

## The Role of Occupational Therapy in End-of-Life Care

The purpose of this statement is to describe the role of occupational therapists and occupational therapy assistants in providing services to clients who are living with chronic or terminal conditions and are at the end of life. It also serves as a resource for occupational therapy practitioners,<sup>1</sup> hospice and palliative care programs, policymakers, funding sources, and clients and caregivers who receive hospice and palliative care services. Occupational therapy practitioners provide skilled intervention to improve quality of life by facilitating engagement in daily life occupations throughout the entire life course. Participation in meaningful life occupations continues to be as important at the end of life as it is at earlier stages. The term *end-of-life care* has replaced the term *terminal care* and encompasses both hospice and palliative care that can occur during the final stages of life.

### Hospice

The contemporary definition of *hospice* encompasses a philosophy of care for individuals of any age with life-limiting illnesses for whom further curative measures are no longer desired or appropriate. Hospice referrals require that the client have a life expectancy of 6 months or less with the usual course of the diagnosis (Centers for Medicare and Medicaid Services, 2010). Hospice care focuses on symptom control and meeting the emotional, social, spiritual, and functional needs of the client and family. As an example, the *Medicare Benefit Policy Manual* states that “Physical therapy, occupational therapy, and speech–language pathology services may be provided for purposes of symptom control or to enable the individual to maintain activities of daily living and basic functional skills.”

Reimbursement for hospice care may be provided by a variety of medical insurers, including Medicare, Medicaid, and private insurance. Some hospice organizations receive funds from grants and private donations that are used to cover services. Local civic, charitable, or religious organizations also may provide funding to help patients and their families with hospice expenses.

The basic philosophy of hospice is described in the *Standards of Practice for Hospice Programs* (National Hospice and Palliative Care Organization, 2002):

Hospice provides support and care for persons in the last phases of incurable disease so that they may live as fully and as comfortably as possible. Hospice recognizes that the dying process is a part of the normal process of living and focuses on enhancing the quality of remaining life. Hospice affirms life and neither hastens nor postpones death. Hospice exists in the hope and belief that, through appropriate care and the promotion of

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<sup>1</sup>When the term *occupational therapy practitioner* is used in this document, it refers to both occupational therapists and occupational therapy assistants (AOTA, 2006). *Occupational therapists* are responsible for all aspects of occupational therapy service delivery and are accountable for the safety and effectiveness of the occupational therapy service delivery process. *Occupational therapy assistants* deliver occupational therapy services under the supervision of and in partnership with an occupational therapist (AOTA, 2009).

a caring community sensitive to their needs, individuals and their families may be free to attain a degree of satisfaction in preparation for death. Hospice recognizes that human growth and development can be a lifelong process. Hospice seeks to preserve and promote the inherent potential for growth within individuals and families without regard to age, gender, nationality, race, creed, sexual orientation, disability, diagnosis, availability of a primary caregiver, or ability to pay. (p. ii)

## **Palliative Care**

Hospice and palliative care are closely related. Both approaches are directed toward providing intervention services to those with life-threatening illnesses. Palliative care differs from hospice care in that it can be initiated at any point in the course of the client's illness. Curative care interventions also may be used within the context of palliative approach, whereas curative services are not provided when a client is receiving hospice care. A client receiving palliative and curative services simultaneously may transition to a hospice service when curative therapies are no longer appropriate or desired and the end of life is more imminent. The World Health Organization (2002) defines *palliative care* as

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.

## **Care Settings**

End-of-life care may take place in a variety of settings, depending on the client's need and situation. Many individuals served by hospice organizations are seen in their homes (Marrelli, 2005). Hospice care also may be provided in freestanding community in-patient facilities and in specified units or beds within a skilled nursing facility or hospital. Some home health care agencies also provide hospice services staffed by designated hospice care providers.

Hospice teams are interdisciplinary. In addition to occupational therapy practitioners, teams include counselors, clergypersons, and volunteers, as well as physicians, nurses, social workers, dietitians, physical therapists, and speech–language pathologists.

