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Embracing Life with ALS: the Role of Occupational Therapy from Diagnosis to End of Life Care

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EMBRACING LIFE WITH ALS: THE ROLE OF OCCUPATIONAL THERAPY FROM
DIAGNOSIS TO END OF LIFE CARE

by

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Submitted to the Occupational Therapy Department

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University of North Dakota

In partial fulfillment of the requirements

for the degree of

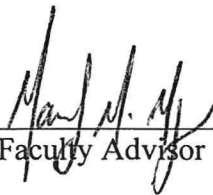
Master's of Occupational Therapy



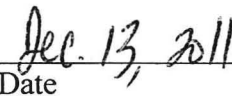
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This Scholarly Project Paper, submitted by Chelsey Edwards, MOTS and Amy Ferguson, MOTS in partial fulfillment of the requirement for the Degree of Master's of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.



Faculty Advisor



Date

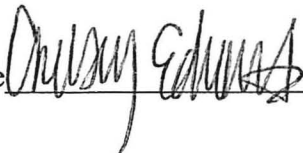
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Title Embracing Life with ALS: The Role of Occupational Therapy
from Diagnosis to End-of-Life Care

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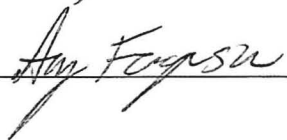
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ABSTRACT

Purpose: The purpose of this scholarly project was to develop a comprehensive document that describes the role of the occupational therapist in working with clients and families affected by Amyotrophic Lateral Sclerosis (ALS) from diagnosis to end-of-life care.

Method: A literature review was conducted using the AJOT, PubMed, CINAHL, and OT SEARCH databases. Information was gathered regarding current literature of ALS, the disease process, occupational therapy's role in ALS treatment, caregiver's role in end-of-life care, assistive technology, palliative care options, and additional support strategies. Additional ALS material was gathered from the ALS Association's informational manuals.

Results: Designed from the perspective of the Canadian Model of Occupational Performance-Enablement, the product, "*Embracing Life with ALS: The Role of Occupational Therapy from Diagnosis to End-of-Life Care*", was created. The role of the occupational therapist was integrated within the Canadian Model's ten enablement skills, eight action points, and significant findings from the literature review. Special attention was placed on an assistive technology section for compensation in order to allow the client to remain as independent as possible throughout the disease progression.

Conclusions: The occupational therapy document created encourages a holistic approach to ALS care that involves both the client and the family in collaboration with the occupational therapist. The document addresses physical, mental, emotional, and spiritual aspects of the client enabling them to engage in meaningful occupation and increase quality of life.

CHAPTER 1

INTRODUCTION

Rationale

Amyotrophic Lateral Sclerosis (ALS) is a degenerative motor neuron disorder. It is the most commonly diagnosed motor neuron disease in adult life (Rocha, Reis, Simoes, Fonseca & Ribeiro, 2005) and approximately 5,600 people are diagnosed with this disorder in the United States every year (The ALS Association, n.d.). It affects motor neurons in the cerebral cortex, brainstem, and spinal cord (Appel, Stewart, Smith, & Appel, 1987; Lewis & Rushanan, 2007). The disease is characterized by slow progression of loss of voluntary control of muscles, hyperreflexia, and spasticity. Currently there is no known etiology or cure for ALS. An individual will live an average of two to four years once diagnosed. The effectiveness of therapy for this population is difficult to determine because the progression of the disease is different for each individual (Appel, Stewart, Smith, & Appel, 1987) and the final outcome of the disease is inevitable.

Theoretical Framework

The Canadian Model of Occupational Performance-Enablement (CMOP-E) was used to develop a document for occupational therapists (OTs) working with clients diagnosed with ALS. The emphasis of this model includes the two core concepts of

enablement and occupation. Within our product the role of the OT was developed in relation to the ten enablement skills (Townsend, et al., 2007):

- Adapt – Providing outlets for clients to engage in meaningful occupations through modification to fit performance challenges.
- Advocate – Raising important aspects of client care to the state and federal level. Also, power sharing and lobbying for clients personal needs.
- Coach – Developing a relationship to help clients engage successfully in their personal and professional lives.
- Collaborate – Sharing power with clients and caregivers related to their occupational needs. Also, developing a relationship to allow for successful performance in their meaningful occupations.
- Consult – Exchanging views with additional team members and clients about occupational therapy practice and outside resources.
- Coordinate – Linking clients and family with outside resources and facilitating interactions with additional team members.
- Design/Build – Creating products to allow for engagement in occupations through the use of assistive technology, orthotics, communication devices, etc.
- Educate – Teaching clients and family about disease process, prognosis, and the role of occupational therapy in the rehabilitative team.
- Engage – The performance of occupations.
- Specialize – The use of precise techniques to manage symptoms and occupational needs.

The eight action points of the CMOP-E (Davis, Craik, & Polatajko, 2007) were also incorporated into the OT document. They include:

- Enter/initiate – Advocate for the use of occupational therapy in the rehabilitative team and educate clients on the role of occupational therapy.
- Set the stage - Build rapport and engage client in occupational readiness.
- Assess/evaluate – Through the use of the COPM, the client’s performance in meaningful occupations is evaluated. The therapist is responsible for consulting and coordinating with other team members to ensure all needs are met.
- Agree on objectives and plan – Collaborate with client to determine goals and treatment plan. Coordinate services with other disciplines and design/build a care plan that is congruent with client and caregivers goals.
- Implement the plan – Engage client in meaningful occupations through the use of a specialized frame of reference.
- Monitor and modify – Adapt and modify the treatment plan in order to engage the client in successful occupations. Consult with the client to ensure all needs are being met through occupational therapy.
- Evaluate outcome – Determine occupational therapy findings and client’s ability to engage in meaningful occupations.
- Conclude/exit – Conclude the relationship upon the completion of the therapy process. Document the conclusion therapy.

Within the CMOP-E, spirituality is considered the core aspect of the individual along with cognitive, affective, and physical aspects. This model divides a person's occupations into self-care, productivity, and leisure. The person and their occupations are encompassed within the environmental aspects: physical, institutional, cultural, and social. Through the therapy process, the collaborative relationship between the client and the therapist enables participation in meaningful occupations (Polatajko, et al., 2007). In addition, the Rehabilitative Frame of Reference was used to teach the client to compensate with assistive technology (Cole & Tufano, 2008).

Statement of the Problem

Current literature displays minimal research or articles related to occupational therapy and the profession's role with ALS. Lewis & Rushanan (2007) report the main goal of OTs is to "maintain independence with functional mobility and activities of daily living" (Lewis & Rashanan, 2007, pp. 451-452). Occupational therapists can accomplish this through the use of assistive devices, splints, wheelchair use/modification, home modification, and more. In addition, caregiver support has been identified as a lacking issue related to ALS but has not been addressed for OTs (Borasio & Voltz, 1997; Lewis & Rushanan, 2007). Research has suggested a full continuum of care is needed, but few articles describe how to do so.

