

Position Statement

The Role of Speech-Language Pathologists, Audiologists and Communication Health Assistants in End-of-Life Care

Position Statement

Speech-Language and Audiology Canada believes that all people should have access to comprehensive end-of-life care, which includes communication health services and resources. Communication health professionals — speech-language-pathologists, audiologists, and communication-health-assistants — are uniquely qualified to provide essential services in end-of-life care. These services aim to support autonomy and improve quality of life while considering the physical, emotional and spiritual needs of patients or clients, families and caregivers.

Rationale

In February 2015, the Supreme Court of Canada ruled unanimously in favour of amending the criminal code to allow for physician-assisted death. The new legislation has prompted many discussions amongst health-care professionals, patient advocacy groups and other concerned Canadians about not only the right to die, but also the importance of quality end-of-life care.

Communication impairments and dysphagia (swallowing disorders) are common in the end-of-life population. These issues contribute to poor social-emotional health and often cause distressing symptoms that may influence people in their decision to seek physician-assisted death. Furthermore, the wishes and directives of patients or clients who are unable to communicate verbally are frequently misunderstood or overlooked by health-care practitioners and family members. The timely identification of communication, hearing and swallowing issues and the implementation of appropriate, evidence-informed interventions can alleviate many of these symptoms and improve quality of life.

This position statement aims to raise awareness about the important role of communication health professionals in comprehensive end-of-life care.

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Role of the Communication Health Professional

Communication health professionals educate and collaborate with patients or clients, families, caregivers and members of interdisciplinary teams to assess, monitor, prevent and manage communication, hearing and swallowing problems at the end of life. They may provide services across the age continuum, from infants to seniors. Communication health professionals may be members of palliative care teams or be consulted externally when communication and/or swallowing issues are identified. Practice settings include long-term care facilities, community health centres, outpatient clinics, patients' or clients' homes as well as tertiary care facilities, including hospitals and palliative care centres.

Communication health professionals may be the first health-care providers to identify and assess the initial symptoms and/or progression of life-limiting conditions. This facilitates consultations with physicians for diagnostic follow-up and referrals to other health-care providers, as well as the initiation of timely interventions and access to education and resources. Communication health professionals may provide services at all stages of a life-limiting illness, including rehabilitative and/or life-prolonging care when it will positively influence disease progression and/or help maintain a level of independence and quality of life.

Hearing and Communication: Communication health professionals provide diagnostic assessment, direct treatment and strategies, environmental modifications and devices or aids to support patients or clients in living as actively and independently as possible. Optimizing communication (including hearing) may facilitate:

- 1. Determination of capacity/competency for making health-care and other decisions;
- 2. Comprehension of prognosis and the risks and benefits of treatment options, which allows for informed decision-making;
- 3. Self-expression and autonomy, so patients or clients can clearly indicate pain, symptoms, needs and preferences;
- 4. Socialization, sharing and closeness with loved ones;
- 5. Advance care planning, including helping patients or clients express their wishes about goals of care and physician-assisted death;
- 6. Fulfillment of end-of-life goals.

Feeding and Swallowing: Speech-language pathologists monitor changes in swallowing function and modify treatment plans that may aim to:

- 1. Maintain pleasure while eating and drinking;
- 2. Reduce the risk of choking and respiratory complications related to aspiration;
- 3. Promote regular oral care to reduce discomfort and risk of illness;
- 4. Respect and support patient or client choices related to hydration and nutrition, including continuing oral intake despite known risk, foregoing texture modified diets, foregoing or discontinuing artificial hydration and nutrition and ceasing oral intake altogether; and
- 5. Provide education and guidance on issues like the natural cessation of intake in the final stage of dying and alternatives to artificial hydration and nutrition, such as individualized **comfort feeding** plans.

