



Speech Pathology Australia's Submission to the
Victorian Parliament's Legal and Social Issues Committee

Inquiry into End of Life Choices

30 July 2015





Speech Pathology Australia's Submission to the Inquiry into End of Life Choices

Introduction

Speech Pathology Australia welcomes the opportunity to provide comment to the Standing Committee on Legal and Social Issues on the Inquiry into End of Life Choices.

Speech Pathology Australia is the peak professional body representing speech pathologists in Australia. At present, Speech Pathology Australia provides professional support services to over 6500 practising speech pathologists in Australia. Speech Pathology Australia is governed by a Board of Directors at the national level with branch committees operating at state and territory levels.

There are a range of special interest groups supported by our Association in relation to specific areas of practice or clinical interests. There is an active Ageing and Aged Care online network as well as a number of state based special interest groups.

Very recently, speech pathology services have been investigated with a federal inquiry by the Senate Community Affairs References Committee into the prevalence of speech, language and communication disorders and speech pathology services in Australia. The Inquiry recognised the important role that speech pathologists play in caring for older Australians, and specifically recommended that further work be undertaken on service delivery models of speech pathology in aged care and how these can be incorporated into current reforms in the sector.

The development of legislation in Victoria will allow citizens to make informed decisions regarding their own end of life choices. Furthermore, Speech Pathology Australia supports the provision of quality palliative care and end of life services to all Australians. Palliative care services should be planned for and provided early in order to optimise quality of life outcomes.

We support that the wide use of advance care planning and adequate training of health professionals is needed to promote and embed the use of advance care plans by an individual when receiving health services.

This submission begins with an overview of the communication and swallowing problems that may be encountered by people at the end of their lives. We then detail the current roles of speech pathologists in palliative care. It concludes with specific recommendations regarding the role of the speech pathology profession in supporting people to communicate their own end of life choices.

Communication and swallowing problems in end of life care

The World Health Organisation (2002) states that, 'Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.

Communication and swallowing difficulties arise from a number of terminal illnesses and life limiting conditions such as cancer, dementia, Parkinson's disease, Huntington's disease, and motor neuron disease. For example, research has indicated that 53 per cent of patients with head and neck cancer admitted to hospice programs experience communication difficulties and 7 per cent experience swallowing difficultiesⁱ; while pneumonia, febrile illness, and dysphagia are frequently occurring challenges for people with advanced dementia in the final six months of lifeⁱⁱ.





Communication problems experienced at the end of life encompass difficulties with speech, producing spoken language (expressive language), understanding (receptive language), voice changes, fluency (stuttering), and pragmatics (the social use of language), or a combination of areas.

Swallowing problems (dysphagia) experienced at the end of life affect the ability to safely swallow food or liquids and can lead to medical complications including malnutrition, chest infections/pneumonia and death.

Difficulties in communication and swallowing can occur in isolation or a person may have difficulties in more than one area. For example, a person may have speech, expressive and/or receptive language, and swallowing difficulties following a stroke.

Speech pathologists are the university trained allied health professionals who specialise in treating speech, language, communication and swallowing problems. Speech pathologists work with infants, children, adolescents, adults and the elderly with communication and swallowing problems. Speech pathologists undertake a four year undergraduate degree or a two-year graduate entry Masters degree to be qualified as speech pathologists. Speech pathologists provide health services in the acute care (hospitals), sub-acute care, rehabilitation and primary care sector (including community health and general practice) as well as within other sectors such as disability, residential and community based aged care, education, juvenile justice and community settings.

The Impact of Communication Difficulties at end of life

Effective communication is recognised as an essential component of high quality palliative care and satisfaction with careⁱⁱⁱ. Communication difficulties can impact upon the palliative care team's ability to provide effective symptom control and supportive psychosocial care^{iv}.

Communication difficulties represent a barrier to advance care planning and execution of choice. As such, communication difficulties can reduce a person's ability to participate in decision making processes about their end of life care. Untreated communication difficulties can have a direct negative impact on a person's potential to make end of life decisions (including acting on these decisions) and ability to access and utilise health services including palliative care.

