



# Speech Pathology and Dementia

**Joint Position Statement**  
November 2024



## Dementia in Australia

Dementia is a term used to describe a group of conditions characterised by gradual impairment in brain function, which may impact memory, speech and communication, swallowing, cognition (thinking), personality, behaviour and mobility. In 2024, it is estimated that more than 421,000 Australians live with dementia. Without a medical breakthrough, the number of people with dementia is expected to increase to more than 812,500 by 2054.<sup>1</sup> Dementia occurs more commonly in older age but can affect people at any age, including children (childhood dementia) and people under the age of 65 (younger onset dementia).

Studies have shown that people living with dementia benefit from allied health services such as speech pathology, and an enabling approach to support them to maintain health, independence and quality of life for as long as possible.<sup>2</sup> Currently, people with dementia receive limited and often inadequate access to speech pathology services.<sup>3</sup>

## The impacts of dementia

Dementia impacts each person differently, but changes to communication skills or eating, drinking and swallowing skills are commonly seen at some stage for most people living with dementia.

### ***Why is this important?***

## Communication is a human right

Being able to communicate is fundamental to who we are. It is how we express our needs, thoughts, and feelings, tell our family about an event or experience, express our choices or decisions, and ask our doctors a question and understand their answer. We communicate when we send a text to a friend, call for help, order a meal at the café, listen to the radio, read and fill in forms or pay a bill online.

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<sup>1</sup> Dementia Australia (2023) Dementia Prevalence Data 2024-2054, commissioned research undertaken by the Australian Institute of Health and Welfare

<sup>2</sup> Yun-Hee Jeon, Luisa Krein, Judy M. Simpson, Sarah L. Szanton, Lindy Clemson, Sharon L. Naismith, Lee-Fay Low, Loren Mowszowski, Peter Gonski, Richard Norman, Laura N. Gitlin & Henry Brodaty (2019) Feasibility and potential effects of interdisciplinary home-based reablement program (I-HARP) for people with cognitive and functional decline: a pilot trial, *Aging & Mental Health*, DOI: 10.1080/13607863.2019.1642298

<sup>3</sup> Laver, K.E., Crotty, M., Low, L.F. et al. (2020). Rehabilitation for people with dementia: a multi-method study examining knowledge and attitudes. *BMC Geriatrics*, 20, 531

Communication skills assist us to stay independent in the community, connected to our social networks and are vital to our psychosocial wellbeing and quality of life. Effective communication positively impacts the person living with dementia and their family and support partners. Knowing how to support communication needs is also essential in the delivery of care.

**“ Instead of getting upset with myself when I couldn’t find the right word or name, I have learnt how to regulate that, I say to myself ‘it doesn’t matter.’ The speech pathologist has taught me to take the time and not get upset and that has helped me immensely. ”**  
*Person living with dementia*

Lack of support for communication needs poses safety risks – including a documented higher incidence of adverse outcomes in care, social isolation, poorer mental health and not being able to communicate medical needs or contact emergency services.<sup>4</sup> Research also shows the potential for earlier admission to residential care with a subsequent increased cost of care.<sup>5</sup>

People living with dementia can experience a range of communication challenges including:

- Expressing needs, thoughts, choices, feelings – e.g. word finding difficulties, ‘empty speech’, unclear speech production
- Understanding what others are saying or following conversation e.g. in group or on TV

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<sup>4</sup> Volkmer, A., Bruns, C., Zimmerer, V., Varley, R., & Beeke, S. (2023). Giving Voice to People With Dementia and Their Carers: The Impact of Communication Difficulties on Everyday Conversations. *International Journal of Qualitative Methods*, 22. <https://doi.org/10.1177/16094069231171096>

Bartlett G, Blais R, Tamblyn R, et al. Impact of patient communication problems on the risk of preventable adverse events in acute care settings. *CMAJ*. 2008;178(12):1555–1562. [doi:10.1503/cmaj.070690](https://doi.org/10.1503/cmaj.070690)

Stransky ML, Jensen KM, Morris M. Adults with communication disabilities experience poorer health and healthcare outcomes compared to persons without communication disabilities. *J Gen Intern Med*. 2018;33(12):2147–2155

<sup>5</sup> Savundranayagam, M., Hummert, M-L., Montgomery, R. (2005) Investigating the Effects of Communication Problems on Caregiver Burden, *The Journals of Gerontology: Series B*, Volume 60, Issue 1, Pages S48–S55, <https://doi.org/10.1093/geronb/60.1.S48>

- Spelling and reading comprehension e.g. writing emails, texts, reminders
- Social skills and maintaining conversations e.g. sticking to a topic, coming up with questions and starting conversations

**“ Having allied health services is critical through the journey, not just after the diagnosis but as this thing progresses and my speech and language and communication moves around. ”**

Person living with younger onset dementia.

## Swallowing difficulties can impact physical health, nutrition and wellbeing

Safe and enjoyable mealtimes are crucial for our physical and mental health, social connection and quality of life. People living with swallowing difficulties may experience choking episodes, coughing during eating and drinking or be unable to finish meals (also known as dysphagia). They also may experience adverse consequences such as pneumonia and poor nutrition with subsequent hospitalisation or even death.

