

Living Well with Dementia

Brisbane North PHN Regional Dementia Strategy 2020-23

SUMMARY

Version 3 – August 2021

About this strategy

Living Well with Dementia, Brisbane North PHN Regional Dementia Strategy 2020-2023, was developed by the Dementia Centre for Research Collaboration at Queensland University of Technology. The strategy's scope is to develop recommendations for priority initiatives over the three-year period to improve access to services and improve quality of life for people living with dementia in Brisbane North. The recommendations are based on knowledge of existing services and draw on findings from extensive engagement with local healthcare professionals, people living with dementia and their carers (consumers).

Dementia describes a collection of symptoms that are caused by disorders affecting the **brain. It is not one specific disease. Alzheimer's disease is the most common cause of dementia**, however, many other disorders can also contribute to the symptoms. Symptoms can include impaired memory, changes in thinking, and behaviour and changes in the capacity to act independently. These symptoms can make everyday activities difficult. While dementia typically affects older adults, younger people and children can also be affected. Carers – most often the spouse or child of the person living with dementia – while finding caring rewarding, are prone to stress and burnout, particularly as the disease progresses and care needs increase.

Good quality of life for people living with dementia and their carers relies on appropriate support from health professionals. Focus groups that were engaged in the development of this strategy reported that existing services are unequally distributed and do not always meet individual needs. People living with dementia, their carers, people concerned they may have dementia, and health care professionals also find navigating the health system and accessing services difficult and confusing.

This strategy aims to enable people affected by dementia to know how to find high quality care services, to be involved in decisions about care, and to seek help early regarding concerns about changes in memory, behaviour, or functioning.

Existing dementia services, systems and structures in Brisbane North

Current services in the Brisbane North region include:

- **Primary care services:** General practitioners (GPs), allied health professionals, nurse practitioners, psychologists, pharmacists, and dentists
- **National services:** My Aged Care; residential aged care facilities; and Dementia Australia (DA), Dementia Support Australia (DSA), and Dementia Training Australia (DTA)
- **Community-based services:** Brisbane North PHN, carer support organisations, respite care, in-home nursing, allied-health and support services; the Complex and Chronic Disease Team, Transition Care Program, Post-Acute Care Service, and Memory Clinics
- **Hospital-based services:** Memory and specialist clinics; Metro North Hospital and Health Service (MNHHS) community services; The Prince Charles, Royal Brisbane and Women's, Redcliffe, Kilcoy, and Caboolture hospitals; and private hospitals.

Pathways to access these various services are not always clear to consumers, health professionals or service providers. Poor integration between services adds to confusion and waiting lists for some services are long. As a result, services are not being used to their full potential and consumers are missing out on services that could help them.

Consultation process

An expert advisory group of consumers, health professionals, general practitioners, service providers, academics and researchers guided the consultation process and developed the recommendations.

Consultation involved an Experience Based Co-Design (EBCD) methodology with a rapid review to assess the literature and current strategies and frameworks. The advisory group also considered the Brisbane North PHN and Metro North Hospital and Health Service's *A five-year health care plan for older people who live in Brisbane North 2017-22*.

Consultation activities included:

- focus groups made up of consumers and health professionals from community care, residential aged care and hospitals
- carer survey
- carer workshop to expand on the survey results
- consultation with local GPs
- individual stakeholder interviews
- workshop and online portal to facilitate feedback on the draft report.

Findings

- **Prompt diagnosis** is essential to give people the opportunity to plan. Lack of awareness of symptoms, a lack of standardised tools for diagnosing, the stigma associated with a diagnosis, and confusion about where to find help, lead to delays in diagnosis and accessing services and care.
- **Carers** are dealing with anxiety, disappointment, concerns about the future, difficulty coping with behaviour changes, being exhausted and overwhelmed, communication difficulties, not having time for themselves, and concerns about their own physical health.
- **Education and training** are essential for people with dementia, their carers, health professionals and the community. High-quality education is needed for all staff in the health sector.
- **Support offered** to people living with dementia and carers must take into consideration that caring can be overwhelming and calls for the right support at the right time, readily accessible services, and help navigating a complex, 'patchwork' care system.
- **Stigma** appears to be widespread in the community and may delay seeking a diagnosis or support. Community education may help change this.
- Healthcare professionals and carers find dealing with '**the system**', difficult. Bureaucracy and lack of communication between services are major challenges.