Communication difficulties further impact an individual's ability to maintain interpersonal relationships and social closeness with family and friends, vitally important for psychosocial wellbeing at all stages of life. Management of psychological problems and social relationships are a central component of palliative care, ensuring the best quality of life for patients and their families.

The Impact of Swallowing Difficulties at end of life

Swallowing is a basic bodily function – that is required to sustain life. Problems with the swallowing reflex and function can be life threatening.

Swallowing difficulties can result in physical, psychological, and social impacts on patients and their families^{iv}. They are associated with discomfort for individuals at the end of life and are of concern for caregivers. Furthermore, swallowing difficulties are associated with aspiration (where liquids or food enter the lungs), which can compromise quality of life and lead to several pulmonary syndromes, including pneumonia. It is also recognised that for many people living with a terminal illness, the inability to swallow may be the symptom that prompts consideration of end of life care^{iv,vi}.

Swallowing difficulties at the end of life may result in a person being deemed unsafe for eating or drinking (given the risk of aspiration or choking). Patient safety must be carefully balanced with quality of life factors, acknowledging that oral intake for pleasure and comfort can be a challenging concept for caregivers and family members to understand^v. This poses a challenge for practitioners who have assessed swallowing safety and deemed it a risk for oral intake – but where the person wishes to eat or drink during the remainder of their life regardless of the risk.

Speech pathology in palliative and end of life care





Speech pathologists provide assessment, direct intervention, consultancy, education, advocacy, and counselling for people experiencing communication and swallowing difficulties. The generalist training received by speech pathologists to achieve entry level standards (as defined within the Competency-Based Occupational Standards utilised by all speech pathology training courses) is expanded and enhanced by further experience in defined areas, including palliative care.

Palliative care services span all stages of disease progression, involving the management and reduction of symptoms and optimisation of a person's quality of life. Speech pathologists are employed across a range palliative care services including hospitals, aged care facilities, and community or domiciliary care settings.

As integral members of an interdisciplinary palliative care team, speech pathologists provide comprehensive assessment of a person's communication, cognitive, language, and swallowing status to inform the development of a treatment or management plan^{iv}. They identify strategies and interventions that will add comfort, alleviate pain or distressing symptoms, and help to ensure the best quality of life and support system possible for the patient and their family.

The key roles of the speech pathologist in palliative care teams include^{iv}:

- (1) providing consultation to patients, families, and members of the palliative care team regarding communication, cognitive, and swallowing function,
- (2) developing strategies in the area of communication in order to support the patient's role in decision making, to maintain social closeness, and to assist the person to achieve end of life goals, and
- (3) developing strategies in the area of feeding and swallowing to optimise comfort and eating satisfaction.

Managing communication difficulties in palliative and end of life care

Individuals with communication difficulties may benefit from speech pathology intervention at many stages of their illness or disease to assist symptom control and improve quality of life outcomes at the end of life^v. Goals of communication intervention may include identifying strategies to help the individual maintain social and emotional closeness with family and friends, optimising the person's ability to express their basic wants and needs, and enabling challenging conversations relating to death and dying^{iv}. Speech pathologists can tailor strategies to the individual that consider factors such as fluctuations in alertness, fatigue, pain, and disease progression.

Speech pathologists play an important role in supporting individuals with communication difficulties and early cognitive impairment to voice their preferences and participate in advance care planning. They can recommend communication support strategies and assistive communication technologies to support the individual's decision making and opportunity for choice in relation to end of life goals. The speech pathologist can assist the health care team to determine an individual's capacity to understand and communicate their wishes related to health care decisions^{iv}.

Speech pathologists can also assist in developing communication accessible health information and facilitate difficult conversations. This helps to ensure that clear and accurate information is provided to the individual and their family so that they can make informed decisions about end of life care.

