

CAOT Position Statement: Occupational Therapy and End-of-Life Care (2017)

The Canadian Association of Occupational Therapists (CAOT) believes people of all ages have the right to quality care at the end of life. **Quality care** allows people to continue engagement in meaningful **occupations**, to die as free of pain and other symptoms as possible, and to choose from the range of service providers available in Canada. To achieve quality **end-of-life care** for all, Canada requires a collaborative, well-funded and sustainable national strategy for **hospice, palliative, and end-of-life care services** from a team of health professionals that includes occupational therapists.

Recommendations for occupational therapists

1. Engage in continuing professional education to identify and provide knowledge-based best practices for quality outcomes in end-of-life care.
2. Promote advance care planning as one way to increase client engagement in their own health and personal care in general and end-of-life care in particular.
3. Promote the development of research among stakeholders that will advance best practices in end-of-life care.
4. Continue to develop partnerships with relevant organizations and stakeholders to promote access to end-of-life care for the people of Canada that promote quality of life and meaningful occupation.

CAOT Initiatives

As a member of the Quality End-of-Life Care Coalition of Canada (QELCCC):

1. Facilitate the development of continuing professional education content and materials that meet practice needs as end-of-life care evolves to include new approaches and interventions and to help ensure more equitable access to the choices each client prefers.
2. Advocate for involvement of occupational therapists in end-of-life services to promote options for clients that enable control, meaning and participation as far as is possible throughout an individual's dying process.

Background information

End-of-life care should aim to relieve suffering and anxiety, **enable** client choice and control, and improve

the **quality of life**, distress and bereavement experience for people living with, declining or dying from advanced illness. Quality end-of-life care encompasses a wide range of options to help individuals manage their dying experience. These options should be explored with the help of others, including family and friends, and health and spiritual care providers.

End-of-life care is appropriate for any individual and, with **advance care planning** (ACP), it can begin at any time. ACP allows individuals to identify preferred future goals of care that are in keeping with their own values to inform future decisions regarding their health care in the event they should be incapable of participating in decision making at a later time. ACP is especially useful for any individual and/or family living with or at risk of developing a life-threatening illness due to any diagnosis and with any prognosis (adapted from Ferris et al., 2002). Fundamental to quality end-of-life care is a palliative approach. The Canadian Hospice and Palliative Care Association (CHPCA) defines a **palliative approach** as one that:

Focuses on meeting a person's and family's full range of needs – physical, psychosocial, and spiritual – at all stages of a chronic progressive illness. It reinforces the person's autonomy and right to be actively involved in his or her own care – and strives to give individuals and families a greater sense of control. It sees palliative care as less of a discrete service offered to dying persons when treatment is no longer effective and more of an approach to care that can enhance their quality of life throughout the course of their illness or the process of aging. (CHPCA, 2014)

Not limited to specialist practitioners and care teams, a palliative approach can be used by any practitioner, in any care setting, at any time throughout the illness trajectory, and can be integrated into care for any individual who may benefit from it. For occupational therapists, aligning a care plan with a client's own goals and basic symptom management should be routine aspects of client-centred practice. Other skills may be more complex, such as mediating a family meeting to discuss difficult topics, responding to existential distress, and managing symptoms requiring the knowledge and support of other providers (Quill & Abernethy, 2013).

Dying involves occupation just as other stages of life. Therefore, dying is amenable to the influence of occupational therapy involvement to make it as good as it can be. Individuals should be enabled to exercise control and autonomy through pursuing care options they feel will offer what they consider to be a good dying process (Jacques & Hasselkus, 2004; Russell & Bahle-Lampe, 2016). When one's values and ideals align with what happens during the dying process, a good experience of dying is achieved. Among the contributions of occupational therapy are the provision of a sense of safety and comfort, and trust in the occupational therapist's ability to know what is needed, especially when a client may prefer someone else to make some of the goal setting decisions (Badger, MacLeod & Honey, 2016).

The end-of-life options open to all in Canada should include evidence-based pain and symptom management, support for psychosocial and spiritual needs, the choice of care in home or hospice, support for engagement in meaningful relationships, and support for loved ones. These everyday palliative interventions adequately alleviate the symptoms of the vast majority of dying people. For a very small percentage of people whose symptoms are exceptional, continuous **palliative sedation** therapy can be one option to reduce the experience of pain by bringing about a deep sleep for the final days of living. For others, **medical assistance in dying (MAiD)** might be their preferred option – bringing about the end of their life sooner than would be the case otherwise. Everyone in Canada should have equitable access to these options, regardless of geographical location, socioeconomic status, or other characteristics.