Scope and Delimitation

An OT is qualified to work with the ALS population due to their training and experience with client-centered and holistic care. In occupational therapy, all aspects of the individual including the physical, mental, emotional, and spiritual should be evaluated and incorporated into treatment. The OT can help the client and his/her caregivers make

modifications to the home as well as provide adaptive equipment to make various activities easier to complete without the need for assistance. Occupational therapists can also consult with the family and other professionals on the client's care team to increase quality of life for the client.

Importance of the Study

This scholarly project provides a document an OT can follow throughout the progression of ALS from diagnosis to end-of-life. It provides a detailed outline of possible topics and interventions to utilize with the client as well as the family to ensure all needs are being met. Verbal and written examples are provided to assist the OT within the various stages of the disease. Suggestions for modification of tools and tasks to meet individual client needs are also included. In addition, it outlines the process of care for clinic use. This product can also be generalized to other terminal illnesses with various modifications.

CHAPTER II

LITERATURE REVIEW

A comprehensive literature review was conducted which included journal articles regarding Amyotrophic Lateral Sclerosis (ALS), the role of occupational therapy in palliative care, and the therapeutic interventions that are available for clients with this disease. Specific areas of intervention included assistive technology, caregiver education, positioning/pressure relief, and sexuality. Pertinent information was summarized and compiled into the following review.

ALS

ALS is the most commonly diagnosed motor neuron disease in adult life (Rocha, Reis, Simoes, Fonseca & Ribeiro, 2005). Approximately 5,600 people are diagnosed with this disease in the United States every year. At any given time 30,000 Americans are living with ALS. The average life expectancy for someone diagnosed with ALS is approximately 2 to 5 years from the time of diagnosis with 10 percent living past 10 years (The ALS Association, n.d.).

The initial signs and symptoms of ALS are different for each person; however, a key characteristic experienced by almost all patients is muscle weakness and atrophy (Forshew & Hulihan, 2007). Simple tasks that once required no effort become tiring and difficult. These may include speaking, chewing, walking, moving an arm or a leg, and more. Cramps, stiffness, difficulty controlling emotions, and trouble breathing or

coughing are also common. Unfortunately, no diagnostic test is available, therefore, other diseases and disorders must be ruled out before a diagnosis of ALS is made. Genetic links are still being tested although little research has been published with strong evidence to support the rationale behind the deciding factors associated with the diagnosis (The ALS Association, n.d.).

ALS is a motor neuron disease characterized by progressive muscle weakness and atrophy of lower and/or upper motor neurons (Forsheew & Hulihan, 2007). Upper motor neuron involvement is characterized by lack of coordination, loss of hand dexterity, spasticity, hyperreflexia, pathological reflexes and pseudobulbar affect. Lower motor neuron involvement is characterized by muscle weakness, atrophy, and widespread fasciculations. Bulbar involvement can also occur which is characterized by hyperreflexia of the jaw, pathological reflexes, pseudobulbar affect, tongue atrophy, tongue fasciculations, dysarthria, sialorrhea, and dysphagia (Rocha, Reis, Simoes, Fonseca & Ribeiro, 2005).

Van den Berg, Groot, Joha, Haelst, Gorcom, & Kalmijn (2004) divided the timeline of ALS progression into three separate phases. The first phase is the diagnostic phase which includes obtaining information about the disease including the course, prognosis, and progression. The second phase is the rehabilitation phase which is characterized by independence, independence with aids and appliances, and dependence. While an individual is independent he or she is shown possible treatment options and works with the rehabilitation team to develop individualized goals. Treatment starts as outpatient and is graded based upon the progression of the disease. When a client is independent with aids and appliances he or she is educated about adaptive equipment that

will be best suited in the case of rapid progression. Management and acceptance of the adaptive equipment is important in this stage and discussion of possible feeding tubes and mechanical ventilation commonly begins. When the client becomes dependent the focus of therapy should be on home adaptations and the support of caregivers. Home visits are completed as the client is no longer able to come to the rehabilitation department. Final decisions are made regarding mechanical ventilation, feeding tubes, last will, and terminal treatment plan. During the third and final phase the client displays increasing respiratory problems until the time of death. Aftercare is provided with condolences sent to the family.

ALS Care Teams

The occupational therapist (OT) is one of the many members of a multidisciplinary team that must work together to diminish the impact ALS will have on the client and his or her family. The team generally consists of a consultant in rehabilitation medicine, social worker, psychologist, OT, physical therapist, speech/language pathologist, dietician, neurologist, physician, the client, and the client's family (Van den Berg, Groot, Joha, Haelst, Gorcom, & Kalmijn, 2004). Quality of life is of the utmost importance and should be addressed by all throughout the therapy relationship (Lewis & Rushanan, 2007; Van den Berg, Groot, Joha, Haelst, Gorcom, & Kalmijn, 2004).

Occupational therapy plays a direct role in supplying and educating clients in regards to adaptive equipment. However, the team effort is essential as speech language pathologists, physical therapists, and OTs work together to ensure the client is having his or her needs met through the use of the equipment provided. Speech language

pathologists will work with the OTs regarding communication devices. These can range from low technology devices such as a notebook or communication board with simple pictures to high technology devices such as voice amplifiers, electronic communication boards, and laptops with communication programs. The client should be provided with options and detailed explanations to allow him to make the final decision on which equipment he prefers to use.

Occupational therapists also work with physical therapists who supply the client with ambulatory aids, such as canes, walkers, and wheelchairs. Canes can have a single point or a four-point base depending on the ability of the client to balance. There are multiple forms of walkers available as well. Pickup walkers have four legs without wheels and require the operator to pick up the walker after each step. Two-wheeled walkers are available with front wheels that remain straight or wheels that swivel for easy turning. Brakes can also be added to these two-wheeled walkers. A walker with four wheels, brakes, and a seat are often the most appropriate for clients with ALS as they fatigue easily and may need to rest (Mendoza & Rafter, 2007). Wheelchairs are another option physical therapists may suggest that are available with multiple features to fit each client. A manual wheelchair is a basic wheelchair with elevated legrests, back and seat cushions, a high reclining back with a headrest, and adjustable armrests. These are not often used for those with ALS due to the effort required by the client to propel the chair forward. Power wheelchairs are generally recommended for clients with ALS and they include special electronics which can be adapted to fit the client's changing needs, a reclining or tilting back with head support to allow for pressure relief, and elevating leg rests. Various seat cushions are available to help prevent pressure sores on the client's

tailbone and ischium. Braces or foot orthotics are also available for the client who is able to walk but displays difficulty due to ankle weakness. A physical therapist or orthotist can provide a client with an ankle-foot orthosis (AFO) that will keep the ankle in proper position while dorsiflexing and plantarflexing during walking (Mendoza & Rafter, 2007).