Recommendations

Support prompt diagnosis by:

- working with GPs to understand current referral practices and raise awareness of diagnostic tools and clinical pathways
- promoting referral protocols for diagnosis and assessment among GPs and other private practitioners
- determining GP training needs, promoting Dementia Training Australia GP education programs, and reviewing the GP guidelines being developed by Dr Dimity Pond ([Primary care guide - Cognitive Decline Partnership Centre \(sydney.edu.au\)](http://Primary%20care%20guide%20-%20Cognitive%20Decline%20Partnership%20Centre%20(sydney.edu.au)))
- supporting general practices by raising awareness of information and resources through Dementia Australia
- raising awareness of effective communication among practice staff.

Raise community awareness of symptoms and risk factors by:

- supporting educational activities
- encouraging people to seek early advice if they are concerned about their cognitive health
- supporting health promotion activities that are aimed at reducing risk factors
- raising awareness about the association between depression and dementia
- promoting awareness of existing education programs (Dementia Training Australia, Dementia Australia, and Dementia Support Australia) among frontline staff who interact with people with dementia
- advocating for inclusion of people with dementia and carers by partnering with local councils, community and support organisations and encouraging them to be more inclusive and expand their dementia community reach
- getting more people involved as research participants through [StepUp for Dementia Research](#).

Provide support and education for carers by:

- promoting resources available on the Dementia Australia website (including the dementia information kit as an initial source of information)
- advocating for a community notice board (directory, website or app) to link all dementia-related services for the Brisbane North region
- staying informed about the current Council on the Ageing (COTA) Aged Care Navigator role trial in 30 sites across Australia, including Metro South Hospital and Health Service
- raising awareness of community-based support groups by providing a list of carer support groups in the Brisbane North region
- providing opportunities for carers and families to undertake education and awareness programs, offering respite care to allow attendance, working with local councils and community groups, and maintaining relationships with dementia researchers
- working with Moreton Bay Dementia Alliance to advance collaboration in the sector and support developing similar alliance groups
- reviewing current support for carers to identify gaps, develop guidelines for respite services, and advocating, promoting, and raising awareness of existing services.

Support education for health professionals by:

- raising awareness of existing education and training programs through Dementia Training Australia, Dementia Australia, and Dementia Support Australia
- facilitating education for GPs, health professionals in residential aged care facilities, hospitals, and community organisations

- partnering with external education providers to develop and deliver dementia education to staff in residential aged care facilities, hospitals, and community organisations in the Brisbane North region
- developing networking groups to bring health professionals together
- ensuring information is consistent, promoting the Dementia Australia guidelines for people living with dementia, and referring to Dementia Australia as the peak body in Australia for dementia information, awareness, and support.

Enhance communication at times of service transition by:

- working with Metro North HHS to enhance communication between organisations when people with dementia transition between services (because timely comprehensive discharge planning information improves care)
- advocating for use of a standard personalising care tool (e.g. the TOP5) when transitioning between services
- reviewing post-diagnostic care planning processes for people living with dementia to make sure a wide range of support services are considered.

Promote high-quality end-of-life care by:

- considering the needs of those under 65 in end-of-life care planning
- partnering with Palliative Care Queensland to raise consumer awareness of early planning
- promoting development of advance care planning by health professionals and providers in partnership with the person living with dementia, their carers, and families.

Include diverse groups by:

- ensuring that people who identify with diverse groups are addressed in all initiatives.

Improve systems by:

- addressing difficulties with navigating government departments and services, including the My Aged Care portal by advocating to pilot dementia navigator roles in the Brisbane North region
- advocating for reforms to the Medicare Benefits Schedule to allow appropriate categorisation of dementia, assessment time, and GP reimbursement
- advocating for reforms to improve the usability of My Aged Care, ensuring that Brisbane North services are included.

Progressing the Recommendations

The Brisbane North PHN will consider these strategies recommendations as part of their future planning. Any initiatives identified will be co-designed, implemented and evaluated with the aim to improve the care of people living with dementia in the North Brisbane.

Definitions

Carer

The term 'carer' has been used to refer to any person who provides care for a person living with dementia and includes family members, friends, relatives, partner or support person.

Consumer

The term 'consumer' has been used to refer to carers and people living with dementia as service users.

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