Managing swallowing difficulties in palliative and end of life care

Speech pathologists assess and manage the implications of swallowing problems for people in the final stages of terminal illness or in the advanced stages of life-limiting disease. Palliative care for swallowing disorders aims to optimise swallow function, maintain pulmonary health and support healthy nutrition despite the presence of swallowing or feeding difficulties^{vi}. This includes helping to clarify the preferences and wishes of the patient and family regarding swallowing and feeding. Speech pathologists also have a role in supporting and educating the care team regarding appropriate consistencies for oral intake including medications^{vii}.

Speech pathologists can make oral feeding and mouth care recommendations weighing up medical indicators, patient preferences, quality of life, and other external factors (e.g. legal issues). Furthermore, speech pathologists can assist the medical team to evaluate the value of medical interventions such as





feeding tubes, taking into consideration evidence and prognostic indicators. For example, in the case of dementia, evidence indicates that alternate routes of feeding (i.e. feeding tubes) do not improve symptom control and in fact may decrease comfort^{ix}.

Speech pathologists can provide education and support to families and caregivers where eating or drinking for pleasure and comfort (as opposed to survival) is recommended. This includes helping families and caregivers understand that decreased hunger and thirst are associated with the end of lifeⁱⁱⁱ.

Current Speech pathology role in end of life care

Quality end of life care requires active involvement from all members of the interdisciplinary team^{ii,iv}, including speech pathologists. However, despite having a clear role, the integration of speech pathology services into palliative care teams is not consistent^x. Developing models of speech pathology service provision within palliative care would assist to ensure that an individual's communication and /or swallowing needs are managed effectively. The inclusion of speech pathology in this way would support the principle of a consultative and collaborative approach to complex clinical decision making and goal setting at the end of life.

End of life care is frequently managed by generalist health professionals and is not limited to palliative care "specialists" or "experts"^{xi}. Feedback from Speech Pathology Australia members indicates that speech pathologists receive limited specialist training in palliative care – but rather develop clinical expertise through an 'apprenticeship' model (like many health professions) where practice, mentoring and other informal methods of skill acquisition occur. Furthermore, speech pathologists express concern around caseload prioritisation and confidence in their role in the management of patients at the end of life^v, given the complex and ethically challenging area of practice. There is a need for consistent inclusion of palliative care topics in entry-level speech pathology training programs^{x,iii}. Furthermore, speech pathologists inexperienced in this area require access to adequate mentoring and supervision from experienced clinicians in order to develop competency in palliative care approaches^{iii,v,xii}. Research indicates that health professionals who have received minimal or no training in palliative care are at greatest risk of experiencing personal and professional challenges^{xiii}. Training should support clinicians to implement appropriate palliative care standards, national guidelines and consensus statements in patient care recommendations. The ACSCH National Consensus Statement^{xii} (essential elements for safe and high-quality end-of-life care) provides excellent recommendations regarding education and training, as well as supervision and support for interdisciplinary team members.

Speech pathologists express concern that some health professionals, patients and their family members have limited understanding of the role that speech pathology services can play in palliative and end of life care. Limited insight into what speech pathology can offer has implications for referrals and equitable access to services at the end of life.





Recommendations

Speech Pathology Australia appreciates the opportunity to provide input into the Standing Committee on Legal and Social Issues Inquiry into End of Life Choices. Speech Pathologists are valuable members of the interdisciplinary teams working to improve the quality of end of life care for Victorians. We provide the expertise in communication and swallowing difficulties that is required to support people to make appropriate choices. We are pleased to provide a range of recommendations that will assist the Victorian government to develop laws to support health care providers and people making end of life choices.