Occupational Therapists' Roles in ALS

Occupational therapists have the skills needed to address many problems encountered by the ALS population. Their knowledge in adaptive equipment, positioning, caregiver training and end-of-life issues allows for them to address the multiple challenges faced by this population. They support the health and participation of individuals by assisting them with engagement in occupations through all aspects of their lives (American Occupational Therapy Association, 2008). This includes ADLs, work, sleep/rest, and more (American Occupational Therapy Association, 2008; Mendoza & Rafter, 2007). As the OT works with the client, he or she will use various forms of interventions to address goals specific to the client. Within the realm of ALS, the OT may help the client be independent in toileting through the use of adaptive equipment, educate the client on methods to make swallowing foods easier, provide pressure relief and energy conservation exercises, train caregivers, and much more. As the disease progresses, the methods used by the OT will change. The client will fatigue easier, have less control over various body functions, and will place more value on spending time with family and friends than being independent with activities. Symptomatic treatment will be important throughout the progression of the disease, although it will be especially important towards end-of-life care (Radunovic, Mitsumoto, & Leigh, 2007). The OT

must anticipate and be prepared to change his or her focus over time and as the client wishes (Van den Berg, Groot, Joha, Haelst, Gorcom, & Kalmijn, 2004).

Specifically, transfers become more difficult as the client loses strength and control of his or her muscles. Transfer boards provide a smooth surface for clients to slide across from one surface to another. Caregivers should be given proper training by an OT regarding transfer boards before attempting to use one. Hoyer lifts are another option for the client requiring maximal assistance or if he is of a larger stature than the caregiver (Mendoza & Rafter, 2007).

Feeding and eating can also be a troublesome occupation for individuals with ALS as arm, hand, jaw, and other oral muscles become weaker. Fortunately, many forms of adaptive equipment are available in the occupational area. Silverware can be purchased or adapted by an OT with cylindrical foam buildups, utensil holders, or bendable silverware to allow the individual to angle the fork or spoon as needed. Rocker knives are available to allow for easier grip and force for cutting. Plates can be adapted with a universal cuff that allows the client to use a built-up edge to push food onto the silverware. Cups with rubber grippers, side holders, straws, or nose cut-outs can also be purchased or fabricated. Foods can be adapted by adding Thick-It, a powder that thickens thin liquids which make them easier for an individual to swallow. Other methods an OT can suggest to make eating easier include smaller portions, foods that are easy to chew, adapting sensation with warm or cold temperatures, and eating small portions throughout the day to prevent muscle fatigue. If the client reaches a stage where he or she can no longer maintain an adequate nutritional intake, feeding tubes may be needed (Carr-Davis, Blakely-Adams, & Corinblit, 2007).

Bathing and grooming can be particularly difficult to complete as these occupations generally require higher amounts of energy expenditure. OTs can instruct clients to use tub benches if getting into a standard tub is required in order to shower (Gruis, Wren, and Huggins, 2011; Mendoza & Rafter, 2007). Shower chairs are available for the individual to sit on while showering to prevent falls. Hand-held shower hoses are another useful option since it allows the client to move the water source to the area he or she desires to wash instead of moving and turning the body. The client can use a long-handled brush to clean his or her back, legs, and feet. The client may want to consider a rolling shower chair although remodeling may be necessary for this adaptation. Other areas of difficulty include oral hygiene which can be made easier with the use of an electric toothbrush and floss holders. The client may experience difficulty reaching the back of his or her head when brushing hair. Long-handled brushes and combs are available to help the individual reach those difficult areas. Nail clippers that are connected to a stable surface are also available if fine motor and in-hand manipulation skills are no longer adequate for trimming nails (Mendoza & Rafter, 2007).

Donning and doffing clothing can be a difficult and frustrating experience for an individual with weakening musculature. OTs can suggest dressing sticks and reachers which can help a client reach and grab clothing as well as move the clothing into a desired position for dressing or undressing. Additionally, fasteners such as buttons and zippers can be difficult to manipulate, therefore button hooks, zipper pulls, and velcro can be beneficial (Mendoza & Rafter, 2007). Socks can be difficult to place over the toes but a sock aide can allow a client to complete this task independently. Shoes can be laced

with elastic shoelaces to eliminate the need for tying and long-handled shoe horns are available to assist with sliding the heel into a tight shoe.

Toileting can be a source of embarrassment to the client who is no longer able to complete this activity independently. OTs may suggest raised toilet seats to make it easier for the client to stand after sitting as well as the addition of grab bars on the side or in front of the toilet (Gruis, Wren, & Huggins, 2011). Commodes are available with raised seats, handles, and wheels which allow them to be easily moved around the home. OTs can address these needs by obtaining the needed equipment and providing training on how to use them. Additionally, OTs can address modifying the environment to allow clients to be safer when using the bathroom.

Another uncomfortable topic for many clients is sexuality and intimacy with a partner. Sexuality and intimacy are greatly affected in patients diagnosed with ALS. Although sex organs are not directly affected by ALS, the act of engaging in sexual activity is often problematic due to physical decline (Ciechoski, 2007). Occupational therapists have the skills needed to provide their patients with additional ideas and tools to engage in sexual expression with their partner.

Occupational therapists can assist those affected by ALS to adapt areas of the home using grab bars, stair lifts, and ramps near doorways (Mendoza & Rafter, 2007). This may include buying dresser drawer handles to place onto walls in locations the client frequently walks. A long grab bar placed in a vertical position can also be beneficial, especially in bathrooms where the client can use one bar to grab onto at various heights. Ramps and stair lifts are available to allow the client to move around his home in areas where stairways would have made this more difficult or impossible. Chair lifts can be

costly to install with little chance of obtaining funding from insurance. Ramps are less expensive although they often require additional space (Lewis & Rushana, 2007; Mendoza & Rafter, 2007).

As it is a room used on a daily basis, Gruis, Wren, and Huggins (2011), found that the type of adaptive equipment rated most highly for usefulness and satisfaction by 63 ALS patients was bathroom devices. These included raised toilet seats, shower seats, shower bars, and grab bars near the toilet. Also highly ranked were transfer boards, electronic seating controls, ankle braces such as AFOs for ambulation, and speaker phones and picture boards for communication. The ALS patients gave the lowest ratings to button hooks, long-handled reaching tools, and dressing sticks. Motorized wheelchairs were used frequently by participants but were rated as moderately satisfying. Overall, devices that improved independence with activities of daily living were ranked highly. This is important for OTs to note when providing options for clients regarding adaptive equipment.

Louise-Bender, Kim, and Weiner (2002) conducted a study and found that personal meanings assigned to assistive technology differed according to the type of disability the individual experienced. Participants who had acquired disabilities used assistive devices to reduce the impact of having a disabling impairment, the experience of environmental barriers, and the decline in function over time. On the other hand, participants with a congenital disability used assistive devices to increase participation in activities and communication. To individuals with a progressive disability, such as clients with ALS, assistive technology was used to control symptoms of the disease and diminish the effects of the disease on participation in desired activities. This information

is important for OTs to consider when providing adaptive equipment for their clients in order to ensure the equipment will be incorporated into their daily routines and that it will meet each client's expectations.