Supporting someone with swallowing difficulty can also have an impact on the family member or carer, including changes in meal preparation, disruption in lifestyle, effects on social life, and feelings of fear of aspiration.<sup>6</sup>

Changes associated with swallowing and eating and drinking skills can include difficulties with:

- The physical ‘mechanics’ of swallowing – e.g. slower swallow reflex, poor coordination of swallowing muscles
- Cognitive/behavioural impacts on mealtimes e.g. unable to remember use of compensatory strategies, impulsive rate of eating, changed food preferences

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<sup>6</sup> Rangira, D., Najeeb, H., Shune, S.E. & Namasivayam-MacDonald, A (2022) Understanding Burden in Caregivers of Adults with Dysphagia: A Systematic Review. American Journal of Speech-Language Pathology [https://doi.org/10.1044/2021\\_AJSLP-21-00249](https://doi.org/10.1044/2021_AJSLP-21-00249)

Some types of dementia tend to produce characteristic changes in communication and swallowing early in the disease, and therefore detailed assessment of communication and swallowing skills by a speech pathologist is useful to help in differential diagnosis.<sup>7</sup> For example, someone with a primary progressive aphasia may have significant difficulties with word recognition and word finding, whereas someone with Alzheimer's disease may have fluent, but 'empty' speech lacking in content words.

**“ My doctor referred me to a speech pathologist, and she was the one who came up with my diagnosis of primary progressive aphasia. ”**  
*Person living with dementia.*

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7 Gallee, J & Volkmer, A. (2023) Role of the Speech Language Therapist / Pathologist in Primary Progressive Aphasia. *Neurology Clinical Practice* Vol 13 (4)



# Speech Pathology is a vital part of the dementia support pathway

**“ My speech pathologist is one of reasons I am doing so well. They’re rock stars! ”**

*Person living with younger onset dementia*

Speech pathologists are university trained allied health professionals with expertise in the diagnosis, assessment and management of communication and swallowing disorders including those seen in dementia. Speech pathologists work with the person and their support network to maximise independence and wellbeing through an enablement approach, either via individual or group therapy. An enablement approach is an individualized, strengths-based approach aligned to that person’s goals. This approach focuses on making the most of someone’s abilities to stay as independent for as long as possible and live well with dementia.

**“ You can’t underestimate the value and difference the speech pathologist has made in our lives - maintaining my language, helping me to communicate with my wife, problem solve, prepare speeches etc. ”**

*Person living with younger onset dementia*

Using an enablement approach, speech pathology may include:

- Assessment of communication and swallowing skills to assist in differential diagnosis of dementia variants
- Post diagnostic rehabilitation including:
  - Direct therapy for impairments such as word finding difficulties or swallow initiation
  - Direct therapy to support maintenance of participation in conversation and social activities
  - Training to use compensatory strategies using strengths to maintain function cue cards, memory books, safe swallowing strategies

- Prescription and training of use of assistive technology for communication e.g. speech generating devices, communication boards
- Training and education for communication partners (carers, family, other health professionals) and those providing mealtime assistance
- Strategies for communication in positive behaviour support
- Strategies to use to aid communication in supported decision-making and capacity assessment
- Palliative and end of life care
- Recommendations for environmental modifications for communication and swallowing needs – ‘dementia friendly environments.’ This might include examples such as changes to signage and wayfinding, quiet and well-lit spaces for communication, on site specific communication aids as well as staff trained in supporting communication needs in dementia.

Speech pathologists work as part of a comprehensive inter-disciplinary team and work across a range of settings including hospitals, rehabilitation services, memory clinics, community health services, residential aged care and in private practice in the community.

**“ That referral and getting allied health services made the world of difference. I can’t stress enough the importance allied health plays in dementia, especially for people with primary progressive aphasia, which is more speech orientated than other forms of dementia. ”**

Person living with dementia

Research has shown that speech pathology can be effective in supporting people living with dementia and their family members and carers. A range of potential benefits found from individually prescribed speech pathology rehabilitation has included:

- Improved word retrieval skills in targeted situations<sup>8</sup>
- Improved capacity to engage in meaningful exchanges and conversations<sup>9</sup>
- Improved mood and social connectedness<sup>10</sup>
- Improved regulation of behaviour<sup>5</sup>
- Improved or maintained carer/family/social relationships<sup>5</sup>
- Improved outcomes for family members, care partners and care staff<sup>11</sup>

**“ Speech pathology is also critical for care partners. My life is better if my care partner is better equipped to support me. ”**  
*Person living with younger onset dementia*

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<sup>8</sup> Beales, A., Whitworth, A., & Cartwright, J. (2018). A review of lexical retrieval intervention in primary progressive aphasia and Alzheimer’s disease: mechanisms of change, generalisation, and cognition. *Aphasiology*, 32(11), 1360-1387. <https://doi.org/10.1080/02687038.2018.1491192>