Occupational Therapy and End-of-Life Care

Occupational therapists are university educated, regulated health professionals. They use evidence-based approaches to enhance the quality of life of individuals and their caregivers by encouraging participation in meaningful occupation. Further, the profession of occupational therapy holds core values about spirituality and holistic client-centred practice, making occupational therapy a natural fit with the philosophies and approaches of end-of-life care. Therefore, occupational therapists should be an integral part of an end-of-life care team. Occupational therapy practice in end-of-life care needs to be evidence-based and contribute to the knowledge base through research and education.

Occupational therapy services delivered in home in end-of-life assists individuals to live safely and comfortably at home, despite decreasing capacity to

participate in their occupations of daily life (Burkhardt et al., 2011). Occupational therapy services are also effective in preventing injury, controlling pain, and assisting the client to carryout valued activities through the provision of education, support, and modifications to the environment for individuals and caregivers (Dawson & Barker, 1995; Hammill, Bye & Cook, 2014; MacLeod, 1997; Rahman, 2000; Sykes, Johnson, & Hanks, 1997).

Additionally, occupational therapists assess client and caregiver needs for assistive devices and technology, as well as education, which enables people to engage in their occupations of choice and more fully participate in their communities. Appropriate use of assistive technology promotes independence and prevents further illness and/or injury (CAOT, 2004). Equally importantly, supportive care from occupational therapy can include interventions to assist with psychosocial and interpersonal concerns (Sleight & Duker, 2016). This care can involve the use of strategies for managing anxiety, depression, and psychological distress; exploration of options for sexual expression; and attention to important life roles, including bringing those to a constructive end where appropriate.

Occupational therapists can also assist in exploring client wishes and priorities for the remaining time leading to end-of-life. They can contribute to evaluating and enabling capacity of individuals making their own end-of-life choices. Quality end-of-life care also supports the best experience of dying for clients' loved ones – memories that are then carried throughout life by others. This enduring legacy of each client's death experience is also important for the healthcare providers involved.

Occupational therapists can also work as educators, advocates, and mediators to assist clients and their families to understand their own needs better and to overcome barriers to meeting those needs (Davis et al, 2013). By focusing on clients' experiences at the end of life, occupational therapists can address what clients find to be most important, including existential concerns that may be identified when reflecting upon life and death (Park Lala & Kinsella, 2011).

Approach to Care

CAOT is a member of the Quality End-of-Life Care Coalition of Canada (QELCCC), a 39-member organization that works to advocate for a collaborative, well-funded, and sustainable national strategy for hospice, palliative, and end-of-life care. Its 2015 document, *The Way Forward: A Roadmap for an Integrated Palliative Approach to Care*, resulted from the Blueprint for Action 2010-2020, which identified five priority areas for action.

CAOT considers these priorities to be highly relevant to occupational therapy, and these five priorities will be discussed below.

1. Availability and Access

In 2016 there were 269,012 deaths reported in Canada (Statistics Canada, 2016). The Quality End of Life Care Coalition of Canada (QELCCC) identified that by the year 2020, the number of deaths will increase to more than 330,000 per year and that 75% of deaths will take place in acute care hospitals and long-term care facilities (QELCCC, 2010).

Occupational therapists work in a wide variety of practice settings including, but not limited to hospitals, home care and independent living facilities. Occupational therapy services include provision of assistive technology and compensatory strategies, caregiver support, client and family education, case management and chronic pain management. End-of-life care can occur in any of these roles and practice settings. Occupational therapy's concern for and attention to social justice, inequity and diversity positions occupational therapists to promote equitable access to services, by providing a palliative approach to care within groups of people who are more vulnerable to harm as a result of intersecting factors (e.g. homelessness, gender, disability, race, illicit drug use, mental health issues, etc.).

More health service providers, including occupational therapists, are needed to practice in end-of-life care to ensure timely access to quality services throughout Canada. This is particularly urgent given that each death affects the immediate well-being of an average of five other people – that is over one million people in Canada every year (Carstairs, 2000). Supporting a positive and empowered death experience for clients can mean a more positive death experience and subsequent memories for those involved. Legislation was passed by the Government of Canada in June 2016 that allows eligible Canadian adults to request medical assistance in dying (Government of Canada, 2017). With the advent of MAiD across Canada, the profession must collectively ensure access to occupational therapy services for clients who choose to participate in MAiD, and those who do not.