Stinson, Porter, and Eakin (2002) completed a study regarding Force Sensory Array (FSA) regarding pressure readings with repositioning and the investigation of changes in interface pressure over a time period of 20 minutes while sitting. The FSA is a tool used to study the distribution of pressure at the junction between a surface and a part of the body. This tool was used to determine the exact point in time in which the most pressure was exerted on the body. A pressure sensing mat provided data that was measured using a color-coded contour map and numerical pressure values. When sitting, an individual experiences pressure on the buttocks and thighs, therefore the FSA measured these areas in this study. The researchers found that pressure had a significant increase within the first six minutes; however no significant increases were reported after the six-minute mark. This information is beneficial to OTs and other healthcare professions who work with patients with ALS or other disabling conditions. Patients should be repositioned every six to ten minutes to avoid pressure sores and the development of further medical problems.

Occupational Therapists and Caregivers

As the research has shown, ALS can have numerous debilitating effects on an individual. Those living with the diagnosis will ultimately need help with their day to day living. Many times the person who takes on this caregiver role is a close member of the family or a friend. Becoming a caregiver for someone diagnosed with ALS has many positive and negative aspects. In 2007, the American Occupational Therapy Association

provided a statement regarding family caregivers. They reported the negative consequences of depression, stress, burnout, and imbalance can have a devastating effect on caregiver's health and their ability to provide adequate care for their loved one. Thus, supporting caregivers is a process just as important as supporting the patient diagnosed with ALS. The ALS Association (2007) reported depression related to care giving burden as the most commonly diagnosed healthcare condition. Because of this, caregivers need support and consideration from healthcare professionals, such as OTs.

Donovan & Corcoran (2010) found when caregivers were uplifted through therapy interventions they were less depressed and more able to focus on the positive aspects of care giving. The researchers also found most therapy interventions were conducted to reduce the negative aspects of care giving, however these interventions could have had a better outcome if focused on the positive aspects related to caring for a loved one. Results of this study indicated engagement of care givers in positive behaviors such as simplifying routines, meeting frequently with family and friends, and making adjustments in attitudes such as using humor and avoiding stress created a more positive care giving experience. Occupational therapists can incorporate these topics and more into their discussions with caregivers.

It is also important to realize that not only caregivers but also the patient diagnosed with ALS may feel a lost sense of self dignity and integrity due to the need for others to care for them. The ALS Association (2007) recommends a bond development between patient and caregiver. They should couple as a team and provide support to one another throughout this difficult time. Occupational therapists can offer the caregiver

suggestions to support the ALS patient by attending appointments, organizing walks and benefits in their name, or taking relaxing vacations to calm both body and spirit.

The relationship with the caregiver is just as important as the relationship with the patient. Occupational therapists creating a therapeutic relationship with the patient may also develop lasting relationships with the caregivers. This can support the development of interventions based on the caregivers' needs.

In 1994, Clark, Corcoran, and Gitlin compiled an exploratory study on how OTs develop relationships with caregivers. Based on this research, they found some discrepancies in occupational therapy intervention and caregiver needs. For example, occupational therapy intervention was directed towards enhancing the patients' independence with completion of ADLs whereas caregivers preferred to complete the ADL tasks for the client. Based on this, it is important for OT's to develop an intervention plan that is congruent with both patient and caregiver goals.

This same study also found four main interactions that OTs used with family caregivers which were caring, partnering, informing, and directing. Caring interactions included showing personal interest in the caregiver's health and well being, and developing and showing support for them throughout the disease process. The second interaction was partnering. This included giving and receiving feedback about the therapy process as well as seeking and acknowledging the caregiver's input about the patient and the disease. The third interaction was informing. This included clarifying, explaining, and gathering information and support resources for the caregiver on the disease. The final and least effective interaction found was directing. This included

advising and directing the caregiver, however research found the caregiver was most disengaged throughout this interaction (Clark, Corcoran, & Gitlin, 2010).

Occupational Therapists and Palliative Care in ALS

When OTs effectively develop a therapeutic relationship with the patient and caregiver, discussing end of life issues becomes more comfortable for all involved. End-of-life issues are often difficult topics to discuss, however, are very important in the beginning stages of the disease to ensure both patient and family wishes for medical treatment are understood.

There is currently no cure for ALS (ALS Association, 2007). Treatment is palliative in nature and aimed at providing the best quality of life for both the patient and their family (Ozane, Strang, & Persson, 2010; Foley, O'Mahony & Hardiman, 2007). Palliative care for ALS patients should begin when they are diagnosed with the disease. At this time, life prolonging measures such as PEG tubes and mechanical ventilation should be discussed and decided upon to allow for family to meet the patient's end of life wishes. Palliative care is best accomplished when it involves the entire family and can help manage the symptoms of ALS to allow the patient to be as comfortable as possible (Borasio & Voltz, 1997). Singer, Martin, and Kelner (1999) found that receiving adequate pain and symptom management was one of the main concerns patients experienced during end-of-life care.

Occupational therapists should research pain management options available to their patients, such as therapeutic touch. This modality involves the practitioner moving their hands over the patient's body, while never making physical contact (Monroe, 2009). During therapeutic touch the practitioner is thought to be balancing the patient's energy

field by removing painful energy out of the body and moving new energy in. Research has found this modality to be successful in the treatment of many different diagnoses (Monroe, 2007).

Other than symptom management, palliative care for ALS used by OTs should help engage clients in meaningful occupations (Benthall & Homles, 2011). These activities can be accomplished through the transmission of legacy. This includes helping a patient pass on the important aspects of their lives to those they care about. Life narratives and lessons can be passed down through pictures, autobiographies, recipes, and movies (Benthall & Holmes, 2011).

The main role of occupational therapy is to engage clients in meaningful occupations. Occupational therapists play a crucial part in end-of-life care for ALS patients. Singer, Martin, and Kelner (1999) found that achieving a sense of control in their end-of-life care was important to many terminally ill patients. Because of this, OTs dealing with ALS patients should engage them in activities that allow for this sense of control throughout the stages of the disease.

Occupational therapists working in ALS palliative care should also be aware of the many rewards and challenges involved in working with terminally ill patients. Prochnau, Liu & Boman (2003) found that OTs working in palliative care strove to develop a personal-professional connection with each patient. Specifically, five themes emerged in working with patients diagnosed with ALS. These were satisfaction, hardship, coping, spirituality, and growth. Many participants discussed how difficult it was to lose a patient to a terminal illness after they had developed a strong bond with that individual. Therefore, OTs working with patients diagnosed with ALS must develop this

personal-professional connection while staying aware of the disease outcome in order to maintain a healthy mind and body.

Presently there is minimal research related to occupational therapy and the profession's role in ALS. Lewis & Rushanan (2007) report the main goal of occupational therapy is to "maintain independence with functional mobility and activities of daily living" (Lewis & Rashanan, 2007, pp. 451-452). Research has suggested a full continuum of care is needed, but few articles have described how to do so.