## **Role of Occupational Therapy**

Individuals with life-threatening and life-limiting illness often have difficulty participating in daily occupations because of decline in their motor, sensory, emotional, cognitive, or communication skills. Occupational therapy practitioners help clients find relief from pain and suffering and improve their quality of life by supporting their engagement in daily life occupations that clients find meaningful and purposeful. The occupational therapy practitioner considers environmental and contextual factors (e.g., caregiver training, accessibility of objects or places in the environment, social contacts available to prevent isolation), as well as personal

factors (e.g., decreased endurance, increased anxiety) that may be limiting a client’s abilities and satisfaction when performing desired occupations. The occupational therapy practitioner collaborates with the client and family members throughout the occupational therapy process to identify occupations that are especially meaningful and to incorporate strategies that support occupational engagement. As Kaye (2006) points out in *Notes on Symptom Control in Hospice and Palliative Care*, “Loss of independence and role can result in social death prior to biological death. Occupational therapy can help a person to adopt new and appropriate functions and roles and to maintain self-esteem.” (p. 214).

**Quality of Life at the End of Life**

Improved quality of life is a primary outcome of all occupational therapy interventions (AOTA, 2008). Occupational therapy practitioners believe that engaging in occupations underlies health and quality of life. At the end of life when clients often face loss of previously established occupational roles, occupations, and performance abilities, their need to identify and sustain meaningful engagement is heightened. Family members and professionals alike may find it difficult to comprehend the diminution of life quality when illness interferes with abilities to carry out familiar occupations. The pleasure and sense of self-worth inherent in participating in familiar occupations, even those as basic as making a cup of coffee at the time one wants to have a cup of coffee, is immeasurable. The value lies not so much in the cup of coffee, which can be provided by someone else, but in having control over choosing when to have the coffee and perhaps making the coffee when desired.

Numerous researchers have examined how persons at the end of life view their quality of life and quality of care. Many of these research studies have identified factors that affect quality of life and quality of care that are similar to the factors that occupational therapy practitioners address during their interventions (see Table 1).

**Table 1. Factors Influencing Quality of Life and Quality of Care at the End of Life**

Factor	Relationship to Occupational Therapy	References
Maintaining functioning and involvement in desired life activities contributes to quality of life.	Occupational therapy practitioners believe that continuing to engage in occupations allows a person to continue his or her life—and is central to health and quality of life. Modifying previous occupations so that they can still be performed and adding new occupations to replace lost ones prevents isolation, a common experience at the end of life, and	Arnold, Artin, Griffith, Person, & Graham, 2006; Egan & DeLaat, 1997; Gourdjii, McVey, & Purden, 2009; Jacques & Hasselkus, 2004; Lyons, Orozovic, Davis, & Newman, 2002; Ryan, 2005

	contributes to the sustainment of self-worth.	
Maintaining a sense of control contributes to quality of life.	By participating in daily life occupations that they value as purposeful and meaningful, individuals make choices that give them a sense of control, identity, and competence.	Christiansen, 1999; Egan & DeLaat, 2003, Singer, Martin, & Kelner, 1999; Vrkljan & Miller-Polgar, 2001
Continuing to contribute to others and staying connected to important relationships contributes to quality of life.	Engaging individuals in tasks and activities is a central focus of the occupational therapy intervention process. Completing tasks such as writing letters to grandchildren or recording favorite recipes within an individual's social context allows a person to feel productive and to strengthen social relationships.	Enes, 2003; Gourджи et al., 2009; Hunter, 2008; Lyons et al., 2002; Singer et al., 1999; Steinhauer et al., 2000
Continuing to search for meaning and purpose in life and one's relationship to a higher being also is referred to as <i>spirituality</i> .	Occupational therapy practitioners recognize spirituality as an important client factor. They believe that the process of engaging in occupations helps the person connect to the meaning and purpose in life, which enhances spiritual well-being, quality of life, and ability to cope. Engaging in occupations can counteract feelings of hopelessness, helplessness, and uselessness that may develop during the end of life. Occupational therapy practitioners help individuals identify meaningful occupations in which they want to engage and teach coping strategies that allow continued participation.	AOTA, 2008; Chochinov & Cann, 2005; Egan & DeLaat, 1997; Lin & Bauer-Wu, 2003; Pizzi & Briggs, 2004; Prince-Paul, 2008; Unruh, Smith, & Scammell, 2000