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References

- Barczi, S. R., Sullivan, P. A., & Robbins, J. (2000). How should dysphagia care of older adults differ? Establishing optimal practice patterns. *Seminars in Speech and Language, 21*(4), 347-361.
- Biddle, C., & Mitchell, E. (2008). *Macmillan Cancer Support: every step of the way*. Retrieved from http://www.rcslt.org/docs/bulletin/bulettin_2008/RCSLT_Bulletin_Dec_08.pdf
- Bogaardt, H., Veerbeek, L., Kelly, K., van der Heide, A., van Zuylen, L., & Speyer, R. (2015). Swallowing problems at the end of the palliative phase: Incidence and severity in 164 unsedated patients. *Dysphagia*, 30(2), 145-151.
- Brownlee, A., & Bruening, L. M. (2012). Methods of communication at end of life for the person with amyotrophic lateral sclerosis (ALS). *Topics in Language Disorders*, 32(2), 168-185.
- Canadian Hospice Palliative Care Association. (2010). Issues paper on euthanasia, assisted suicide and quality end-of-life care. Retrieved from http://www.chpca.net/media/7835/PAD_Issues_
 Paper_-_April_24_2010_-_Final.pdf
- Costello, J. M. (2009). Last words, last connections: How augmentative communication can support children facing end of life. *The ASHA Leader, 14*, 8-11.
- Eckman, S., & Roe, J. (2005). Speech and language therapists in palliative care: What do we have to offer? International Journal of Palliative Nursing, 11(4), 179-81.
- Groher, M. E., & Groher, T. P. (2012). When safe oral feeding is threatened: End-of-life options and decisions. *Topics in Language Disorders 32*(2), 149-167.
- Jackson, P., Robbins, M., & Frankel, S. (1996). Communication impediments in a group of hospice patients. *Palliative Medicine*, 10, 79-80.
- Palecek, E. J., Teno, J. M., Casarett, D. J., Hanson, L. C., Rhodes, R. L., & Mitchell, S. L. (2010). Comfort feeding only: A proposal to bring clarity to decision-making regarding difficulty with eating for persons with advanced dementia. *Journal of the American Geriatrics Society, 58*(3), 580-584.

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- Pollens, R. D. (2012). Integrating speech-language pathology services in palliative end-of-life care. *Topics in Language Disorders*, *32*(2), 137-148.
- Roe, J. W. G., & Leslie, P. (2010). Beginning of the end? Ending the therapeutic relationship in palliative care. International Journal of Speech-Language Pathology, 12(4), 304-308.
- Smith, A. K., Jain, N., & Wallhagen, M. L. (2015). Hearing loss in palliative care. Journal of Palliative Medicine, 18(6), 559-562.
- Statistics Canada. (2015). Hearing loss of Canadians, 2012 and 2013. Retrieved from http://www.statcan.gc.ca/pub/82-625-x/2015001/article/14156-eng.htm
- World Health Organization. (n.d.). Definition of palliative care. Retrieved from http://www.who.int/cancer/ palliative/definition/en/

Other References

These resources provide additional information about end-of-life care and were considered in the development of this position statement.

The Communication Health Professional's Role in End-of-Life Care

- Eckman, S., & Roe, J. (2005). Speech and language therapists in palliative care: What do we have to offer? International Journal of Palliative Nursing, 11(4), 179-81.
- Mathisen, B., Yates, B., & Crofts, P. (2011). Palliative care curriculum for speech-language pathology students. *International Journal of Language & Communication Disorders*, 46(3), 273-285.
- Pollens, R. (2004). Role of the speech-language pathologist in palliative hospice care. *Journal of Palliative Medicine*, 7(5), 694-702.
- Pollens, R. D. (2012). Integrating speech-language pathology services in palliative end-of-life care. *Topics in Language Disorders*, 32(2), 137-148.
- Polovoy, C. (2015). Stepping up to the plate. The ASHA Leader, 20(10), 44-53.
- Roe, J. W. G., & Leslie, P. (2010). Beginning of the end? Ending the therapeutic relationship in palliative care. International Journal of Speech-Language Pathology, 12(4), 304-308.
- Toner, M. A., & Shadden, B. B. (2012). End of life: An overview. Topics in Language Disorders, 32(2), 111-118.
- Toner, M. A., & Shadden, B. B. (2012). End of life care for adults: What speech-language pathologists should know. *Topics in Language Disorders*, 32(2), 107-110.
- Vescovich, M. (2015). 3 questions that could change how you provide end-of-life care. *The ASHA Leader,* 20(7), 38-39.
- Weinstein, B. E. (2015). Palliative care: Defining the role of the audiologist. Hearing Journal, 68(1), 23-24.