2. Professional Education

More research and education is needed to raise the profile for end-of-life care (Hammill, Bye & Cook, 2014). Education of students of occupational therapy in the areas of spirituality and issues related to end-of-life care should be addressed in entry-level professional

programs (Rose, 1999). Courses or workshops offered by interdisciplinary groups can be beneficial for entry-level occupational therapists (Hillier, Coles, Mountford, Sheldon & Turner, 2001). As end-of-life care options continue to grow for clients with changes in practice and improvements in access, it is important to continue to identify potential occupational therapy contributions across all of end-of-life care and to increase professional development opportunities to enable collaborative practice in keeping with individual conscience and choice (Bernick et al 2015; Bernick, Winter and Reel 2015; Gordon, Drolet and Reel 2015).

3. Research and data

The personal-professional connection and experiences of working in end-of-life care occupational therapy has been examined by Prochnau, Liu, and Boman (2003). Further research is needed to examine the relationship between these themes and strategies for recruiting and retaining occupational therapists in end-of-life care.

Future research in occupational therapy practice and end-of-life care includes effective pain and symptom management, psychosocial aspects of care, effective methods of delivering services, including home care and the needs of family and professional caregivers supporting dying people (Harding & Higginson, 2003; Rokach, 2015).

4. Family and caregiver support

The QELCCC calls on the federal government to take a strong leadership role in improving access to palliative and end-of-life care. QELCCC's advocacy contributed to changes to the Compassionate Care Benefits resulting in expanded eligibility for the benefit.

5. Public education and awareness

The QELCCC continues to encourage advance care planning through promotion of Speak Up! Advance Care Planning in Canada resources. The QELCCC calls on the federal and provincial governments to undertake public awareness campaigns about advance care planning specifically, and end-of-life care, generally.

Occupational therapists in collaboration with the QELCCC and CHPCA can access initiatives, resources, and tools for healthcare professionals designed to help them ensure more people in Canada have advanced care plans and promote awareness of the end of life choices available in Canada.

Glossary of Terms

Advance care planning: a process of reflection and communication on and around values and wishes regarding health and personal care and what one might

want in the future if unable to speak for oneself.

Enabling: Focused on occupation, this is the core competency of occupational therapy – what occupational therapists actually do – and draws on an interwoven spectrum of key and related enablement skills, which are value-based, collaborative, attentive to power inequities and diversity, and charged with visions of possibility for individual and/or social change (Townsend & Polatajko, 2007).

Enabling occupation: Refers to enabling people to ‘choose, organize, and perform those occupations they find useful and meaningful in their environment’ (CAOT 1997, 2002, p. 180).

End-of-life care: care that begins when a person is actively dying, continuing until death and afterward - into family bereavement and care of the body. It is care provided to relieve suffering and improve the quality of living until death in all settings across the continuum of care.

Hospice palliative care: Care that aims to relieve suffering and improve quality of life for any client and/or family living with, or at risk of developing, a life-threatening illness at any time they have unmet needs (CHPCA, 2002).

Medical assistance in dying (MAiD): (a) the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or (b) the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death (Government of Canada, 2017).

Occupations: Groups of activities and tasks of everyday life, named, organized, and given value and meaning by individuals and a culture; everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure) and contributing to the social and economic fabric of their communities (productivity); the domain of concern and the therapeutic medium of occupational therapy (CAOT, 1997, 2002); a set of activities that is performed with some consistency and regularity; bring structure and are given meaning by individuals and a culture (adapted from Polatajko et al., 2004 and Zimmerman et al., 2006).

Outcome: A measurable end result or consequence of a specific act on, usually related to the person's health or overall well-being.

(Integrated) Palliative approach: Care that focuses on meeting the full range of needs of a person and family – physical, psychosocial and spiritual – at all stages of a

progressive illness. It reinforces the person's autonomy and right to be actively involved in his or her own care – and strives to give individuals and families a greater sense of control. It sees palliative care as an approach to care that can enhance quality of life throughout the course of illness or the process of aging. It includes regular opportunities to review the person's goals and plan of care and referrals, if required, to expert palliative care services (adapted from QELCCC, 2015).

Palliative sedation: practice of relieving distress in a terminally ill person in the last hours or days of a dying client's life by means of continuous sedative medication.

Quality care: The continuous striving by an interdisciplinary team/organization to meet the expectations and needs of the people and families it serves and the standards established by the organization, health authority, profession and accreditation bodies.

Quality of life: Well-being as defined by each individual. Quality of life relates both to experiences that are meaningful and valuable to the person, and his/her capacity to have such experiences (CHPCA, 2014).

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