### Research to Support Practice

Although occupational therapy practice with clients at the end of life is not new, evidence that supports this area of practice is less well developed. Since the 1970s, occupational therapists have investigated and described how occupational therapy practitioners provide services to clients at this life stage (Bye, 1998; Picard & Magno, 1982; Pizzi, 1984; Pizzi & Briggs, 2004; Rahman, 2000; Tiggs & Sherman, 1983). These studies have pointed out occupational therapy's

role in supporting the individual's quality of life by facilitating role performance and function in desired occupations, competence, control, and coping to assist the person in bringing closure to his or her life. Several phenomenological studies conducted by occupational therapists have elucidated how occupations contribute to living at the end of life and how individuals at the end of life describe the benefits of engaging in daily life occupations (Lyons et al., 2002; Unruh et al., 2000).

The validity of specific interventions that occupational therapy practitioners may use is beginning to be investigated. La Cour, Josephsson, and Luborsky (2005) and La Cour, Josephsson, Tishelman, and Nygård (2007) have explored the effects of using creative activities with clients who have life-threatening illnesses. In both studies, the researchers found that participation in creative activities allowed clients to cope with declining abilities and to create connections to life. Clients reported an improved existential awareness of their past, their present, and possible future.

Hunter (2008) further explored the ideas of existential meaning, which people at the end of life confront. She explored the responses of 38 women to understand how they defined legacy and its importance in their lives. She found that legacy is closely related to transmitting one's sense of who they are to others. Legacy transmission can be effected by transmitting actions (behaviors) as well as artifacts (concrete items). In either case, these legacies are closely connected to the occupations and occupational identities that people develop throughout their life. Occupational therapy practitioners who are sensitive to the client's occupational profile and identity can facilitate the client's ability to identify and transmit purposeful legacies.

Effectiveness of palliative care programs also is beginning to be documented. Several studies have reported on how outpatient palliative rehabilitation programs, palliative day care programs, and inpatient palliative care units have improved patient satisfaction, functional performance, emotional well-being, and symptoms (Cohen, Boston, Mount, & Porterfield, 2001; Hospital Case Management, 2003; Strasser et al., 2004; Svidén, Fürst, von Koch, & Borell, 2009). In two of these studies (Hospital Case Management, 2003; Strasser et al., 2004), an occupational therapist was specifically mentioned as a member of the team.

Saarik and Hartley (2010) reported on a 4-week fatigue management program in Britain carried out by an occupational therapist and a physiotherapist specializing in palliative care. The program was delivered in a hospice day care program with patients with cancer. Clients who completed the program reported decreased fatigue levels, overall improved functioning, and enhanced ability to cope.

Occupational therapy practitioners have recognized the need to provide evidence that supports the profession's contribution to quality of life at the end of life. Pearson, Todd and Fletcher (2007) have proposed that occupational therapy practitioners use a quality of life measure during their evaluations to measure the effectiveness of occupational therapy interventions in palliative care practice. They identified 24 possible tools and plan to evaluate them further for application by occupational therapists.

## **Occupational Therapy Process**

### ***Evaluation***

A client may be referred for occupational therapy at any point during the end-of-life process. Any health care provider may identify the need for occupational therapy.

The occupational therapist begins the evaluation process by conducting an occupational profile. The occupational therapist gathers information for the profile by talking to the client to gain an understanding of meaningful and relevant occupations, daily routines, interests, values, and priorities as well as the client's view of life and expectations of dying. Interviewing caregivers, including family or significant others, to determine their priorities and concerns is important, especially when the client is unable to express his or her desires and wishes pertaining to end-of-life care. The interview also examines cultural, spiritual, and social factors that influence a client's expectations for the end of life.

