrated multidisciplinary team [12]. Studies have shown that involving Allied Health results in higher levels of functional independence [19]. The NSW Agency for Clinical Innovation has an Allies in Dementia Health Care Project outlining the roles of Allied Health professionals in dementia care which can guide decision making for teams and individuals. These roles include addressing functional abilities, correcting impairments, future planning, carer support and counselling. Whilst evidence supports involvement at every stage of the disease, district health services are often concentrated at the later, more advanced stage of dementia care.

Within the Sydney Local Health District geographical region, Allied Health can be accessed via public health inpatient, outpatient, community or virtual teams; private providers; aged care providers or the NDIS. The District offers Allied Health services including multidisciplinary teams under a range of Clinical Streams.

Oral Health Services provide community clinics for eligible consumers including a significant number of people with dementia, with the opportunity to refer to Special Care Dentistry. The role of dental care in delirium prevention is addressed throughout the district services. Technology such as 3D scanning of dentures has the potential to significantly improve long term oral health outcomes for people with dementia.

Within the sector there are multiple formalised carer support groups or dementia cafes. The District operates a monthly general Dementia Carers Group and a Men's Dementia Carers Group.

> Being able to attend a local group is an enormous help for burnt out carers. In a group you are no longer struggling on alone. Facilitators are a wonderful source of support and advice.
>
> — Anonymous, Annandale

> Specifically, it is the collective intelligence of a dementia support group that has got me through.
>
> — Past carer group member

One of the most consistent messages via the District consultation process has been the need for a single contact point following diagnosis, for education and information, episodic help, crisis management and/or carer counselling. This need is compounded by the lack of funded case management services and will be addressed in the *Roadmap 2024-30 section*.

> By the time someone comes to a group, the carer is burnt out. We don't want to do forms et cetera, no more assessments!
>
> — Anonymous, Annandale

Ongoing community-based nursing services are provided by the Sydney District Nursing Service, within RPA Virtual. Veterans and their partners can choose to access Department of Veterans Affairs (DVA) funded nursing services. At the time of writing there are no other Australian Government funded aged care community nursing providers. There are various NDIS nursing providers, and private nursing organisations.

A pathway into NDIS is available for people under 65 years, following a formal diagnosis of younger onset dementia (YOD). Since the introduction of the NDIS, allied health assessment and services for people with disability are mostly provided via the disability sector rather than NSW Health. Accessing Allied Health prior to an NDIS plan commencing can be difficult. Other factors specific to YOD for consideration include ongoing employment, family priorities and needs, and familial dementias and their effects.

Currently there is inequitable access to care across all the District's clinics and services. Workforce strategies are outlined in the *Workforce Development section*.

Current Strategies: Ongoing medical and clinical management in Sydney Local Health District

- Inpatient, outpatient, outreach, community, virtual multidisciplinary teams
- Individualised dementia care plans
- Carer support programs
- Link with primary care (Health Pathways and General Practitioner communications)
- Facilitate access to relevant service sector community and social supports

Behavioural and psychological symptoms of dementia

Behavioural and Psychological Symptoms of Dementia (BPSD) occur in almost all people with dementia at some stage of the disease and are associated with significant carer stress [3]. Despite the high impact on quality of life and care needs, there are no current national prevalence estimates of Behavioural and Psychological Symptoms among people with dementia in Australia. The best estimates reported by older Australian studies range from 61–88 per cent of people with dementia in the community setting, 29–90 per cent of residents in Australian aged care facilities and 95 per cent of hospitalised patients in long term acute care [20].

BPSD can present at any stage and exist in any setting, so identification of symptoms and education is important in supporting carers and staff. It can be active and obvious, or passive and ignored. The Neuropsychiatric Inventory is the gold-standard assessment for identifying BPSD [21], and planning care for BPSD is classified in a scaled model, from Tier 1 (nil) through to Tier 7 (extreme) [22]. Individual characteristics play a major role in management and strategies need to be highly individualised, taking into account available carer and supports already in place [23].

The interplay between delirium and dementia in inpatient settings can affect the nature of BPSD. People who experience BPSD anecdotally have longer hospital stays, exacerbated as traditional hospital design does not support strategies to de-escalate behaviours [22] [25]. Health Infrastructure NSW has developed a NSW Government publication; Design Guidance Note 070, Design Guidance to support the care of patients with Extreme Behavioural Persistent Symptoms of Dementia to outline best practice design for managing BPSD within state hospitals.

Facts about dementia

NSW Health consultation suggests that people from culturally and linguistically diverse (CALD) backgrounds, particularly refugees, may be at greater risk of extreme BPSD. This may be due to a history of trauma, cultural stigma, dementia-related language loss, delays in seeking health care, or unfamiliarity with or lack of trust in the health care system. The person experiencing extreme BPSD often has very limited ability to communicate, some having lost their ability to communicate through speech. If English was not their first language, they may have lost more recently acquired language skills, making it harder to communicate and understand, and exacerbating behavioural disturbance. [24].

Staff find the management of BPSD challenging, with each hospital facility offering differing strategies and teams. Care is often provided by multiple clinical streams, based on the individual. Balmain Hospital has redesigned space to include communal dining rooms, and thoroughfares where patients can walk freely with positive behavioural results. Concord Hospital's redevelopment has included a purpose built ward for specialist dementia care (Ward 17), and inclusion of dementia friendly general design throughout. The Jara Unit within Mental Health at Concord Hospital incorporates general design principles to assist the older inpatient.

> The best outcomes, and sometimes a safe outcome for the person living with dementia, can only arise from the consistent combined input of the "medical expert" and the "patient expert." It is upsetting to a carer when medical services do not recognise and rely upon a patient expertise when offered.
>
> — David, Carer

Government Funded National Services for BPSD Management

Dementia Support Australia is funded by the Australian Government to provide specialist programs;

Dementia Behaviour Management Services (DBMAS)	Tier 3-4 BPSD	Short term case management and tailored recommendations/advice
Severe Behaviour Response Team (SBRT)	Tier 5-6 BPSD	24/7 mobile dementia specialists for RACF residents
Specialist Dementia Care Program (SDCP)	Tier 5-6 BPSD	Residential specialised dementia care

The Australian Government funds the Specialist Dementia Care Program, which aims to establish a Specialist Dementia Care Unit in each Primary Health Network region nationally. A Specialist Dementia Care Unit supports the needs of people with very severe (Tier 6) behaviours within commissioned RACFs [24]. Currently the closest facility is in Western Sydney (Southwood), with assessment and allocation undertaken centrally in NSW by Dementia Support Australia.

Evaluation from the Specialist Dementia Care Program completed in 2023 concludes it would not be suitable to expand the program to include Tier 7 BPSD due to the need for increased medical and security staffing, higher staffing ratios, and specialist training to deliver the required level of care [26]. It is estimated that at any one time each Local Health District in NSW may need to provide inpatient care for between one and eight people experiencing persistent extreme (Tier 7) BPSD [24]. A government report in South Australia (the Oakden Report) found that Tier 7 services should be provided by the public health sector and this has been adopted by the NSW Health Project Report on Extreme BPSD [24].

People with BPSD experience unique challenges in ongoing care. Ward 17 at Concord Hospital is a 12 bed ward for the inpatient management of BPSD, mostly Tiers 5-7 across all age groups bringing together staffing expertise and a dementia friendly environment. Ward 17 found that patients with behavioural symptoms often have multiple short term residential care placements due to differing needs, availability and ability of facilities to provide the required care [23]. The Sydney Local Health District Mental Health Service Policy Directive outlines the services under the Mental Health clinical stream.

Multidisciplinary care is vital in the management of BPSD [25], with non-pharmacological approaches preferred as initial strategies. This has further been regulated following the Aged Care Royal Commission recommendations on restrictive practices in Residential Aged Care Facilities requiring additional measures and protocols. In NSW, the NSW Civil and Administrative Tribunal (NCAT) changes in relation to restrictive practices have increased the complexity. A NSW NCAT tribunal is the only authority which may appoint a decision maker to approve restrictive practices. This change may have resulted in more admissions to hospital facilities from Residential Aged Care Facilities for medical management, an increase in guardianship applications, with an associated increase in hospital length of stay in order to fulfil legislative requirements and meet admission criteria to facilitate discharges to Residential Aged Care Facilities. A trend has been noted with increasing length of stay in Concord Hospital's Ward 17 and the District's Aged Care wards and is thought to reflect the severity of behaviours present, the need to seek authorisation for restrictive practices, varying risk appetite to accept people with restrictive practices into Residential Aged Care Facilities, and reduced workforce [26]. This in turn impacts occupancy rates and availability of beds with periods of 100 per cent occupancy.

Younger people with BPSD can be moved between disability, aged, mental and general health systems due to a lack in specific skills and services [15]. Suitable discharge destinations are as difficult to access as aged care, and this may be the catalyst for a younger person to enter residential care, often prematurely. Few suitable accommodation options exist for young people, as discussed in the *Residential Care section*.

Hospital discharge planners regularly cite the challenge of finding appropriate discharge destinations for people with BPSD within Sydney Local Health District and the Sydney metropolitan area. Finding an appropriate discharge destination in a timely manner is an issue experienced by all Local Health Districts.