In an attempt to describe the symptoms, experiences, and other aspects concerning an ALS diagnosis, it is the authors' purpose to portray the roles of occupational therapy in regard to the stages of ALS as evidenced by Van den Berg, Groot, Joha, Haelst, Gorcom, & Kalmijn (2004). The role of occupational therapy will be described from diagnosis to end-of-life, addressing issues faced by patient and family.

CHAPTER III

METHODOLOGY

The product, “Embracing Life with ALS: The Role of Occupational Therapy from Diagnosis to End-of-Life Care”, is designed as a go-to document for occupational therapists working with ALS patients. This document is to be used as a reference guide in developing interventions for ALS patients.

The Canadian Model of Occupational Performance and Enablement (CMOP-E) was chosen to guide this document as it focuses on a holistic approach to treatment and encompasses the spiritual aspect of the individual as they develop their sense of self worth. Through the use of the ten enablement skills described in the model, this document allows for an enveloping approach to occupational therapy that involves all aspects of the individual. In addition, through the use of this model, the importance of the caregiver is emphasized throughout the therapy process.

The process of developing this product began with an extensive review of current literature of ALS, the disease process, occupational therapy’s role in ALS treatment, caregiver’s role in end-of-life care, assistive technology, palliative care options, and additional support strategies. The literature included a diverse selection of both quantitative and qualitative research studies. Through the use of many search engines that included PubMed, AJOT, OT Search, Cinahl, and various medical journals, the literature review was created. Additional data was gathered through the ALS

Association's seven informative documents that were published for patients and families affected by the disease.

With the vast amount of literature found on this topic, the authors narrowed the information to be presented into the literature review and the final project. With personal and professional experience in working with ALS patients, the authors used their knowledge of the disease to determine which specific material would be presented in this project. Although the reviewed literature lacked resources for the use of occupational therapy in the treatment of ALS, the authors used the Berg et al. (2004) Dutch ALS protocol as an outline for the disease progression. Through these stages, the role of occupational therapy in the treatment of ALS from diagnosis to end-of-life care was created.

The authors then combined the CMOP-E into the disease stages described by Berg et al. (2004) using the ten enablement skills described in the literature. The eight action points were incorporated into the therapy process to develop the role of the occupational therapist. These roles focused on advocacy, education, assistive technology, caregiver inclusion and support, collaboration with all medical professionals, and issues related to maintaining sense of self worth. In addition, this manual is beneficial in the fact that it can be used across diagnosis and treatment settings as a generalized description of the role of OT in terminal illness treatment. This allows for a holistic approach to occupational therapy that involves both the client and their caregivers.

Consideration of the Rehabilitative frame of reference was taken into account when developing the assistive technology section. As ALS is a terminal illness, this

frame of reference was used in regard to teaching the client how to compensate through the use of assistive technology to increase occupational independence.

A bound document format proved to be the most appropriate choice for production of this manual as it allows for the information to be easily transferable to multiple treatment facilities in the area. This document provides the opportunity for occupational therapists to integrate a holistic approach to therapy that is encompassing for both the client and the caregivers and provides intervention ideas for the whole process of the disease from diagnosis to end-of-life care.

Embracing Life with ALS: The Role of Occupational Therapy from Diagnosis to End-of-Life Care

[Type the document subtitle]

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Introduction

The role of the occupational therapist (OT) will be integrated into the Berg et al. (2004) Dutch ALS protocol which describes the stages of ALS as it progresses. These phases include the diagnostic phase, rehabilitation phase, and terminal phase. The diagnostic phase is characterized by revelation of the diagnosis to the client and caregivers by the neurologist. At this time, the multidisciplinary team is introduced and the client is referred to ALS associations within their state.

The rehabilitation phase is separated into three distinct stages. The independent stage includes discussion of possible treatment options where the client is also educated about ALS and various associations that can provide additional support and resources. This stage is characterized by a collaborative relationship between the client and therapist based on trust. In this stage, individualized treatment goals are developed and regular team meetings are established. The initial conversation regarding life sustaining options such as percutaneous endoscopic gastrostomy (PEG) and mechanical ventilation must be discussed. The second stage is independence with aids and appliances. This stage includes the integration of assistive technology and training on utilization of these devices. Therapy is directed towards management and acceptance of these devices to encourage use and prevent abandonment. The third stage is the dependent phase which is characterized by home treatment aimed at enhancing the home environment. Caregiver support becomes a main focus of therapy and final decisions are made regarding life sustaining procedures.

The final phase of the Dutch ALS protocol is the terminal phase which includes life sustaining devices as well as symptom management. Once the patient has deceased, aftercare is provided to family and friends through various forms of support.

Guiding Theory

The Canadian Model of Occupational Performance and Enablement (CMOP-E) was primarily used in developing the role of the OT with ALS from diagnosis to end-of-life care. The emphasis of this model includes two core concepts: enablement and occupation. The role of the OT was developed in relation to the ten enablement skills and eight action points in the model. The ten enablement skills (Townsend, et al., 2007) include:

- **Adapt** – Providing outlets for clients to engage in meaningful occupations through modification to fit performance challenges.
- **Advocate** – Raising important aspects of client care to the state and federal level. Also, power sharing and lobbying for clients personal needs.
- **Coach** – Developing a relationship to help clients engage successfully in their personal and professional lives.
- **Collaborate** – Sharing power with clients and caregivers related to their occupational needs. Also, developing a relationship to allow for successful performance in their meaningful occupations.
- **Consult** – Exchanging views with additional team members and clients about occupational therapy practice and outside resources.
- **Coordinate** – Linking clients and family with outside resources and facilitating interactions with additional team members.
- **Design/Build** – Creating products to allow for engagement in occupations through the use of assistive technology, orthotics, communication devices, etc.

- **Educate** – Teaching clients and family about disease process, prognosis, and the role of occupational therapy in the rehabilitative team.
- **Engage** – The performance of occupations.
- **Specialize** – The use of precise techniques to manage symptoms and occupational needs.

The eight action points (Davis, Craik, & Polatajko, H. J., 2007)

include:

- **Enter/initiate** – Advocate for the use of occupational therapy in the rehabilitative team and educate clients on the role of occupational therapy.
- **Set the stage**- Build rapport and engage client in occupational readiness.
- **Assess/evaluate** – Through the use of the COPM, the client's performance in meaningful occupations is evaluated. The therapist is responsible for consulting and coordinating with other team members to ensure all needs are met.
- **Agree on objectives and plan** – Collaborate with client to determine goals and treatment plan. Coordinate services with other disciplines and design/build a care plan that is congruent with client and caregivers goals.
- **Implement the plan** – Engage client in meaningful occupations through the use of a specialized frame of reference.
- **Monitor and modify** – Adapt and modify the treatment plan in order to engage the client in successful occupations. Consult with the client to ensure all needs are being met through occupational therapy.

- **Evaluate outcome** – Determine occupational therapy findings and client’s ability to engage in meaningful occupations.
- **Conclude/exit** – Conclude the relationship upon the completion of the therapy process. Document the conclusion therapy.