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Hearing Loss and Tinnitus

- Shaw, G. (2015). Dying to be heard: Hearing healthcare at the end of life. Hearing Journal, 68(1), 18-22.
- Shulman, A., & Goldstein, B. (2009). Subjective idiopathic tinnitus and palliative care: A plan for diagnosis and treatment. *Otolarygologic Clinics of North America*, *42*(1), 15-37.
- Smith, A. K., Jain, N., & Wallhagen, M. L. (2015). Hearing loss in palliative care. *Journal of Palliative Medicine*, 18(6), 559-562.

Speech, Language and Communication

- Brownlee, A., & Bruening, L. M. (2012). Methods of communication at end of life for the person with amyotrophic lateral sclerosis (ALS). *Topics in Language Disorders*, *32*(2), 168-185.
- Costello, J. M. (2009). Last words, last connections: How augmentative communication can support children facing end of life. *The ASHA Leader, 14*, 8-11.
- Salt, N., & Robertson, S. J. (1998). A hidden client group? Communication impairment in hospice patients. International Journal of Language & Communication Disorders, 33(Suppl.), 96-101.

Swallowing, Feeding and Nutrition

- Bogaardt, H., Veerbeek, L., Kelly, K., van der Heide, A., van Zuylen, L., & Speyer, R. (2015). Swallowing problems at the end of the palliative phase: Incidence and severity in 164 unsedated patients. *Dysphagia*, 30(2), 145-151.
- Good, P., Richard, R., Syrmis, W., Jenkins-Marsh, S., & Stephens, J. (2014). Medically assisted nutrition for adult palliative care patients. *Cochrane Database of Systematic Reviews*, (4).
- Groher, M. E., & Groher, T. P. (2012). When safe oral feeding is threatened: End-of-life options and decisions. *Topics in Language Disorders 32*(2), 149-167.
- Hinson, D., Goldsmith, A. J., & Murray, J. (2014). Dysphagia in hospice care: The roles of social work and speech-language pathologists. *Perspectives on Swallowing and Swallowing Disorders* (*Dysphagia*), 23(4), 173-186.
- Levy, A., Dominguez-Gasson, L., Brown, E., & Frederick, C. (2004). Managing dysphagia in the adult approaching end of life. *The ASHA Leader*, 9, 1-17.
- Palecek, E. J., Teno, J. M., Casarett, D. J., Hanson, L. C., Rhodes, R. L., & Mitchell, S. L. (2010). Comfort feeding only: A proposal to bring clarity to decision-making regarding difficulty with eating for persons with advanced dementia. *Journal of the American Geriatrics Society, 58*(3), 580-584.
- Sharp, H. M., & Shega, J. W. (2009). Feeding tube placement in patients with advanced dementia: The beliefs and practice patterns of speech-language pathologists. *International Journal of Speech-Language Pathology*, 18(3), 222-230.

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- Vitale, C. A., Berkman, C. S., Monteleoni, C., & Ahronheim, J. C. (2011). Tube feeding in patients with advanced dementia: Knowledge and practice of speech-language pathologists. *Journal of Pain and Symptom Management*, 42(3), 366-378.
- Wager, L. C. B. (2008). Dysphagia: Legal and ethical issues in caring for persons at the end of life. Perspectives on Swallowing and Swallowing Disorders (Dysphagia), 17(1), 27-32.
- Winter, S. M. (2000). Terminal nutrition: Framing the debate for the withdrawal of nutritional support in terminally ill patients. *The American Journal of Medicine*, 109(9), 723-726.