Current Strategies: Behavioural and psychological symptoms of dementia (BPSD) in Sydney Local Health District

- Individually manage BPSD presentation in various settings
- Provide specialist inpatient care for severe-extreme BPSD in Ward 17 Concord Hospital
- Carer education services

Residential care

The setting with the highest proportion of people living with dementia is residential aged care facilities (RACFs). In Australia an average of 54 per cent of people living in Residential Aged Care Facilities have dementia [27], and over half the expenditure directly attributable to dementia is in subsidising RACFs [9] [14]. In 2021 it was estimated 62.1 per cent of people in a Residential Aged Care Facility in the Inner West Aged Care Planning Region had a diagnosis of dementia [9]. Detection and diagnosis of dementia in care facilities is essential for providing dementia-specific care and predicting increased care needs and hospitalisation frequency [14]. The new Australian National Aged Care Classification funding instrument should enable more accurate data to be collected regarding dementia prevalence in Residential Aged Care Facilities, providing an incentive to diagnose dementia in residents.

For most people, it is preferable to continue living at home with dementia, yet individual needs may eventually exceed the capacity of in-home aged care programs, and moving to a Residential Aged Care Facility becomes necessary. For some there is resistance to transition. Many carers have experienced this process and identify transition to a Residential Aged Care Facility as the most difficult period and felt a gap in help to navigate the process.

There are currently 54 residential aged care facilities, with approximately 4000 beds in Sydney Local Health District. The District's Residential Aged Care Facility Outreach service is a nursing and medical team that facilitates care transitions between acute facilities and RACFs and provides important alternatives to accessing specialist care in the residential facility. The RACF Outreach Model of Care, 2023 outlines the benefits and challenges of providing care in a Residential Aged Care Facility setting. RACF Outreach service core business includes the assessment and management of dementia; management of associated complications including BPSD, falls, infections and end of life care. An important goal of the service is enhanced forward planning to facilitate providing care in the preferred location. RACF Outreach uses traditional and virtual formats to deliver care, education, and a community of practice.

There are well developed partnerships with many Sydney Local Health District services including Oral Health (REACH Dental), the Public Health Unit, Sydney District Nursing, Older Persons Mental Health and Specialist Palliative Care (Palliative Care Clinical Nurse Consultancy Model of Care 2022), Infectious Diseases, Vascular Surgery and Dermatology.

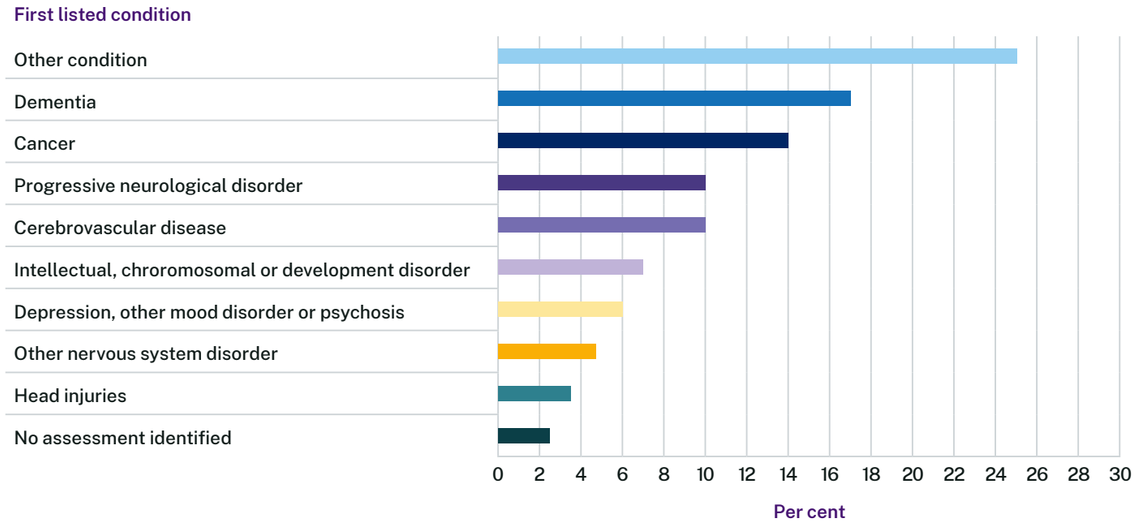
Hospital discharge can be delayed due to occupancy and workforce issues in RACFs, and/or lack of safe and suitable RACF beds. A small number of culturally specific RACFs exist to cater for the needs of people from diverse backgrounds, with their own specific services and programs to address dementia care. Changes to restrictive practices are also contributing to delays in discharge as patients await appropriate documentation, behavioural management plans and NSW NCAT hearings.

A recommendation of the Aged Care Royal Commission was to prevent people under the age of 65 years from entering an RACF. Currently there is a single private group home within the District with a model specifically for dementia, available for all ages. There is no dementia specific provider available for those with severe BPSD. The Sydney Local Health District Disability Inclusion and Assistance Service (DIAS) is able to support hospital discharges of people under 65 years to appropriate NDIS accommodation and find suitable partnerships. Once a person's needs are beyond supported independent living accommodation, there are limited other options available. Transition to RACF frequently occurs as there is no alternative. Disability accommodation does not provide the nursing and personal care that is required for some people, particularly with end stage dementia and/or BPSD.

If someone completes the process to enter an aged care facility under 65 years, it is possible to retain some services within an NDIS Plan. However most people on an NDIS plan are required to forfeit their plan and eligibility if they enter the aged care system. This includes respite care.

For individuals with severe dementia care needs (Tier 6 support needs), Dementia Support Australia facilitates a centralised referral process to assist these people into Specialised

Proportion of people who first entered permanent residential aged care under 65, most common first-listed condition by remoteness of facility (MM1), 2013–14



Notes: First listed condition indicates the 'main' condition or the condition with the most significant impact on a person's care needs. Remoteness refers to the location of the facility. MMM stands for Modified Monash Model, which measures remoteness and population on a scale between MM1 (major city) and MM7 (very remote).

In 2013-4, Dementia accounted for 16.6 per cent of the proportion of people under 65yrs to enter a residential aged care facility.
Source: www.gen-agedcaredata.gov.au/resources/dashboards/pathways-of-younger-people-entering-permanent-residential-aged-care

Dementia Care Units, as discussed in the *Behavioural and Psychological Symptoms Of Dementia section*.

Sydney Local Health District also provides specialist residential care at Yaralla House. This is a unique facility that provides care for people with a HIV diagnosis who have developed HIV-associated dementia and is the only known facility to provide this service globally. It is supported by the District and external providers.

Current Strategies: Residential care in Sydney Local Health District

- Supports best practice health care for residents of Residential Aged Care Facilities
- Provides help to identify appropriate accommodation via NDIS
- Unique residential care facility for people with HIV-associated dementia

End of life care

> I didn't do a Power of Attorney, purposefully, because I didn't want her to be ignored. I could see that the dementia patient gets ignored and not considered.
>
> — David, Carer

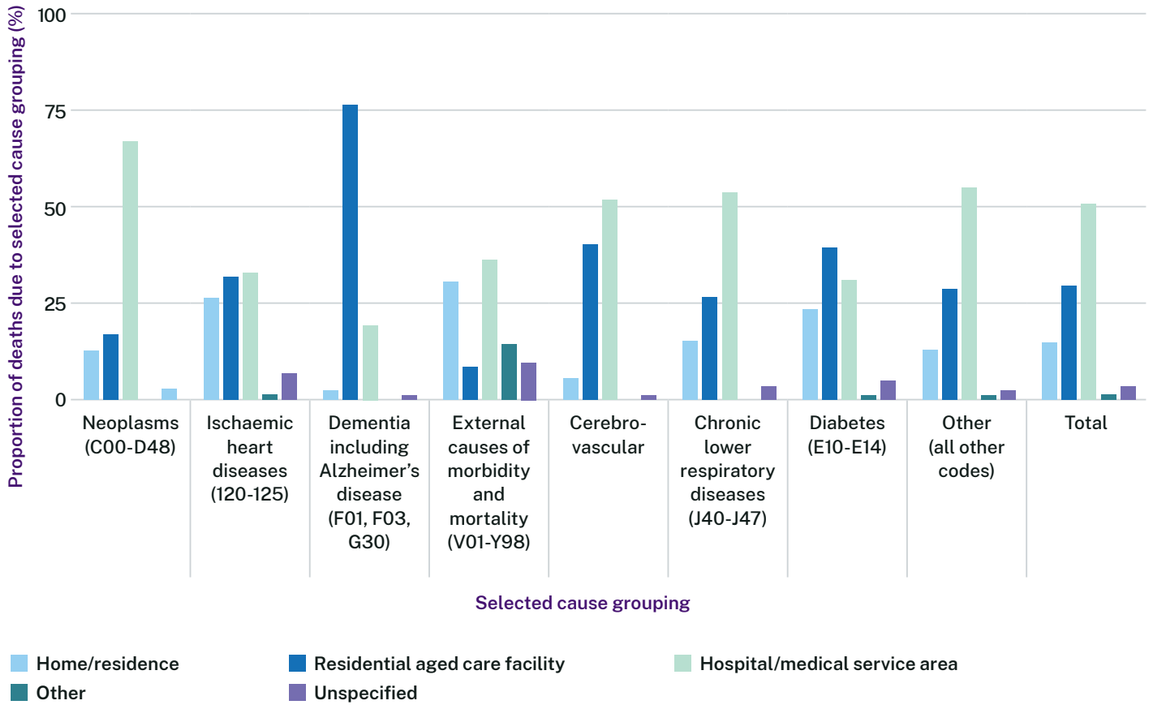
Dementia is a terminal, progressive disease that reduces life expectancy and affects ability to perform activities of daily living. Since 2013 dementia has been and remains the second leading cause of death in Australia and the leading cause of death for women since 2016 [28] [18]. As such, end of life care is a core component of dementia care, needed from the point of diagnosis through to loss of usual abilities and functions, through the end of life to carer bereavement [1]. However, the dementia disease course is unpredictable, characterised by fluctuating stability and unstable care needs with no clear timeframe or trajectories to death. People over the age of 85, who are typically multimorbid [4], account for 72 per cent of total dementia incidence in Australia's major cities [29]. Interaction with other acute illnesses impacts the dementia trajectory.