In the CMOP-E, spirituality is considered the core aspect of the individual along with cognitive, affective, and physical aspects. This model divides a person's occupations into self-care, productivity, and leisure. The person and their occupations are encompassed within the environmental aspects: physical, institutional, cultural, and social. Through the therapy process, the collaborative relationship between the client and the therapist enables participation in meaningful occupations (Polatajko, et al., 2007). An additional frame of reference was utilized throughout this document. The Rehabilitative Frame of Reference was used in regard to teaching the client to compensate with assistive technology (Cole & Tufano, 2008).

**Embracing Life with ALS: The
Role of Occupational Therapy
from Diagnosis to End-of-Life Care**

Diagnostic Phase

**Advocate the benefits occupational therapy services can
provide for client and family members with doctors and other
team members**

Occupational therapy can provide various methods of intervention which can include management of symptoms, adaptive equipment and techniques to promote independence, home modifications, supports in the community for ALS, and more. Occupational therapists are trained to view the client in a holistic manner and treat problems associated with the mind, body, and spirit. Interventions are client-centered and will focus on improving the quality of life of the client as well as his or her caregivers'.



<http://docsharp4health.com/about.html>

Occupational therapist makes contact with client and family/caregivers and educates both on occupational therapy and potential services

The OT should introduce him/herself to the client and caregivers/family members while being aware of the recent diagnosis and how this news has been received. Allow the client and family to ask questions about the disease. Explain what occupational therapy is and what services an OT can provide for someone with ALS.

For example:

"ALS may affect many activities you do every day. It could make showering more difficult for you to do on your own. I can provide you with choices of equipment you can use that will help you do this, such as a shower chair, removable shower head, and more. I can also teach you techniques that will help you save energy while showering so you are not so tired afterward."

Document consent of the client and family to receive occupational therapy services

Once the client and family members agree to receive occupational therapy services, ask them to sign a consent form for documentation purposes. An example may include:

Consent to Receive Occupational Therapy Services

By signing my name below I confirm the following:

- All my questions have been answered to my satisfaction.
- The purpose and possible benefits and risks of receiving occupational therapy services have been explained to me.
- I agree to receive occupational therapy services.

Client's Signature

Date

Signature of Witness

Date

Therapist's Signature

Date

Rehabilitative Phase

A) Independent Stage

Assess and evaluate the client's performance skills

The OT should complete an evaluation of the client's current ability to perform desired tasks in his or her home. This can be done through clinical observation or use of various standardized assessments. The Canadian Occupational Performance Measure (COPM) should be completed by the client to ensure therapy services are focused on occupations the client finds important and meaningful. The COPM is a self-assessment that includes a rating of performance in regards to desired occupations. This assessment was designed to be used as an outcome measure, although this may not be feasible with this population. It can be used to provide data for the therapist regarding which occupations should be the focus of therapy sessions.

Occupational therapist and the client should agree on objectives and treatment plan

The OT should collaborate with the client in regards to short-term and long-term goals. The long-term goals should include a meaningful occupation for the client. The short-term goals should include performance skills necessary to engage in the desired occupation. Goals should also be realistic and achievable.

The OT should also educate the client and family on possible treatment options. This could include activities that may be completed during therapy and how they are relevant to the occupation. The family and caregivers should be allowed to offer suggestions of activities the client enjoys and could incorporate into sessions. For example, if the client enjoys playing card games but is experiencing difficulty holding the cards in his or her hand, the therapist can discuss adaptive equipment options as well as different techniques to hold the cards.



<http://www.skillclinics.com/>

Educate the client and family on ALS associations and additional support options within their region

The client and family members should be educated on the ALS Association and how they can provide adaptive equipment or other resources. The OT can provide the website and explore the website with the family and client if they wish. They should also be provided the contact information for any associations within the state that can help provide support and additional resources. Support groups may be available in more populated areas which may be of interest to the caregivers.



<http://gameoncancer.wordpress.com/2011/07/28/how-cancer-support-groups-aid-cancer-patients/>

B) Independent with Aids
and Appliances

Implement treatment plan

Every client with ALS will have a treatment plan that is unique to his or her lifestyle and desired occupations. The OT should specialize in the rehabilitative frame of reference with the use of assistive technology (see equipment section). Equipment needs will also vary from client to client, therefore the OT should be aware of the many options that can assist the client in overcoming a single barrier. For example, the client may have problems with feeding. Built-up silverware, universal cuffs, arm supports, rocker knives, and much more are available but must be analyzed in regards to meeting the client's needs.

Aside from feeding, other occupations will be meaningful to the client and he or she should be encouraged to participate in them with the assistance of the OT. Folding laundry, spending time outside, driving, visiting with family and friends, and dressing independently may be important to the client. The OT is responsible for assisting and encouraging the client with engagement in these activities.

The home environment may need to be adapted to help the client maneuver around the necessary rooms. This can be done with ramps, stair lifts, or simply moving equipment and tools into a place that is easily accessible for the client. For example, the washing machine and dryer may need to be moved onto the main level of the home if they are in the basement.

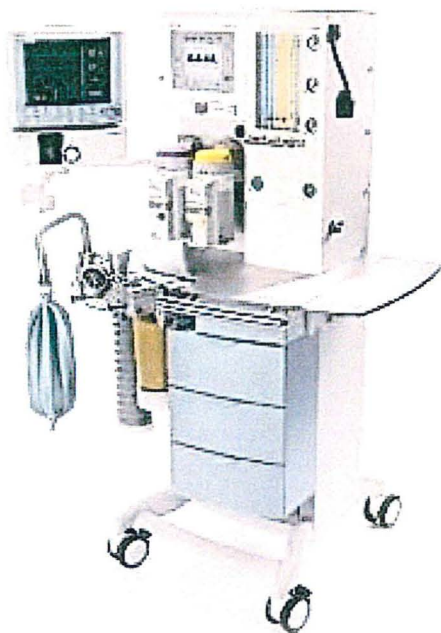
As this disease can be difficult for the client to tolerate, the OT plays a vital role in coaching him or her through the development of self-worth and sense of self (spirituality). The client may experience a loss of meaning or purpose in life. The OT should address this frequently to ensure quality of life does not diminish.

Monitor and modify treatment plan and assistive devices as needed

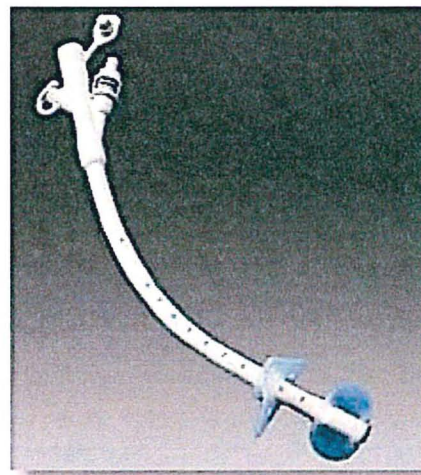
As the disease progresses and the client gains and/or loses independence the OT will need to modify the treatment plan and assistive devices (see assistive technology section). The goals may change in focus as the client finds certain tasks and activities more meaningful than others. Assistive devices will also change as the client loses strength and control of body functions. Devices should be monitored for use and satisfaction from the perspective of the client and the OT should make changes accordingly. Family/caregivers can also be a source of additional information, problems, or concerns regarding assistive devices.