This client-centered approach enables the occupational therapy practitioner to establish a relationship that facilitates discussion of important occupational areas. For example, the client may prefer to be dressed by the caregiver to save energy to tape stories to share with his or her grandchild.

On the basis of these priorities and concerns, the occupational therapist may specifically assess and analyze the client's or caregivers' performance skills in the desired activities and roles. Although clients receiving hospice or palliative care services may have declining performance skills, the occupational therapist assesses strengths and capacities that can support continued performance of desired occupations. The occupational therapist analyzes the demands of activities important to the client and the supports and barriers of the context or environment as they affect outcomes. The evaluation also may include assessment of caregivers' skills and need for skill training and support, as well as identification of the adaptive or compensatory strategies needed to carry out task performance and/or the environmental modifications that need to be implemented to support the client's skills and capabilities. Identification of the client's needs and wishes, combined with analysis of the client's performance capacities, allows the occupational therapist to identify effective and client-centered occupational therapy interventions, which are then incorporated into the interdisciplinary plan of care.

### ***Intervention***

The occupational therapist develops an intervention plan in collaboration with the client and the caregivers. The intervention plan identifies the outcomes of intervention and the approaches to be used. Occupational therapy interventions are targeted toward creating a fit between the client's and caregivers' capabilities and the demands of the activities that are important to the client and caregivers. Intervention may be provided directly to the client or the caregivers or family members. Intervention directed toward caregivers frequently consists of education and consultation to support efficacy and satisfaction with the care they provide. Interventions chosen will depend on the client's needs and desires and medical status at the time of referral. For

example, a client with cancer who is alert and aware of his or her surroundings but dealing with issues of pain management, symptom control, and loss of occupational roles and relationships will face different challenges than a client who is referred in the later stages of Alzheimer’s disease who is cognitively disoriented but is experiencing little pain. In the latter situation, intervention may more appropriately be directed at numerous challenges facing caregivers, such as instruction in managing behaviors and safety precautions.

Interventions for the client may focus on relieving symptoms that interfere with function. For example, if pain or shortness of breath is limiting function, repositioning to a supported sitting position in bed may relieve pain and improve breathing, enabling the client to write letters. Engaging in meaningful occupations not only improves quality of life but also can serve as an important tool for symptom management. Clients whose attention is focused on meaningful occupations pay less attention to physical symptoms.

Approaches most commonly used by occupational therapy at the end of life are compensation, adaptation, and preservation of existing capacities. Occupational therapy practitioners focus on modifying the demands of activities or the habits and routines associated with the occupations to match the client’s or caregiver’s performance skills, tolerances, and capacities. Occupational therapy practitioners also use interventions targeted toward minimizing barriers to performance.

Ongoing review of occupational therapy interventions is critical in evaluating effectiveness and progress toward targeted outcomes. Because clients may experience sudden and sometimes unexpected changes, interventions may have to be modified significantly as the client’s status changes. Progress also is defined by the nature of care. Acceptance and improved quality of life is progress, even as a client’s body systems and performance skills decline. Occupational therapy services may be appropriate at different points during the course of hospice and palliative care for a given client as that client’s needs, priorities, and abilities change over time.

**Outcomes**

The ultimate outcome of end-of-life care is supporting or improving the client’s and family’s quality of life. The following case examples (Table 2) illustrate how occupational therapy intervention may be provided to address different needs and priorities for clients, caregivers, and families that contribute to quality of life.