Along the course of dementia there may be several stages of grief and loss, for example due to cognitive decline, functional decline, loss of communication and recognition of loved ones, residential care placement and death [30]. Decisions regarding treatment and care have the additional complexity of supported decision-making and potential loss of decision-making capacity of the person with dementia. The patient directed care model of palliative care services for people with dementia may therefore differ significantly from that delivered to people with other illnesses more commonly associated with palliative care, such as cancer [31]. The majority of palliative care services are traditionally for the last three to six months of life.

End of life care can occur in the home, hospital or residential care. Once someone becomes house bound, their care often becomes limited, with fewer General Practitioners providing home visits, and some medical clinics not providing ongoing in-home outreach. As dementia advances, newer care modalities such as telehealth become less applicable for the person living with dementia and may not be the most suitable option, with the health professional needing to use their clinical judgement to decide on best available options for ongoing care. Telehealth support for carers continues to be a valuable option.

Approaching end of life with dementia can occur when decision making capacity is no longer functional. Formulating an Advanced Care Plan or Advanced Care Directive at a suitable time following diagnosis can ensure a person with dementia's wishes are considered and documented to carry out if required. This can assist healthcare decisions that can be difficult for others to make on someone's behalf as well as set expectations for the family, carer and others involved in care. Preventing unwanted interventions and transfer of care between services and settings can improve quality of life for everyone involved [30].

Place of death by proportion of deaths due to selected cause groupings, Australia, 2019



Source: Australian Bureau of Statistics, Classifying Place of Death due to selected causes 14/04/2021

The majority, 51 per cent, of deaths in Australia occur in a hospital or medical service, however deaths from dementia occur principally in RACFs (77 per cent), as shown in the figure above. Deaths from dementia have the lowest proportion of deaths that occur in hospitals (20 per cent) and the home (2.5 per cent) [32].

> The grief was difficult, both before and after death… Everyone grieves differently…
>
> The most helpful thing after they were gone was talking to another carer. Our shared experience helped.
>
> — Past carer group members

Within Sydney Local Health District, Aged Health, Sydney District Nursing and Palliative Care provide supportive end of life care to people with dementia, and their carers. This includes medical, nursing, allied health in all settings including RACFs, and non-clinical care packages in the home (Out of Hospital Care). The District also offers a specific Bereavement Service to all who live in or are bereaved of someone who died in the District, or for staff. Culturally and linguistically diverse resources are also available.

The introduction of the voluntary assisted dying (VAD) legislation in NSW excludes people with dementia from accessing this type of care.

Current Strategies: End of life care in Sydney Local Health District

- Inpatient, residential, community and outreach end of life care services
- End of life bereavement service

Vulnerable groups

Dementia carries with it a stigma which can marginalise anyone with the disease. This is a key focus in Australia as well as internationally as outlined in the *Dementia Awareness section*.

Australia, and more specifically Sydney Local Health District, has several diverse and vulnerable communities, with specific needs relating to their dementia. These groups can have higher rates of dementias, present with different dementia types, associated with different risk factors, and may face significant barriers to accessing care. Key issues for these vulnerable groups include dual or multiple stigmas (associated with dementia, and identifying as one or more vulnerable groups), documented lack of engagement and/or mistrust of health services, lack of direct access to services, as well as non-traditional social and cultural structures compared with the general Australian population.

People often identify as several of the below vulnerable groups which adds to the complexity [33].

Vulnerable groups in Sydney Local Health District

Younger onset dementia (YOD)	• 7 per cent of the NSW population who have a dementia diagnosis receive it before they are 65 [5] • Individuals often have fewer co-morbidities • Social and economic impacts are significantly different; 1 in 4 people with YOD have children <18 years at symptom onset [34], and/or can occur at peak financial, social and occupational responsibilities. Carer and family support (often for children) is required [15] • Fewer high care residential options exist for younger people • People with YOD live longer than older people following diagnosis, but lose 10–15 years of life [15] • This group are more likely to have an inherited dementia type. Genetic testing and counselling is highly recommended [15]
Disability	• More than 28,000 people with a disability live in Sydney Local Health District [8] • Dementia onset is 10 years younger than the general population for people with an intellectual disability [15] • By 40 years, almost all people with Down Syndrome will develop Alzheimer's Disease on brain imaging, with 50 per cent of people developing the disease by 60 years [35]
First Nations Peoples *Also refer to the Aboriginal Health Impact Statement section*	• Dementia prevalence is 3-5 times higher than the general population [15] [36] • 10-15 year earlier onset of dementia • Increased risk factors to the general population (head injury, stroke, diabetes, high blood pressure, renal disease, cardiovascular disease, obesity, hearing loss, childhood stress and trauma, and lower socio-economic status) [36] • Low uptake of in-home services: 1.4 per cent of people using Commonwealth Home Support Program services in the Inner West region identified as First Nations [9] • First Nations peoples are able to access aged care supports from the age of 50 [37] • Stolen Generation survivors are now over 50, with a third of First Nations adults descendants of the stolen generation: the risk factors of age and trauma perpetuate dementia risk [37]
Culturally and Linguistically Diverse (CALD) Communities	• 44 per cent of people in Sydney Local Health District were born overseas, 55 per cent speak a language other than English at home [38] • In 2021 the number of people born overseas living in the Inner West aged care planning region accessing entry-level Commonwealth services was 68.1 per cent, and those who preferred to speak a language other than English was 42.5 per cent [9] • 1 in 5 people with dementia are from a CALD background [18] • High rates of YOD (Australian Institute of Health and Welfare study found 41 per cent of the YOD cohort were born overseas, and 21 per cent were born in a non-English speaking country) [39] • Higher risk of extreme BPSD [24] • Loss of subsequently learnt languages • The District has an on-demand interpreter service strategy
Homelessness	• Sydney Local Health District has the highest number of registered boarding houses in NSW, and an estimated 6000 homeless population [8] • Earlier onset of cognitive impairment compared to the general population may be due to lifestyle factors • A Sydney study found dementia six times higher than the general population [40]
LGBTIQ+ communities	• A number of Sydney Local Health District suburbs have the highest proportions of same-sex couples in Australia [8] • Barriers exist to accessing care and receiving appropriate care • Maintaining identity within the context of memory changes can relive past traumas [33] • Aspects of NSW Health Systems – for example electronic medical records do not accurately capture gender identity and same sex relationships which can impact accessing care [33]
Veterans	• The National Centre for Veterans' Healthcare, an Australia-wide health service for veterans and their partners is based at Concord Hospital • Veterans generally have more risk factors for dementia including post traumatic stress disorder (PTSD) and head trauma [41] • Veterans with dementia and PTSD have more severe BPSD [42] • Anecdotally, the current aged care veteran cohort presenting in Sydney Local Health District with dementia served in the Korean War and experience high rates of chronic traumatic encephalopathy. Chronic traumatic encephalopathy is associated with the development of dementia [4] • Korean War veterans are several times more likely to experience PTSD, anxiety or depression [43]

Regional, Rural and Remote communities	• Living in rural and remote locations can mean poor access to specialist healthcare services, longitudinal care and fewer care options including in home supports • A preliminary review of the Specialist Dementia Care Program found that due to the limited accessibility to a Psychogeriatrician, regional, rural and remote areas had less eligibility to access to the national Specialist Dementia Care Program for BPSD management [26]
Children	• Childhood dementia refers to a diagnosis <14 years [15] • Over 70 rare neurodegenerative genetic disorders have been identified as causing childhood dementia [44]. These are individually rare, but collectively common. • Raw Sydney Local Health District facility data shows an increase in hospital admissions for children with dementia coding *(Refer to the Dementia Data section)* • Need for genetic counselling expertise • Average age of onset: 2.5 years; average age of diagnosis: 4 years; median survival: 9 years, with 1 in 3 reaching adulthood
Those who have experienced trauma	• Trauma associated with institutional care – for example refugees, stolen generation, persecution etc can mean fewer presentations to hospital and health facilities and a preference for staying at home rather than enter a RACF, and low uptake of in home supports

> "Dementia is a multifactor issue. People try to help you without considering every aspect of you for the service. We are Chinese background. It is important that cultural factors should be included. There are four areas important to us; religion, medical, social and family. To really help one person you have to break these down to handle all their issues as a whole, not separate.
>
> Our whole family is involved in this. We try our best."
>
> — Peter, carer

By ensuring the provision of individualised care and building on existing internal and external partnerships such as diversity hubs, the Aboriginal Medical Service, and the National Centre for Veteran's Healthcare, the District will continue to address the individual needs of all vulnerable groups. The Commonwealth Aged Care Diversity Framework (2017) and Action Plans as well as other key documents outlined in the *Key Documents section* provide the structure and strategies of best practice.