It is recommended that:

1. There be a Review undertaken into the integration of allied health services, including speech pathology services, in palliative care teams in Victoria to inform future palliative care plans and recommended care models. High quality speech pathology services should be readily available and accessible as part of delivery of specialist palliative care.
2. That documentation supporting legislation includes reference to allied health professionals, including speech pathologists, as integral members of interdisciplinary teams providing palliative and end of life care. This would be informed by the preparation of case studies that demonstrate the role of allied health professionals in palliative care for symptom management, education and advocacy purposes.
3. Strategies are identified to increase knowledge of end of life care amongst all clinicians and services. Speech Pathology Australia would welcome the opportunity to work with the Victorian Government to prepare tailored educational resources for speech pathologists.
4. Increase training and education opportunities for speech pathologists in palliative care principles and advance care planning skills in both undergraduate and postgraduate training programmes.
5. Develop and identify strategies to implement guidelines and resources for health professionals to support advance care planning and end of life conversations with individuals with communication difficulties.
6. Develop information for consumers regarding the role of allied health, including speech pathologists, in palliative and end of life care. Speech Pathology Australia would welcome the opportunity to work with the Victorian Government to prepare educational material for patients and family members.

If Speech Pathology Australia can assist in any other way or provide additional information please contact National Office on 03 9642 4899, or contact [REDACTED]





Appendix A: Evidence used in the development of this submission

- ⁱ Forbes, K. (1997). Palliative care in patients with cancer of the head and neck. *Clinical Otolaryngology*, 22, 117–122.
- ⁱⁱ Smith, H., & Kenny, B. (2015). A speech-language perspective on “doing good” in end-of-life care for people with advanced dementia. *Journal of Clinical Practice in Speech-Language Pathology*, 17(2), 98-103.
- ⁱⁱⁱ Seccareccia, D., Wentlandt, K., Kevork, N., Workentin, K., Blacker, S., Gagliese, L., ... & Zimmermann, C. (2015). Communication and Quality of Care on Palliative Care Units: A Qualitative Study. *Journal of Palliative Medicine*, 18(9), 1-7.
- ^{iv} Pollens, R. (2004). Role of the speech-language pathologist in palliative hospice care. *Journal of Palliative Medicine*, 7(5), 694-702.
- ^v Eckman, S., & Roe, J. (). Speech and language therapists in palliative care: What do we have to offer? *International Journal of Palliative Nursing*, 11(4), 179-181.
- ^{vi} Langmore, S. E., Grillone, G., Elackattu, A., & Walsh, M. (2009). Disorders of swallowing: Palliative care. *Otolaryngologic Clinics of North America*, 42(1), 87-105.
- ^{vii} The Society of Hospital Pharmacists of Australia. *Don't rush to crush handbook*. The Society of Hospital Pharmacists of Australia.
- ^{viii} Manrique-Torres, Y. J., Lee, D. J., Islam, F., Nissen, L. M., Cichero, J. A., Stokes, J. R., & Steadman, K. J. (2014). Crushed tablets: does the administration of food vehicles and thickened fluids to aid medication swallowing alter drug release? *Journal of Pharmacy & Pharmaceutical Sciences*, 17(2), 207-219.
- ^{ix} Goldberg, L.S., & Altman, K.W. (2014). The role of gastrostomy tube placement in advanced dementia with dysphagia: a critical review. *Clinical Interventions in Aging*, 9, 1733.
- ^x Pascoe, A., Breen, L.J., & Cocks, N. (2015). Being prepared for working in palliative care: The speech pathology perspective. *Journal of Clinical Practice in Speech-Language Pathology*, 17(2), 82-84.
- ^{xixi} National Health and Hospitals Reform Commission. (2009). *A healthier future for all Australians: Final Report*. Retrieved from <http://www.health.gov.au/internet/nhhrc/publishing.nsf/content/nhhrc-report>
- ^{xii} Australian Commission on Safety and Quality in Health Care. (2015). *National consensus statement: Essential elements for safe and high-quality end-of-life care*. Sydney: ACSQHC.
- ^{xiii} Melo, C.G., & Oliver, D. (2011). Can addressing death anxiety reduce health care workers' burnout and improve care? *Journal of Palliative Care*, 27(4), 287-295.