Discuss implementation of life sustaining devices such as PEGs and mechanical ventilators with the client and family

Although this topic is generally difficult for family members and clients to address, it is necessary to discuss this phase of the disease before the client reaches it. The family members and client should be shown life-sustaining device options such as a percutaneous endoscopic gastrostomy (PEG) and a variety of ventilators. A final decision is not necessary at this point, although a tentative plan will be useful to have in case the disease progresses rapidly.



<http://www.udmercy.edu/cma/agm/08.htm>



http://oralcancerfoundation.org/dental/tube_feeding.htm

Document the client's desires regarding end-of-life care

The client's desires regarding a plan for end-of-life care should be documented in writing and signed by the client, a family member, and witness. This will help to ensure the client is provided with as much or as little life support as he or she desires. This information can also be put into the client's will if he or she wishes. The OT may need to mediate disagreements among family members and the client. In many situations, the family will want their loved one to receive as many life support options as possible while the client will want to pass in peace. This can be a delicate situation although the therapist should be supportive of all involved while reiterating the importance of allowing the client to make this decision.

I, (Client's written name), wish to refuse use of life sustaining methods, including but not limited to percutaneous endoscopic gastrostomy and mechanical ventilation when decisions need to be made for end-of-life care.

Client Signature

Date

Family member signature

Date

Witness signature

Date

Assistive Technology

Mobility

Orthotics (AFO)/Brace/Splints



<http://www.podiatrytoday.com/article/1167>

http://www.goldbamboo.com/topic-t1157-a1-6Carpal_Tunnel_Syndrome.html

- **Used to help arrange arms/feet in functional positions**
- **AFO's prevent foot drop to allow for ambulation**
- **Splints prevent wrist drop to allow for functional hand positioning and use**

Wheelchairs



<http://www.1800wheelchair.com/product/1371/pride-stylus-wheelchair>

- **Different wheelchair options for various mobility needs**
- **Power wheelchairs for long distance**
- **Power wheelchairs available with various propulsion settings**
- **Manual wheelchairs are less complex**
 - **Determine caregiver needs**

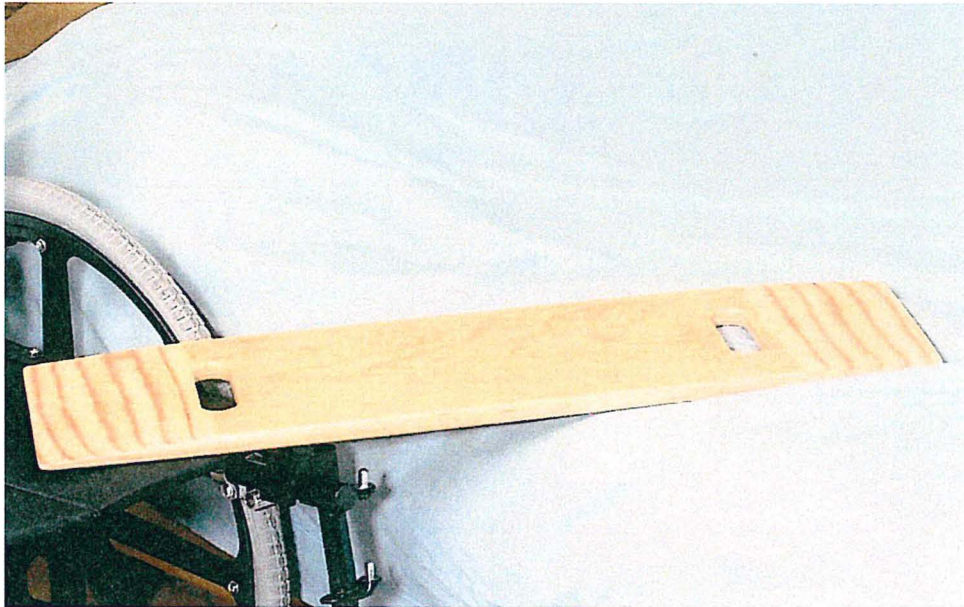
Cushions



http://www.phc-online.com/Wheelchair_Cushion_p/tcc-cu-fn.htm http://www.phc-online.com/Roho_Cushion_p/roho_hi_profile.htm
http://www.shermanoaksmedical.com/Honeycomb_Cushions_s/705.htm

- **Basic cushions used for standard wheelchair use**
- **Air inflated cushions used to distribute pressure to prevent problem areas**
- **Honeycomb cushions used primarily to allow for air ability**

Transfer Board



<http://homepage.ntlworld.com/h.camilleri/ability/moving%20and%20handling/moving%20and%20handling.html>

- **Sliding boards used to assist clients with functional transfers**
 - **Relatively strong upper extremities are required**

Hoyer Lifts



http://www.ezmedshop.com/invacare-reliant_plus-450_power-lift-with-low-base-450-lbs-invrpl450-1.html

- **Hoyer lifts used for dependent transfers**
 - **Utilized when client has no functional ability to move on their own**

Feeding/Eating

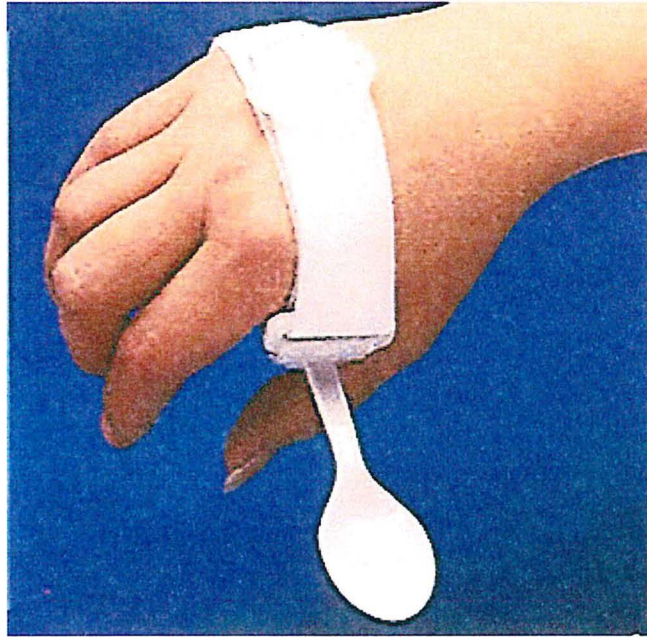
Adaptive Cups



<http://www.elderstore.net/Images/products/Maryusa/MY1001EasyGripMED.jpg>
<http://adaptiveshops.com/specialty-shops/aids-for-the-home/kitchen-aids-3/eating-aids/adaptive-cups/>