Research and quality

Research is seeking new solutions in dementia care, with dementia treatments evolving around the world. However, as dementia is not a single disease, a single solution is not expected. All types of research from basic research, including the biological causes of common forms of dementia, to clinical studies of new effective interventions on prevention and treatment, or focusing on specific strategies such as BPSD management, through to the best methods to provide clinical and community services would build on current data [1] [3]. Pharmaceutical clinical trials abound in targeted research [19], with some being conducted within Sydney Local Health District.

The District's services must be designed to be responsive to new research outcomes, in order to provide the most flexible, current and effective models of care. While the scope of research seems infinite, research must translate into continuous improvement of care for people with dementia, focusing on quality of life with consideration of the person with dementia's personal goals and perception of care [45].

It is necessary to generate new knowledge that will optimise the quality of life of people with dementia, and their families and/or caregivers, and to create systems to monitor people with dementia, while providing comprehensive, quality care (45). Effective immunotherapies, if and when they are developed, approved and funded, will require a major refashioning of health services for dementia.

The Centre for Education and Research on Ageing (CERA) is part of Geriatric Medicine at Concord Hospital. Along with the ANZAC Research Institute, CERA supports researchers with interests in aged health, aged care and dementia. Additionally various Sydney Local Health District staff specialists hold senior positions in peak bodies and interest groups such as the Australian and New Zealand Society of Geriatric Medicine. Research is needed to understand more about the implementation of District wide dementia services. CERA (and the District) are ideally placed to contribute to this knowledge.

Other research groups with District involvement include:

- Sydney Dementia Network
- Concord Hospital's Cognitive Disorders Service, which is implementing the LaTCH Trial via Australian Dementia Network
- RPA Memory and Cognition Clinic is currently involved with various clinical trials
- RPA Memory and Cognitive Service and Concord Hospital Young-onset Dementia Clinic which has a research focus with links to ForeFront Research and the Frontier Research Group, and the Brain and Mind Centre, University of Sydney.
- The Intellectual Disability Service, and Older Persons Mental Health which is linked with the Centre for Healthy Ageing Brain, UNSW
- The Australian Veterans' Brain Bank, founded by Royal Prince Alfred Hospital's Head of Neuropathology, in partnership with the National Centre for Veterans' Healthcare at Concord Hospital is an initiative to help understand the impact of head injuries among the nation's veterans.

Workforce development

Quality healthcare relies on a skilled and supported workforce.

Caring for people with dementia in any setting requires skill, compassion, patience and empathy. These expert staff provide clinical leadership and support across the District, role modelling and supporting other staff to create a skilled workforce.

The role of inpatient senior nursing staff is essential to provide clinical leadership, education and consultancy within their field of care [46]. Aged Health senior nurses can provide this for dementia care, with extensive experience existing within the District. Skilled dementia senior nursing staff should be available in all Sydney Local Health District inpatient, ambulatory and community settings.

Currently there are no mandatory training programs or courses for District staff including those working in aged health. Forty five per cent of consultation survey reports stated they had no dementia training, with 100 per cent of respondents indicating they provide care to people with dementia (Appendix 14.1: Consultation Report). Some staff may choose to undertake self-directed learning via My Health Learning or Sydney Education – for example Graduate Certificate in Aged Care for nursing, or various external programs for example, University of Tasmania Understanding Dementia Massive Open Online Course or Graduate Diploma in Dementia, but this is rare. The high level of expertise that exists within Sydney Local Health District could be used to provide training for staff, including in-house training in BPSD management.

Support of staff who are carers or care for people with dementia is required to maximise staff well-being and effectiveness. De-briefing, counselling and protected time may be required. This can be provided by the Employee Assistance Program (EAP), or via colleagues and managers.

While not specific to dementia care, career pathways, succession planning, staff rotation schemes, and supporting a diverse workforce are all areas of need for the health workforce generally.

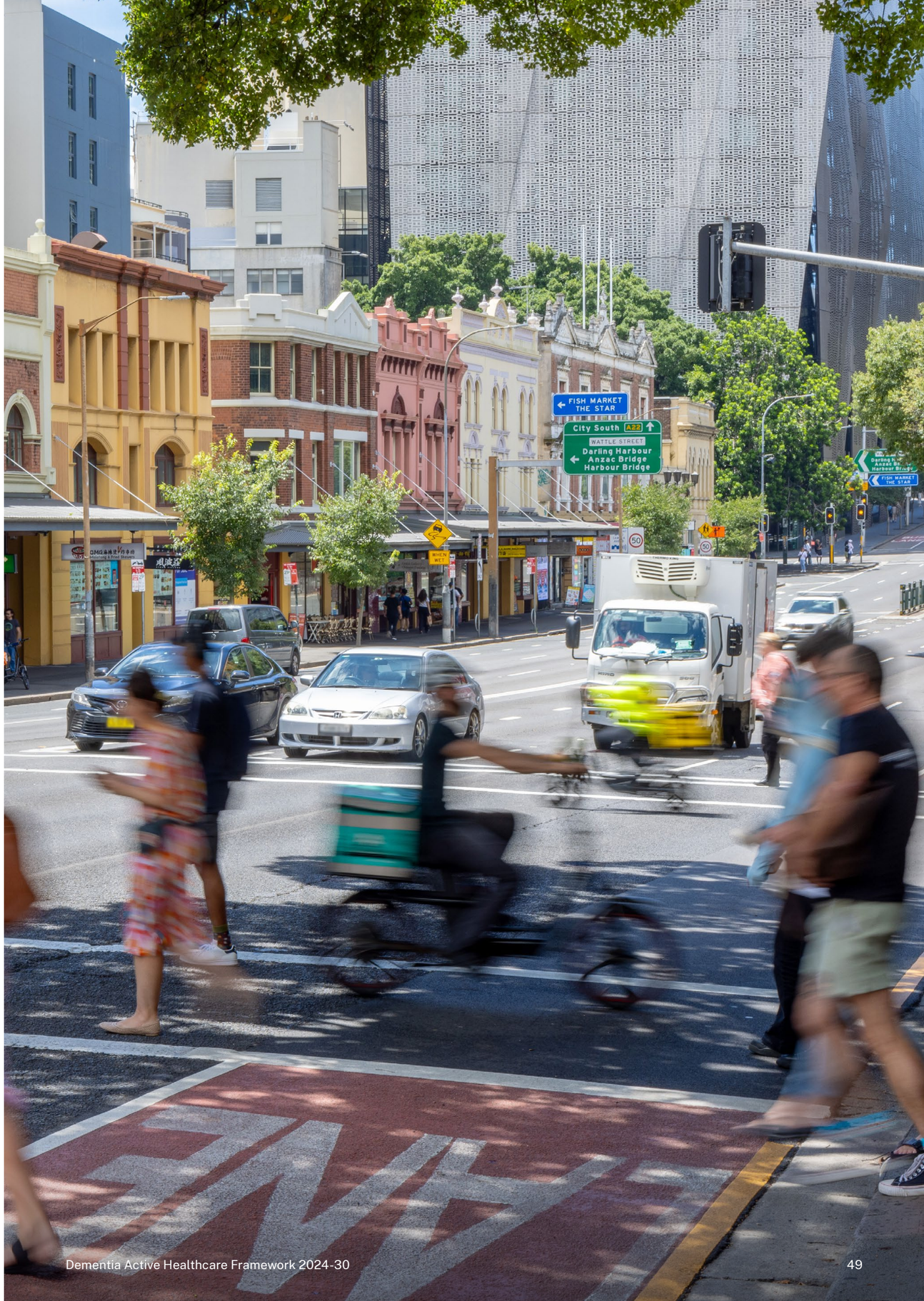
Dementia Active Healthcare Roadmap 2024-30

	Dementia Roadmap 2024–30	Timeframe	Resources
1	Establish Dementia Roadmap Steering Group to oversee development and implementation of the Dementia Active Care Roadmap • Representation of District services and targeted vulnerable groups • Representation from primary care, consumers (including carers) and vulnerable population groups • Advice relating to roadmap activities • Performance measures to monitor and report on progress • Lead position to provide leadership, coordination and reporting on roadmap activities	Short term (< 1 year)	Lead; Quarterly Committee Meeting commitment by members
2	Document and develop a repository for dementia specific service information, initially for staff, then consider external facing site • Leverage existing digital platforms and programs for a consistent approach to centralised information • Generate intelligent solutions to internal service navigation and maintaining current data • Facilitate links between dementia services within the district to support integrated services • Link internal processes to repository – for example cognitive screening pathways • Maintenance of Health Pathways navigation for Primary Care • Health literacy processes to reach scope of target audience	Short term	Existing internal Digital, Health and Innovation support, health literacy protocols/workforce, annual review by services within existing internal workforce, Central and Eastern Sydney Primary Health Network partnership, including Health Pathways