General End-of-Life and Palliative Care Information

- Botsford, A. L., & King, A. (2005). End-of-life care policies for people with an intellectual disability. *Journal of Disability Policy Studies*, 16(1), 22-30.
- Javier, N. S. C., & Montagnini, M. L. (2011). Rehabilitation of the hospice and palliative care patient. *Journal of Palliative Medicine*, *14*(5), 638-648.
- Lamber, H. (2012). The allied health care professional's role in assisting medical decision making at the end of life. *Topics in Language Disorders*, 32(2), 119-136.
- Lin, Y., Lin, I., & Liou, J. (2011). Symptom patterns of patients with head and neck cancer in a palliative care unit. *Journal of Palliative Medicine*, *14*(5), 556-559.
- Murray, S. A., Kendall, M., Boyd, K., & Sheikh, A. (2005). Illness trajectories and palliative care. *British Medical Journal*, 2005;330:1007–11.
- Royal College of Paediatrics and Child Health. (2004). Withholding or withdrawing life sustaining treatment in children: A framework for practice (second edition). Retrieved from http://adc.bmj.com/content/100/Suppl_2/s1.full
- Rushton, C. H., Kaylor, B. D., & Christopher, M. (2012). Twenty years since Cruzan and the patient selfdetermination act: Opportunities for improving care at the end of life in critical care settings. *Ethics in Critical Care*, 23(1), 99-106.
- Sachs, G. A., Shega, J. W., & Cox-Hayley, D. (2004). Barriers to excellent end-of-life-care for patients with dementia. *Journal of General Internal Medicine*, *19*(10), 1057-1063.
- Strasser, F., Sweeney, C., Willley, J., Benisch-Tolley, S., Palmer, L., & Bruera, E. (2004). Impact of a half-day multidisciplinary symptom control and palliative care outpatient clinic in a comprehensive cancer centre on recommendations, symptom intensity, and patient satisfaction: A retrospective study. *Journal of Pain and Symptom Management, 27*(6), 481-491.
- Thuné-Boyle, I. C. V., Sampson, E. L., Jones, L., King, M., Lee, D. R., & Blanchard, M. R. (2010) Challenges to improving end of life care of people with advanced dementia in the UK. *Dementia*, 9(2), 259-284.

Resources for Palliative Care in Canada

- Canadian Association of Occupational Therapists. (2011). *CAOT position statement: Occupational therapy and end-of-life care*. Retrieved from http://www.caot.ca/default.asp?pageid=1284
- Canadian Medical Association. (2015). Palliative care: Canadian medical association's national call to action. Retrieved from https://www.cma.ca/Assets/assets-library/document/en/advocacy/palliative-care-report-online-e.pdf
- Canadian Nurses Association, Canadian Hospice Palliative Care Association, & Canadian Hospice Palliative Care Association Nurses Group. (2015). *Joint position statement: The palliative approach to care and the role of the nurse*. Retrieved from https://www.cna-aiic.ca/~/media/cna/page-content/pdf-en/the-palliative-approach-to-care-and-the-role-of-the-nurse_e.pdf?la=en
- Canadian Physiotherapy Association. (2015). *Physician assisted death*. Retrieved from http://www.physiotherapy.ca/Advocacy/Federal-Election-Resources/shoPTalk-Physician-Assisted-Death-What-does-this-m?lang=en-ca
- Carstairs, S. (2010). *Raising the bar: A roadmap for the future of palliative care in Canada*. The Senate of Canada. Retrieved from http://www.chpca.net/media/7859/Raising_the_Bar_June_2010.pdf
- Schüklenk, U., Van Delden, J. J. M., Downie, J., Mclean, S. A. M., Upshur, R., & Weinstock, D. (2011). End-of-life decision-making in Canada: A report by the Royal Society of Canada expert panel on end-of-life decision-making. *Bioethics*, 25(Suppl. 1), 1-73.

Online Resources

Canadian Hospice Palliative Care Association

Canadian Society of Palliative Care Physicians

Canadian Virtual Hospice

eHospice

Government of Canada Palliative and End of Life Care

Hearing Loss of Canadians, 2012 and 2013

Quality End-of-Life Care Coalition of Canada

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