**Table 2. Case Examples**

<b>Case Description</b>	<b>Occupational Therapy Interventions</b>	<b>Outcomes</b>
<b>Gertrude</b> , an 80-year-old grandmother with 11 supportive grandchildren, moved into a hospice facility after a significant decline in	After talking to Gertrude, the occupational therapist determined that Gertrude avoided taking her pain medication because she was	With her anxiety about frightening her grandchildren lessened, Gertrude was more agreeable to taking her medications regularly. The

<p>her physical status. The hospice team was concerned about her refusal to follow the pain medication regime and requested an occupational therapy referral to address strategies for pain management.</p>	<p>afraid of having slurred speech and being confused and lethargic, symptoms that might frighten her grandchildren when they visited. Although without pain medications, she was alert when her grandchildren visited, but her pain limited her ability to enjoy these visits or to participate in other activities that were important to her. The occupational therapist recommended changes in Gertrude’s daily routines to accommodate her desired roles, meaningful occupations, and pain management needs. The occupational therapist facilitated the collaboration of the hospice team. Together, they worked with Gertrude and her family to develop a modified visitation and medication schedule so that family visits were not occurring at times when the medication’s effects on Gertrude’s alertness were most intense.</p>	<p>resulting effective management of her pain allowed her to increase involvement in valued occupations and to maintain her role as a loving grandmother.</p>
<p><b>Gustavo</b>, a man in his 50s, had several metastatic tumors, including one recently removed from his right shoulder. Gustavo was ambulatory, and although he did not have any active right shoulder movement, he was able to complete basic self-care and was to be discharged to his home with hospice care. Gustavo expressed discouragement at his inability to complete two meaningful projects at home: a mural on</p>	<p>The occupational therapist worked with Gustavo on fatigue management, ergonomics, pacing, and setting priorities for activities. Strategies included positioning his right arm on a leaning pole to act as a support while completing the mural. Adaptive techniques for building the boat included having his nephew work as an apprentice to help with the heavy tasks while Gustavo passed on his boat-building</p>	<p>Gustavo now looked forward to going home, “because I’m not going home to die, I’m going back to my art.”</p>



<p>the living room wall and a wooden boat he was building.</p>	<p>skills.</p>	
<p><b>Asuka</b>, a 60-year-old woman from Japan, had difficulty expressing her desires even with the support of an interpreter. She appeared depressed and usually stayed in her room sleeping with the lights off rather than visiting with her daughters when they arrived at the facility.</p>	<p>The occupational therapist met with Asuka’s daughters to identify any meaningful activities that she had done in the past. Her daughters identified origami as a valued family activity that their mother used to enjoy. The occupational therapist encouraged the daughters to bring in origami supplies and to work on this activity even though their mother did not respond. As the daughters struggled to remember how to fold the paper to look like a crane, they began laughing. Their laughter woke Asuka, who sat up, asked to have the lights turned on, took the paper from them, and demonstrated how to create an origami crane.</p>	<p>Engagement in this activity allowed Asuka to resume the role of mother and teacher of activities that she valued as culturally significant. She went on to draw each child’s name in Japanese calligraphy. This generated increased family interactions and provided meaningful time together.</p>
<p><b>Dmitri</b> resided in an assisted living facility (ALF) with his wife of 52 years. When Dmitri’s health condition was considered terminal, he elected to receive hospice care. Dmitri, his wife, and the hospice team were concerned that, as his abilities declined, his need for assistance might exceed the level permitted for him to remain in the ALF. Care provided by professionals or paraprofessionals was limited to a specific number of hours per week for Dmitri to remain in the ALF, but care provided by his wife was not included in this limit. During the initial occupational therapy</p>	<p>The occupational therapy practitioner implemented an intervention plan that involved both Dmitri and his wife. Instructions were provided regarding techniques for completing activities of daily living—bathing, dressing, and toileting—as well as assuring both Dmitri and his wife’s safety. Planning with his family to address his continued physical decline included introducing adaptive equipment and modifications to the home, which reduced the demands of important activities and made them manageable for Dmitri and his wife. His environment was adapted to allow him to</p>	<p>Dmitri was able to stay in his ALF home environment without the need of additional staff time. His wife was able to care for him effectively, and he was able to maintain his roles as husband and community member during his last days as a result of these interventions.</p>