	Dementia Roadmap 2024–30	Timeframe	Resources
3	Determine interventions within Sydney Local Health District scope as a basis for a suite of dementia services including ‘dementia hub’ • Multidimensional care and management strategies to promote equity and holistic care • Link to Sydney Local Health District dementia services • Identify partnerships and key opportunities to engage sectors external to healthcare • Create a flexible approach to allow for new services and partnerships in the dementia service scope including future funding opportunities • Centralised dementia service access point for all people with dementia and their carers in the district • Support innovative, proactive dementia care opportunities • Develop carer-support initiatives to address unmet needs • Promote Sydney Local Health District dementia services and dementia hub widely • Identify and target specific needs of vulnerable groups	Short term	Physical space, new ongoing funding
4	Develop and lead a sector-wide Dementia Community of Practice bringing together all stakeholders • Support community partners to navigate and interpret healthcare systems and supports • Provide healthcare inputs to local dementia initiatives • Seek involvement of vulnerable groups and consumers to promote inclusive and diverse representation • Provide opportunities to a range of staff to share inputs	Short term	Nominated convenor, existing workforce to provide expertise

	Dementia Roadmap 2024–30	Timeframe	Resources
5	Analyse equity and access to current Sydney Local Health District services, and implement remedial actions • Identify structures and models of care to support best practice dementia care for vulnerable communities • Determine suitable resourcing of all services for best practice care • Equitable key workforce across the district, and within facilities	Medium term (2-4 years)	Internal Digital, Health and Innovation and Performance Unit expertise; new funding
6	Conduct an environmental ‘dementia-friendly’ audit of Sydney Local Health District facilities • Existing facilities and new/re developments to meet dementia-friendly guidelines to create safe and supportive environment for people with dementia • Culturally safe care spaces • Environmental capacity to manage BPSD throughout all facilities and clinics • Identify adaptable space for new technologies and therapies – for example therapeutic modalities, pathology capabilities	Medium term	Facility representatives, Disability Inclusion Action Plan
7	Agree on standard activity data collection District-wide, including identifying people with dementia and their carers • Utilisation of standardised measures for data collection and analysis across all services • Generate a profile of the dementia cohort in Sydney Local Health District • Capture consumer/carer satisfaction measures • Support the personal identity of consumers within Sydney Local Health District within the medical record systems • Support carer identification within internal dementia processes	Medium term	Internal Digital, Health and Innovation and Performance Unit expertise, digital technologies

	Dementia Roadmap 2024–30	Timeframe	Resources
8	Develop a dementia training pathway for staff, including BPSD • Mandatory training module on quality dementia care for all staff focusing on the Sydney Local Health District Dementia Principles of Care • Vulnerable group services supported to include dementia training pathway for staff • BPSD management education and strategies developed and available to all staff • Opportunities for innovative development of skills and approaches to dementia care • Support services to provide regular care to consumers with dementia as a secondary presentation	Medium term	Sydney Education expertise, dementia experts to inform content of training
9	Analyse the District's resources against expected population growth, clinical developments and necessary business cases • Use routine data to review capacity and scope of existing services against population growth • Develop specialist allied health positions and services within context of funding shifts and reallocation • Maintain Dementia Active Healthcare Framework Principles of Care within our services • Adapt and translate research into practice • Increase capacity to implement future therapeutic modalities	Long term (5 years+)	Planning Unit, Performance Unit
10	Evaluate the Sydney Local Health District Dementia Active Healthcare Framework and further develop broad dementia research • Progress reports at fixed time points to maintain short, medium and long term goals • Develop and implement original research to determine current service effectiveness and future planning	Long term	New funding (research)



Key documents

Key documents informing this project

- World Health Organisation Guidelines: The Global Action Plan on the Public Health Response to Dementia 2017-25
- Risk Reduction of Cognitive Decline and Dementia: World Health Organisation Guidelines 2019
- National Dementia Action Plan Consultation Paper (November 2022)
- Australian Government Intergenerational Report 2023 at a Glance
- The National Framework for Action on Dementia 2015–19
- NSW Health State Health Plan: Future Health Guiding the next decade of care in NSW 2022-32
- 1997 Aged Care Act
- The National Safety and Quality Standards
- The Aged Care Quality Standards (Quality Standards)
- Royal Commission into Aged Care Quality and Safety
- Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability
- The Australian Government 2017 Aged Care Diversity Framework and associated action plans
- The Clinical Practice Guidelines and Principles of Care for People with Dementia: NHMRC and Cognitive Decline Partnership Centre, and Implementing guideline recommendations into practice; A companion document for the Clinical Practice Guidelines and Principles of Care for People with Dementia
- NHMRC; Strategic Roadmap for Dementia Research and Translation, Aboriginal And Torres Strait Islander Roadmap For Dementia Research And Translation, and Culturally and Linguistically Diverse (CALD) Dementia Research Action Plan
- Sydney Local Health District Strategic Plan 2018-23, as well as consultation into proposed 2024 onwards plan
- Sydney Local Health District Aged Health, Rehabilitation, General Medicine, Chronic And Ambulatory Care, Endocrinology, Andrology And General Practice Clinical Stream Position Paper 2020-25
- Previous Sydney Local Health District Dementia Action Plan 2013-18 and progress reports
- Sydney Local Health District Equity Framework
- Sydney Local Health District Population Health Strategic Plan 2019-24
- Intersectoral Homelessness Health Strategy 2020-25 and NSW Homelessness Strategy 2018-23
- Sydney Local Health District Digital Health Strategy 2022-27
- Clinical Principles for End of Life and Palliative Care; NSW Health and Agency for Clinical Innovation (ACI)
- NSW Health End of Life and Palliative Care Framework 2019-24
- Future planning and advance care planning: Why it needs to be different for people with dementia and other forms of cognitive decline Cognitive Decline Partnership Centre and Hammond Care, 2016 (best practice for dementia end of life care)
- Palliative Care and Dementia; Palliative Care Australia and Dementia Australia
- The Assessment and Management of People with Behavioural and Psychological Symptoms of Dementia ("the BPSD Handbook") from NSW Health and the Royal Australian and New Zealand College of Psychiatrists
- RACGP Aged Care Clinical Guide (Silver Book), Silver Book – Part A: Behavioural and psychological symptoms of dementia, published by the Royal Australasian College of General Practitioners,
- Behaviour Management: A Guide to Good Practice, Managing Behavioural and Psychological Symptoms of Dementia (BPSD) by Dementia Collaborative Research Centre
- Extreme Behavioural and Psychological Symptoms of Dementia (BPSD) Project Report, NSW Health
- 2023 Commonwealth Closing the Gap Implementation Plan, National Indigenous Australians Agency
- NSW LGBTIQ+ Health Strategy 2022-27
- Veteran Mental Health and Wellbeing Strategy and National Action Plan 2020-23
- The Sydney Local Health District Framework for Working with Cultural and Linguistic Diversity
- Sydney Local Health District Culturally and Linguistically Diverse Health Strategic Plan 2022-26
- Australia's Disability Strategy 2021-31 and supporting documents
- NSW Regional Health Strategic Plan 2022-32
- National Aboriginal and Torres Strait Islander Health Plan 2021-31

Aboriginal Health Impact Statement

The Sydney Local Health District Dementia Active Healthcare Framework and Roadmap has been developed in a collaborative and detailed analysis of the current and future needs of the District to provide the best quality of life and healthcare for people with dementia in our district.

The impact of dementia on First Nations people is significant, dementia is currently the second leading cause of death for the Australian population, and First Nations populations experience dementia at 3 to 5 times the rates of the general population.

Sydney Local Health District is committed to equity principles, recognising the need to provide innovative and flexible healthcare options in order to meet the needs of every individual. Structured by available guidelines, best practice and research, the process of developing the Sydney Local Health District Dementia Active Care Framework has been consumer informed and collaborative to permit ownership and applicability to the unique Sydney Local Health District community.

The life-course of dementia disease is often fragmented, causing incomplete or complex navigation of care. First Nations people face many barriers to all aspects of dementia care, from cognitive screening, awareness of the disease, appropriate and timely assessment and diagnosis, ongoing management, through to end of life care. Working towards these issues in a planned and collaborative way via the Sydney Local Health District Dementia Active Healthcare Roadmap 2024-30 will improve the dementia care that is provided to First Nations people in Sydney Local Health District.

The health context for Aboriginal people

Dementia can have a profound impact on First Nations populations. Dementia affects more than just the individual, it extends to the family, carer and social supports that surrounds them. Each person is affected in different ways, requiring a biopsychosocial approach to provide appropriate care.

Studies have consistently found that dementia prevalence rates for urban, rural, regional and remote dwelling First Nations populations are 3–5 times higher than rates for Australia overall, with more men affected than women, contradictory to the overall Australian data affecting more women. These figures are amongst the highest reported in the world [36].