Beales, A., Whitworth, A., Cartwright, J., Panegyres, P & Kane, R (2021) Making the Right Connections: Maximising Lexical Generalization in lexical impairment in PPA and Alzheimer’s Disease. *American Journal of Speech-Language Pathology* Vol 30 (2) p 697 - 712

<sup>9</sup> Murphy, J., Gray, C. and Cox, S. (2007), “The use of Talking Mats to improve communication and quality of care for people with dementia”, *Housing, Care and Support*, Vol. 10 No. 3, pp. 21-28. <https://doi.org/10.1108/14608790200700018>

Volkmer, A., Walton, H., Swinburn, K. et al. (2023) Results from a randomised controlled pilot study of the Better Conversations with Primary Progressive Aphasia (BCPPA) communication partner training program for people with PPA and their communication partners. *Pilot Feasibility Stud* 9, 87. <https://doi.org/10.1186/s40814-023-01301-6>

Eggenberger, E., Heimerl, K., & Bennett, M. (2013). Communication skills training in dementia care: A systematic review of effectiveness, training content, and didactic methods in different care settings. *International Psychogeriatrics*, 25(3), 345-358. doi:10.1017/S1041610212001664

<sup>10</sup> Swan, K., Hopper, M., Wenke, R., Jackson, C., Till, T & Conway, E (2018) Speech-Language Pathologist Interventions for Communication in Moderate-Severe Dementia: A Systematic Review. *American Journal of Speech-Language Pathology*. Vol 27 (2) p 836-852. Mooney, A., Beale, N. & Fried-Oken, M. (2018) Group Communication Treatment for Individuals with PPA and their Partners. *Semin Speech Lang* 2018; 39(03): 257-269 Volkmer, A., Spector, A., Meitanis, V., Warren, J.D. & Beeke, S. (2020) Effects of functional communication interventions for people with primary progressive aphasia and their caregivers: a systematic review, *Aging & Mental Health*, 24:9, 1381-1393, DOI: 10.1080/13607863.2019.1617246 DOI: 10.1055/s-0038-1660784

<sup>11</sup> Folder, N., Power, E., Rietdijk, R., Christensen, I., Togher, L., Parker, D (2024) The Effectiveness and Characteristics of Communication Partner Training Programs for Families of People With Dementia: A Systematic Review, *The Gerontologist*, Volume 64, Issue 4, April 2024, gnad095, <https://doi.org/10.1093/geront/gnad095>. Eggenberger, E., Heimerl, K., & Bennett, M. I. (2013). Communication skills training in dementia care: a systematic review of effectiveness, training content, and didactic methods in different care settings. *International psychogeriatrics*, 25(3), 345-358.



# Access to speech pathology for people living with dementia in Australia

Despite the many benefits, people living with dementia are frequently not referred or not able to access the speech pathology services that they need.

This is due to a number of factors including:

- **Stigma and lack of awareness of the role of speech pathology and benefits of rehabilitation.**

Referrers such as GPs, and sometimes people living with dementia or speech pathologists themselves, may be unaware of the benefits of rehabilitation and other supports provided by speech pathologists. Lack of timely referral leads to missed opportunities to implement early intervention and avoid other issues.

- **Funding mechanisms and referral pathways for speech pathology are unclear and difficult to navigate for both referrers and people living with dementia.**

No clear pathway to allied health rehabilitation post-diagnosis has been established. Funding for services may be sought through My Aged Care (>65 years) or NDIS (<65 years), Chronic Disease Management plans (with a limited number of sessions shared across allied health and likely gap fee payable), residential facilities or private health insurance (limited benefits). Funding is therefore complex, can be location dependent and often does not meet the needs of people living with dementia.

- **Availability of speech pathologists with expertise and knowledge in dementia.**

Ongoing work is occurring to increase the number of speech pathologists with skills and confidence in dementia practice. As the peak body for the profession in Australia, Speech Pathology Australia has recently published national Practice Guidelines in Dementia and holds professional development and community of practice events for speech pathologists. It also hosts a searchable Find a Speech Pathologist ([speechpathologyaustralia.org.au](https://speechpathologyaustralia.org.au)) function on its website to help people locate a speech pathologist in their area. Using a filter to search for those with experience in dementia, or at least neurological conditions, is recommended.

## Speech Pathology Australia and Dementia Australia's Position

- Speech pathologists play an important role in the multidisciplinary healthcare team in maintaining the health and wellbeing of people living with dementia
- People living with dementia have a right to access rehabilitation services including speech pathology, using a wellness and enablement approach with an emphasis on maintaining strengths and capacities, to live well for as long as possible
- A clear post-diagnostic pathway to allied health services such as speech pathology, with appropriate funding, should be available to people living with dementia
- Increasing dementia care content in tertiary speech pathology course curriculums (and those of other health professionals) alongside a continued focus on education and professional development for speech pathologists (and other health professionals) will make a significant contribution to improving access to high quality speech pathology services for people living with dementia.



# National Dementia Helpline

## 1800 100 500



For language assistance  
call **131 450**

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Find us online  
**dementia.org.au**



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