<p>encounter, it became evident that Dmitri's concern was not to burden his wife with his increasing needs for assistance.</p>	<p>continue to participate in his long-standing weekly poker party and to maintain his role as a vital and active member in the ALF.</p>	
<p><b>Fatima</b> wanted to maintain her role as a mother despite being diagnosed with terminal cancer. Because Fatima had two small children, a referral was made to occupational therapy to identify strategies for her to participate in caring for her children and engaging in other occupations related to being a mother.</p>	<p>The occupational therapist provided services to both Fatima and her husband. The occupational therapist recommended positioning techniques to allow Fatima to hold and feed her toddler. Other interventions focused on strategies so that she could bathe her toddler, assist her older daughter with picking out clothes for school, and participate in family outings. The occupational therapy assistant worked with Fatima to write letters and make video recordings and other remembrances so that she would be able to leave something for each of her children as they went through milestones of life, such as high school graduation, entering college, marriage, and the birth of a child.</p>	<p>This occupational therapy intervention supported Fatima's desire to maintain her role as mother until her death and then to leave something behind so that she would still be a presence in the lives of her children.</p>
<p><b>Peter</b> was a 5-year-old boy who received hospice care. Both of his parents and two older siblings lived with Peter and were involved in his care. Occupational therapy was included in the hospice plan of care to maintain Peter's ability to play and engage socially with his family despite declining physical and cognitive abilities.</p>	<p>The occupational therapy practitioner involved both Peter and his family in interventions, which included modifications for current games and activities that Peter enjoyed and appropriate positioning strategies to support his participation.</p>	<p>Peter was able to successfully maintain his ability to engage in play and family interaction even as his condition deteriorated.</p>
<p><b>Ethel</b>, an older woman with cancer, lived with her husband. When her cancer metastasized, Ethel made the</p>	<p>The occupational therapy practitioner taught Ethel how to use energy conservation strategies to reduce fatigue</p>	<p>Ethel still could participate actively in valued activities such as planning meals and helping her husband prepare a</p>

<p>decision to terminate planned interventions and to elect hospice care. Initially, Ethel's ability to engage in daily routines and roles was unchanged, but she gradually experienced significant fatigue and had difficulty performing valued activities, such as cooking and cleaning her house.</p>	<p>and accommodate her limited tolerance while continuing to perform household tasks. As Ethel's disease progressed and her ability to perform these occupations declined, interventions focused on interdependence by using modifications to activities that she and her husband could do together.</p>	<p>grocery list, while her husband completed components of the activities to reduce stress and fatigue. At all stages the occupational therapist worked with Ethel to help her to begin to plan for her death. Occupational therapy interventions involved occupations such as passing on recipes to family members, teaching family members how to make specific foods and recipes, and bequeathing a favorite cooking utensil to a particular family member.</p>
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## Summary

Occupational therapy practitioners are an important part of hospice and palliative care teams as direct care providers and consultants. Occupational therapy practitioners educate other team members on the meaning and importance of occupation in a person's life and in the dying process. An occupational therapy practitioner's deep understanding of the meaning of occupation makes a powerful contribution to the process of caring for the dying person.

To this end, occupational therapy practitioners function across the continuum of end-of-life care to help support the roles of the client with terminal illness. Although a client's body systems and skills may deteriorate, occupational therapy interventions can support the client's ability to maintain important roles and relationships and to engage in the occupations related to those roles. Having choices and being able to participate in daily activities of self-care can support a sense of self-efficacy and control during the dying process. Continuation of important rituals of everyday activity can support meaningfulness in the dying person's final days (Thompson, 1991).

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*Adopted by the Representative Assembly 2011AprC14*

*Note: This replaces the 2004 document “Occupational Therapy and Hospice” (previously published and copyrighted in 2005 by the American Occupational Therapy Association in the American Journal of Occupational Therapy, 59, 671–675).*

To be published and copyrighted in 2011 by the American Occupational Therapy Association in the *American Journal of Occupational Therapy*, 65(6 Suppl.)