Onset of dementia symptoms in First Nations people occurs 10-15 years earlier than the general population [36]. It is well documented that a diagnosis of dementia in the general population can take up to 4 years for an accurate diagnosis. With no specific estimates for First Nations people available, the general health service uptake within First Nations populations is much lower which could lead to a longer delay in diagnosis.

The types of dementia common in First Nations populations reflect the same contributing types as the total Australian population and populations worldwide, with Alzheimer's Disease the main form. While some risk factors are unknown or not modifiable, a preventive approach is required, focusing on reducing the prevalence of common risk factors for physical and mental health rather than on specific disease or medical specialities [47].

The Aboriginal and Torres Strait Islander Health Performance Framework – Summary report July 2023 summarises the latest information relating to First Nations health status in Australia. Dementia is not a leading cause of death or contributor to burden of disease for First Nations people, with neurological conditions grouped together accounting for just 4-5 per cent of total disease burden. However the burden of disease among First Nations people is 2.3 times higher than non-Indigenous Australians.

Latest figures from the report show deaths due to cardiovascular and kidney disease have declined for First Nations populations in 2010-19. Other relevant positive changes over time include an increase in health checks, and chronic disease management service utilisation. Trends reflective of this in the general Australian population data has contributed to the rise in dementia, and this could be mirrored in First Nations populations with a continuation of these changes.

The Stolen Generation survivors are now aged over 50 years and eligible for aged care sector support [36] [48]. This population has experienced significant trauma which is associated with a higher risk of developing dementia. This is coupled with a negative association towards government and church affiliated organisations such as state health services and community and residential service providers. Dementia is a progressive, life-limiting disease that can necessitate supports beyond family and friends, often including government and service provider supports.

Navigating dementia care can be complex, as it is a collection of diseases rather than a single disease, with large variability in presentation, risk factors and treatment. The stigma surrounding dementia, cultural understanding of dementia, and terminal nature can present barriers to seeking care or accepting a diagnosis, with factors present that affect all chronic disease detection such as perceived lack of culturally specific services, financial costs, and many competing priorities within family and communities. Other confounding factors are the interplay between the NDIS and aged care systems, as well as their internal navigation as a standalone issue.

The National Aboriginal and Torres Strait Islander Health Plan 2021–31 acknowledges dementia with the objective: Enhance access to aged care services that integrate place-based, culturally safe and trauma-aware and healing-informed care. The Final Report of the Royal Commission into Aged Care Quality and Safety addressed First Nations aged health care priorities with similar recommendations. Many standards, guidelines and information exist regarding dementia care, as outlined in the Sydney Local Health District Dementia Active Care Framework, with the aim for these to continue to provide the overarching quality and direction of the District's services, while remaining relevant to updates and new developments. There are existing documents guiding the provision of healthcare to First Nations populations, including for aged care services such as the Closing the Gap Implementation Plan 2023, Aged Care Diversity Framework, and those mentioned above.

Sydney Local Health District has many services to meet the specific community needs, including First Nations, and dementia populations. The Framework aims to review and unite the suite of services available to people with dementia, considering best practice and research, current services available and future predictions.

The potential impact of the policy, program or strategy on Aboriginal people including approaches to mitigate any potential undesired effects

The aim of the Sydney Local Health District Dementia Active Healthcare Framework is to create a cohesive and united approach to providing dementia care. It considers the current strengths and future direction of the service provision in Sydney Local Health District and aims to work towards strategies to address these and meet best practice care standards. The vision for Sydney Local Health District Dementia services is relevant to all individuals and population groups, committing to the value of individualised care. This extends to the social, economic and cultural context, recognising the unique considerations and needs of First Nations people. Recognising each individual within the context of their larger social and cultural relationships and is culturally safe [49].

The background consultation completed for the development of this Framework found that dementia data is scarce, and therefore could not inform the documentation or describe specific groups such as prevalence rates of First Nations populations. Subjective and anecdotal consultation found that First Nations people do use the dementia services in the district, with cultural support for mainstream services available. The Roadmap aims to continue these initiatives and partnerships and improve data and service monitoring to plan for the future. By planning data capture, initiatives and research to specifically record information relating to First Nations populations, it will be possible to strengthen the service availability and connections between services for the future.

Interventions and treatments for dementia are varied according to individual diagnosis and based upon preferences for care rather than a simple prescription of therapy. There are many different services and information sharing points with relevant information. This Frameworks seeks not to add to this but work in ways to make useful information available to broader staff groups and consumers to better meet needs and improve the experience of finding appropriate care.

It is documented that providing dementia care to First Nations people requires consideration of the individual and the culture important to them. The Focus Areas of dementia detailed in the Sydney Local Health District Dementia Active Healthcare Framework each require cultural appropriateness for safe delivery of dementia healthcare.

Key considerations for dementia focus areas

Dementia Awareness	The interpretation of dementia symptoms can be complex. A dementia query generally arises from those closest to the person, recognising changes in usual behaviours. First Nations people may have different cultural and social environments and have exposure to differing social networks to the general population, so targeting symptom identification and surrounding social structures appropriately is necessary. General chronic health prevention strategies also relate to dementia prevention such as managing high blood pressure, obesity and physical inactivity [47]. Any risk management strategies would bring about a positive impact on health.
Dementia Diagnosis and Assessment	A First Nations diagnosis tool, the Kimberly Indigenous Cognitive Assessment (KICA) is available for use, with a modified version for regional and urban dwelling people if an adapted tool is considered most appropriate by the treating team. Appropriate carer identification is important.
Ongoing Clinical and Medical Management	Partnering with Aboriginal Community Controlled Health Services ensures culturally safe care, with the Redfern Aboriginal Medical Service located within Sydney Local Health District, an essential service for First Nations people. Sydney Local Health District Geriatricians provide an outreach clinic at the Aboriginal Medical Service, as well as co-located services such as the HIV Community Allied Health team. Wyanga supports First Nations people in Sydney Local Health District by providing NDIS supports and aged care services specifically for First Nations populations. The Aboriginal Health Unit works towards providing appropriate care throughout all NSW Health facilities and services.
Behavioural and Psychological Symptoms of Dementia	The NSW Health Assessment and Management of Behaviours and Psychological Symptoms associated with Dementia (BPSD) A Handbook for NSW Health Clinicians providing services for people experiencing BPSD has a section relating specifically to First Nations people.
Residential Care	There are no First Nations specific or run residential care facilities within Sydney Local Health District, however all accredited providers must provide culturally safe care via the Aged Care Standards. Guidance and resources have been developed to educate on the residential care experience reflecting the institutionalised care experienced by the Stolen Generations and those who have been removed by their families. Approaching this appropriately must be standard. Sydney Local Health District provides a residential care facility at Yaralla House for people with an HIV associated dementia diagnosis, which may at times provide care for First Nations residents.
End of Life Care	The NSW Health End of Life and Palliative Care Framework 2019-24 outlines principles of care with consideration of First Nations populations. Western approaches to death and dying may not be appropriate for First Nations people, mainstream approaches must be matched to the needs of the individual. Resources such as the Indigenous Program of Experience in the Palliative Approach (PEPA)'s Cultural Considerations: Providing end-of-life care for Aboriginal peoples and Torres Strait Islander peoples can support our staff.

There is limited research in the area of dementia in First Nations people. The National Health and Medical Research Council (NHMRC) National Institute for Dementia Research (NNIDR) Aboriginal and Torres Strait Islander Roadmap for Dementia Research and Translation document provides current guidance. Monitoring and evaluation will ensure translational data is captured and analysed, services remain relevant, and meet the needs of the community.

The Framework includes a Roadmap of actions to 2030 and will develop a steering group to advise and participate in the implementation of the actions. Representation within the Roadmap will be an important part of the strategy to ensure the identified vulnerable populations including First Nations people will monitor and advise on the actions.

Engagement with Aboriginal people

The National Dementia Action Plan currently in development, and the previous National Dementia Framework specify the need for targeted care for First Nations populations, however as yet no specific details have been provided. The Sydney Local Health District Dementia Active Healthcare Framework sought consultation from Sydney Local Health District staff as individuals and teams and aligns with Sydney Local Health District Strategic Plans and overarching key consultations. The following methods were completed, ensuring all vulnerable groups were given a voice, including First Nations staff and services:

- Literature search, current research, statistics, relevant documents and standards
- Consultation with teams/specific services for First Nations populations
- Open consultation for all staff and partners to contribute
- Consideration of culturally specific care and best practice within the current services and facilities and the future
- Identification and recognition of partnerships important in providing culturally safe care including community supports
- Statements and inclusion in report documentation relating to vulnerable groups

Specifically targeted consultations with the Director of Aboriginal Health Services, the Aboriginal Planned Care Program and Aged Health who provide a Geriatrician Outreach service in partnership with the Aboriginal Medical Service provided initial input. District wide services including Population Health, Community Health and RPA Virtual were included which all have First Nations specific services or positions. A district wide staff survey was available to all staff to provide their input into the dementia consultation process which provided further detail of available services and their experiences in providing dementia care. This included the HIV Allied Health Community team which provide services from the Aboriginal Medical Service Redfern clinic.

Important partnerships with the Aboriginal Medical Service, and aged care providers have been considered, with the scope of the Framework currently focusing on Sydney Local Health District's specific service provision role within holistic dementia active health care. Each consultation discussed care provision to vulnerable groups, and strategies used to match care requirements. The consultations placed importance of the Aboriginal liaison officer positions, outreach and services provided at the Aboriginal Medical Service, linkages with services of high frequency by First Nations populations, gender matching of health professionals with the patient/consumer (men's business/women's business), and flexibility of care.

The Roadmap developed as an outcome of the Framework outlines actions to work towards 2030 to provide the best quality of life and healthcare for First Nations people with dementia.

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Appendix

Consultation Report

The Sydney Local Health District Dementia Active Care Services Framework was initiated by Aged Health with the view to bring together the wide range of dementia key documents, plans, guidelines and supporting information, and analyse these in relation to the District's dementia services. The aim of this consultation was to include the whole of Sydney Local Health District, targeted services and positions, and external stakeholders including consumers to produce a comprehensive, inclusive analysis.

From here a Framework and Action plan were created to work towards improving the overall service delivery and experience for consumers and staff, providing a voice for all those consulted.

To gain the most representative and inclusive scope, a list of streams, clinical specialties, positions and teams was developed in order to allow for the input from everyone in the District.

The stakeholders targeted included:

- Facility Heads: Royal Prince Alfred Hospital, Concord Repatriation General Hospital, Canterbury Hospital, Balmain Hospital, Sydney Dental Hospital
- Aged Health Chronic Care & Rehabilitation
- Nursing
- Allied Health: Social Work, Physiotherapy, Nutrition and Dietetics, Occupational Therapy, Speech Pathology
- Mental Health
- Palliative Care
- RPA Virtual
- Consumer Participation
- Population Health
- Neurology
- Aboriginal Health
- Performance Unit
- Sydney Education
- Planning
- Carer Program
- Community Health
- Various vulnerable communities
- Multiple carer groups
- Non-Government Organisations in the district

Face to face and virtual consultations were held with teams and individuals to understand the context, challenges and future of dementia care. In total, more than 140 people provided their expertise, comments and opinions on Sydney Local Health District dementia services and dementia care as a whole. Focus groups with two existing dementia carer groups and internal Sydney Local Health District communications and networking were also completed.

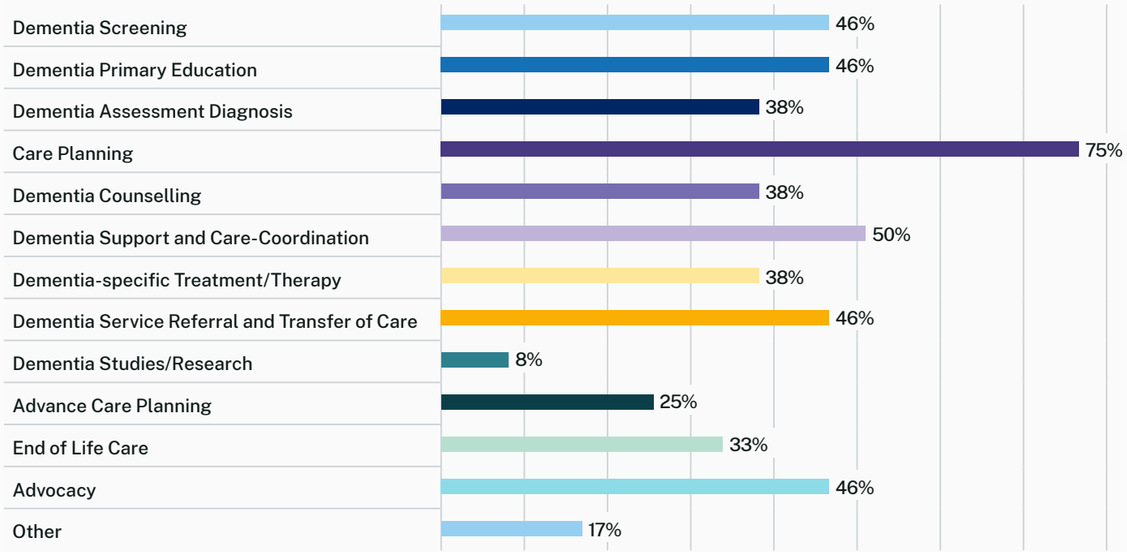
Key themes and details have been included in the final report.

Dementia Survey Summary

An electronic survey was developed and sent to all services within Sydney Local Health District via managers, and placed on staff bulletin boards accessible to all staff. Twenty-four written survey responses were collected from staff. Further follow up was provided over the phone or in person if information was available to be expanded upon. Some information provided has been de-identified for the purpose of this report.

Survey responses are as follows:

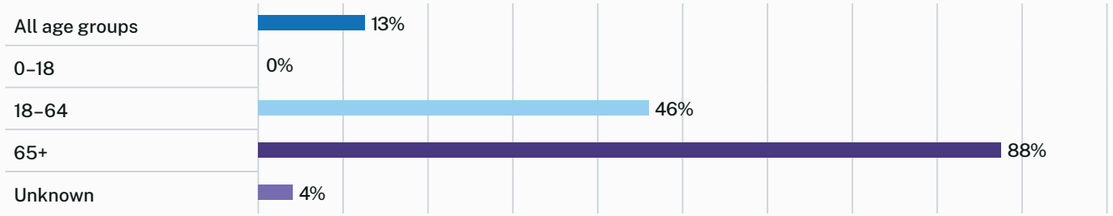
1. **Which ward/service do you work in?**
2. **Do you provide care to people living with dementia, and/or their carers in your current role?**
   100 per cent of respondents answered yes
3. **What aspects of dementia care does your service provide?**



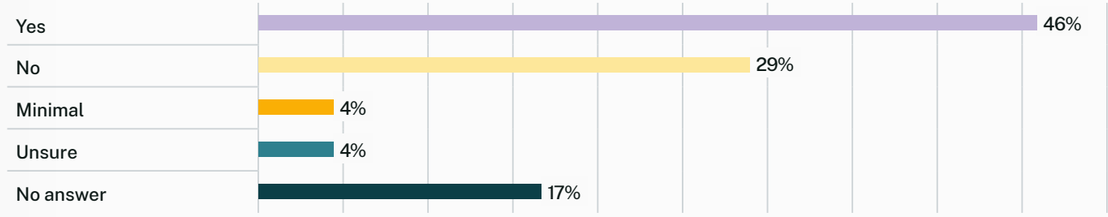
The 16.7% who answered 'other' noted the following:

- Nutrition
- Assisting in ensuring Top 5 strategies are in place and families bring familiar items for patients on the ward
- Mental health diagnosis for patients with an overlap/co-morbidity

4. **Which patient age group does your service provide care for?**



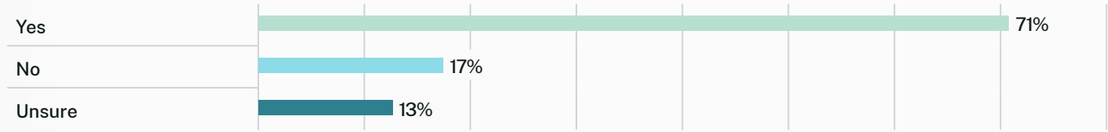
5. **Does your service provide any dementia-specific adaptations (for example adapted communication strategies, adapted functional options)?**



The 45.8 per cent who answered 'yes' noted the following:

- Diversional cart, security or AINs for specialling
- Equipment and home modifications, orientation clocks, personal alarm systems, bed and chair alarms
- Re-orientation strategies
- Dementia-specific behaviour management plans
- Dementia specific dysphagia education handouts for families/carers
- Adapted communication styles
- Dementia specific communication strategies acquired as part of the job and from Dementia CNC

6. **Do you refer people with dementia on to other services?**

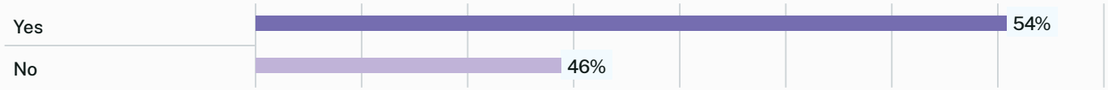


The 70.8 per cent who answered 'yes' referred to the following services:

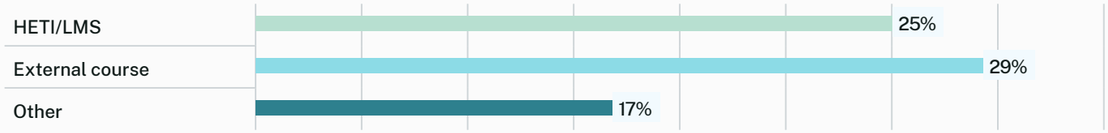
- Ward 17, Dementia Advisory Service, DBMAS, RACF Outreach, Severe Behaviour Response Team
- MyAgedCare, Carer support services, Dementia support services
- CHSP, Home Care Packages, residential care
- ACAT, RAS, Dementia Australia, Dementia Support Australia, Carer Gateway
- Sydney Local Health District Geriatricians, local Day Centres, social support groups
- Uniting Dementia Café (Leichhardt), relevant CALD organisations
- Older persons mental health services
- ADAHPS, Neuropsychology, Yaralla
- Young dementia clinic in neurology
- Sydney Local Health District dementia advisory service
- Home Based Therapy
- Day Hospital service at RPA for ongoing speech pathology service in the community
- Social workers, outpatient physiotherapy follow up, COMPACKs

7. Would you know where to refer people living with dementia, and/or their carers?

8. Have you completed any dementia-specific training in your role?



9. Was the training provided by:



The 16.7 per cent who answered 'other' noted the following:

- Geriatric Medicine training
- Short courses provided through Dementia Australia and similar organisations
- A mix of training over the years

10. 87.5 per cent of respondents provided additional comments:

- Communication, problem solving, entertainment and educational services, patient focused additional care specific to unique needs, behavioural management in dementia, appropriate non-pharmaceutical management, when pharmaceutical management is appropriate, family education with simplified educational pamphlets/ written information
- Patience, emotional care and overall wellbeing

- Carer identification – many carers do not identify as such as they perceive their input to be based on their relationship to the individual i.e. wife, daughter etc.
- Carer health and wellbeing – many carers neglect their own health and wellbeing as they prioritise the needs of the person they are caring for
- Awareness of carer supports – many carers and staff are not aware of the Carer Gateway, the National Network of support for carers, impacting on uptake of carer dedicated services

- Not enough day care/day centres, community-based education/behaviour support/counselling, inpatient environments suitable for needs of dementia patients (esp. ED), resources/supports for carers of inpatients, education/support for inpatient staff caring for dementia patients

Suitable facilities:

- Appropriate dementia specific facilities at RPA hospital (behavioural unit)
- Inpatient geriatric wards not equipped to manage delirium (for example dining room for mobile dementia patients, diversional therapy, music and art therapy, pet therapy etc)
- Appropriate RACF discharge facilities for BPSD patients and appropriate training to RACF staff

- In home support, home visits to assist with social support and to be an extra set of eyes on at home. What I describe is a service that can visit a home, see what is needed and provide support to that carer and patient: a ComPacks service for dementia

- Need for more flexibility/reliability in relation to respite care (both in home and residential); more options in relation to carer support (for example different groups/workshops to meet different needs); a clearer pathway of support following diagnosis (for example access to cognitive stimulation programs; exercise and evidence based therapies)
- Better access to case management, especially at key points (for example accessing services through CHSP/HCP; assisting with identifying appropriate residential care)

- Too many to discuss in a survey

- Regular diversional therapies
- Adequate staffing in ACF and community services to provide specialised dementia services
- Basic training for carers on how to manage agitation, confusion or aggressive behaviour from their loved one

- Lack of services (for social support) in a client's area (Redfern)
- Unclear what referral pathways there are
- Many services aimed at carer and not client (a client with early onset mild form of dementia who is currently independent with all activities of daily living)

- Someone with dementia needs to care navigate a complex and fluid environment with no set pathways

- Overall, very limited support for carers – difficulty accessing CHSP services, difficulty navigating MyAgedCare system, limited financial support for carers (for example getting assistance to complete Carer`s Allowance or Payment, CAPS for continence products), limited dementia specific residential care, limited day centre respite options in local area
- Limited resources and care for clients and carers from diverse cultural background

- The gap between disability support and dementia support. Often our patients are under 65 years. Training for paid carers is not always available and although it should be provided by the employer it isn't always. Now Sydney Local Health District has a dementia OT back, I am hopeful to link together for some of our patients

- Lack of services available
- Follow up support in community
- In home respite options as wait times can be long

- Lack of appropriate care facilities and funding for individuals with Dementia on a background of mental health difficulties. This has become increasingly difficult for consumers over the age of 65 who cannot access the NDIS
- Limited understanding of the various forms of dementia and identifying early warning signs

- Trained staff in dementia care

- Access to and understanding of services available
- Education about the illness and its management

- Supports ongoing if managing diet/fluids in acute hospital, but suspect/expect further deterioration in community
- No current service that provides ongoing dementia specific Speech Pathology communication and swallowing services
- No current service that has the capacity to provide detailed education and supports to carers for dementia-related communication impairments
- A gap in our district for primary progressive aphasias

- Knowledge about available services (for example care services, dementia day care, in home respite), navigating MyAgedCare, information about dementia specific pharmacotherapies, education about BPSD and how to manage the symptoms, role of antipsychotic medications, tools to navigate advance care planning as well as formulation of will, appointing Enduring Guardian and power of attorney

- The road to diagnosis of dementia, especially younger-onset dementia is difficult for almost all families I've come in contact with. Better education for medical profession is required
- Support for carers
- Support for patients and more behavioural management techniques (i.e., non-pharmacological)
- Better support for non-metro patients and families
- Education and resources should be more easily found for carers as many have mentioned it's been hard to find information easily
- Better information about progression, what to expect, why apply for NDIS/My Aged Care early in the process
- Education re: legal aspects (Advanced Care Planning, Power Of Attorney, etc)

- Support for carers
- Identifying respite options

- Clinical psychology services, including a specific education/training role (similar to dementia CNCs or CNEs); dementia day-programs; behaviour management support including assessment, monitoring, intervention, for carers/staff within the hospital (inpatient/outpatient) and in the community

11. Please provide any additional comments:

- A directory of services in Sydney Local Health District and externally
- Behavioural issues with dementia, Mental Health or dissociative disorder are becoming an everyday presentation to emergency departments for home and RACFs
- Management plans on patient in RACF for patients with known behaviour issues. Discharge to RACF's without specific plan or referral to specific services

- I believe we as a district do not manage dementia/Alzheimer's effectively on the wards. We do not have the skills, time or staffing

- A more coordinated approach to assisting clients with dementia and their carers across Sydney Local Health District would be great
- Also, more training of staff is vital on how to assist clients and carers

- Activity room for dementia specific activities

- Often a difficult terrain for both care workers and the families to navigate

Dementia data

Planning Unit data

Below is hospital admission data for financial years 2015/2016 – 2021/2022 for all Sydney Local Health District facilities with the primary diagnosis of 'dementia' by episode and average length of stay (ALOS). Dementia is not listed in the top 20 Diagnostic Related Groupings (DRGs) for clinical specialties but should be more closely analysed by the Performance Unit.

The data below reflects only 320-400 episodes every financial year reflecting significant under reporting. A review of this data by age notes an increase in younger people being identified with dementia, but this is a very small number. It appears that people are generally admitted under the specialty they require – for example cardiac for chest pain, but may not have existing dementia coded unless it is documented clearly.

	July 2015–June 2017		July 2017–June 2019		July 2019–June 2021		July 2021–June 2022*	
	Episodes	ALOS	Episodes	ALOS	Episodes	ALOS	Episodes	ALOS
Balmain Hospital								
65–74 years	1	6	1	7	5	5		
75–84 years	2	7	4	12	23	28	7	10
85+ years	8	16	10	23	24	46	17	76
Total/Average	11	10	15	14	52	26	24	43
Canterbury Hospital								
60–64 years	1	20	1	5				
65–74 years	7	27	9	68	7	19	9	54
75–84 years	31	50	42	49	45	75	27	73
85+ years	58	83	46	59	67	122	27	139
Total/Average	97	45	98	45	119	72	63	89
Concord Hospital								
40–64 years	12	11	6	20	21	25	5	19
65–74 years	31	31	32	38	35	35	18	45
75–84 years	102	71	142	77	113	88	52	144
85+ years	144	73	177	104	151	109	57	99
Total/Average	289	47	357	60	320	64	132	77
Royal Prince Alfred Hospital								
17 – 29 years					2	5	1	5
30 – 54 years	6	35			4	8	1	19
55 – 64 years	15	25	10	31	4	46	4	30
65 – 74 years	33	58	27	39	46	100	16	52
75 – 84 years	85	69	93	87	117	148	44	148
85+ years	91	114	85	121	113	111	57	147
Total/Average	230	60	215	70	286	70	123	67
Grand Total/Average	627	40	685	47	777	58	342*	69

*12 months

Concord Hospital Performance Unit Data:

1/7/2021 – 30/6/2023 discharges from Concord Hospital

2897 of total discharges from Concord Hospital (including mental health services) in this two year period were coded with one or more of the 56 unique dementia codes. Multiple codes are possible and some individuals had several.

The following applied to these patients:

- Age range = 28– 106 years
- Average age = 84years
- Length of stay range = 0-722 days
- Average length of stay = 19 days
- 7 patients had a length of stay > 1 year,
  3 x JARA, 3 x Ward 17, 1 x Ward 2B
  Age range 53-77 years
- 3% of discharges were people <65 years
- Average length of stay for those with dementia aged <65 years = 59 days

Concord hospital had a total of 99,995 discharges in this 2 year period.

Concord Hospital Cognitive Disorders Service Data

	Routine service	Service with Neuropsychology	General geriatrician / home visit
Jan 2022 – Dec 2022	106	59	409
Jan 2023 – Jun 2023	51		236

Royal Prince Alfred Hospital Memory and Cognition Clinic Data

Total number of patients seen by Neurology and/or Geriatrics:

	Neurology	Geriatrics	Total
July 2018- June 2019	493	328	821
July 2019- June 2020	698	359	1057
July 2020- June 2021	697	427	1124
July 2021- June 2022	573	241	814
July 2022- June 2023	662	385	1047

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