- **Adaptive cups may be used for various grip and drinking abilities**
 - **Cups with grips may be added**
- **Nose cups used to allow client to sip with chin tucked instead of using the whole arm to sip**
- **Straws may be utilized for ease of drinking**

Universal cuffs



<http://www.bindependent.com/cgi-bin/shopper.cgi?preadd=action&key=snk134>

- **Cuff allows for independent eating for individuals with decreased functional grasp**

Foam buildups



<http://www.independentyou.com/catalog/index.cfm?fuseaction=viewProductsSubCat&SubCatID=24>

- **Foam buildups used to manipulate silverware and objects when grasp is limited**

Mobile arm supports



http://www.rehabmart.com/resizeimage_send.asp?path=/imagesfromrd/SP-MobileArmSupport555807L.jpg&width=200&height=200

- **Mobile arm supports used to stabilize arm for feeding support when arm function has been lost**

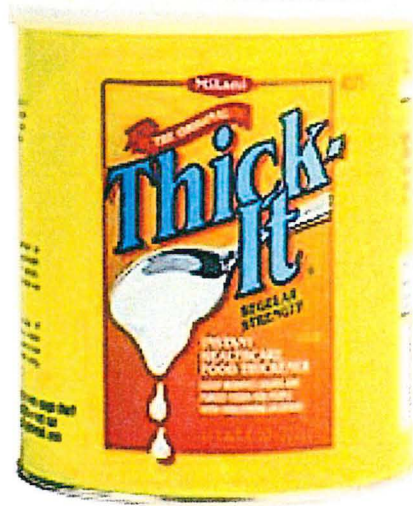
Rocker knife



<http://www.rehabmart.com/product/thandle-rocker-knife-135.html>

- **Rocker knife provides ease of cutting for individuals with weak grasp**

Thick-It



<http://www.allegromedical.com/dietary-supplements-c522/thick-it-powder-8-oz-cans-p192089.html>

- **Instant food thickening for dysphagia**

Suction machines

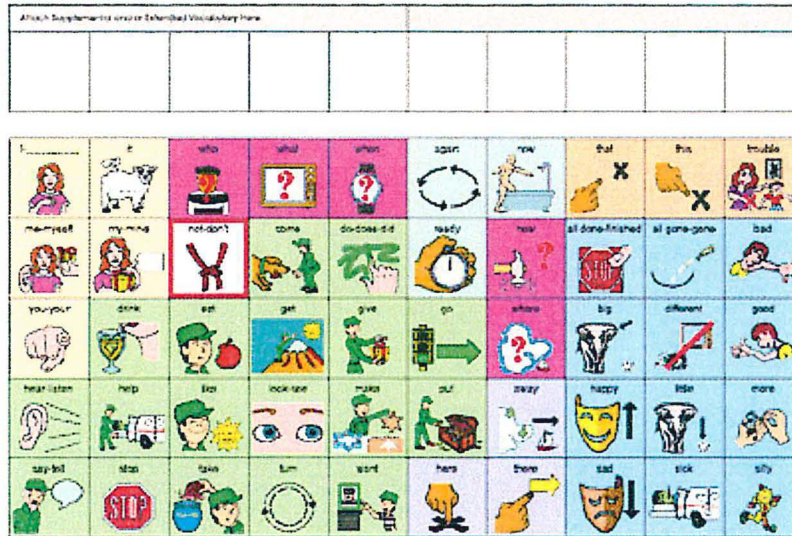


<http://www.mountainside-medical.com/products/Heavy-Duty-Suction-Machine-with-Accessories.html>

- **Suction machine used to eliminate excessive saliva during the feeding process**

Communication

Communication Board



http://store.prentrom.com/product_info.php/cPath/30/products_id/163

- **Communication board used when speaking becomes difficult or obsolete**
 - Many different options available
 - Both electronic and manual

Voice amplifier

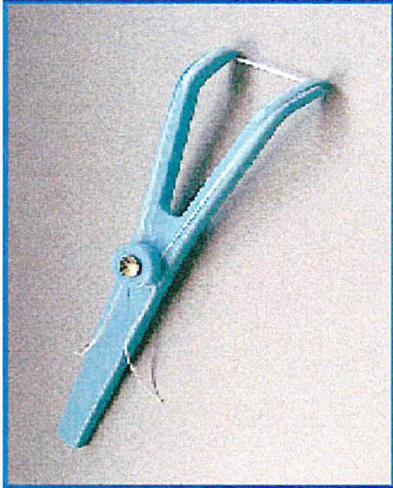


<http://img.en.china.cn/0/0,0,221,932,494,494,3ea2dfa3.jpg>

- **Used to amplify voice when muscles needed for communication become weak**

ADL's

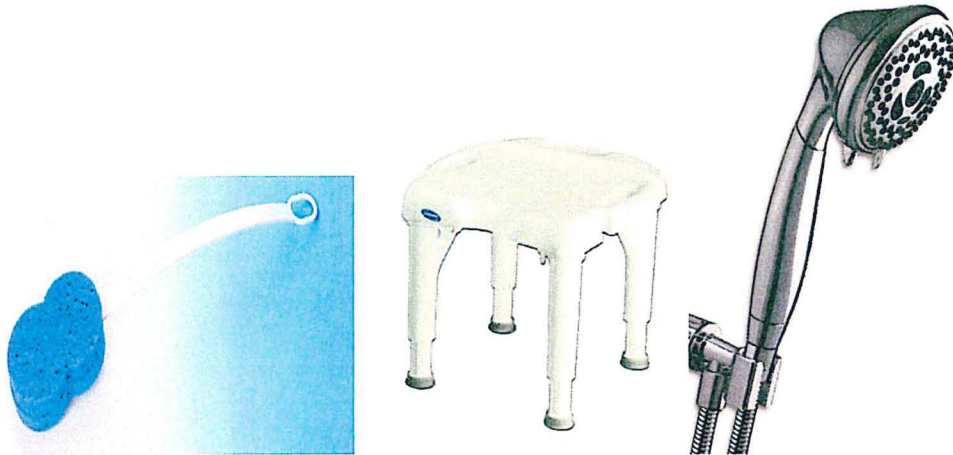
Oral Care



http://cdn.dentaldepot.com/images/uploads/175_640_large.gif http://www.oralb.com/en-US/assets/images/products/gallery/pc1000_1.jpg

- **Floss holders allow client to utilize floss with the use of one hand**
- **Electric toothbrush provides opportunity to exert less energy when brushing**

Bathing



<http://www.caring-for-aging-parents.com/long-handled-sponge.html> <http://www.homehealthmedical.com/c/Bath-Safety/Basic-Shower-Chairs/> <http://www.bestframelessglassshowerdoors.com/hand-held-shower-heads.php>

- **Long handled sponge is used to reach back and lower extremities when strength has diminished**
- **Shower chair allows for sitting and energy conservation throughout shower**
- **Removable shower head allows for washing while seated**

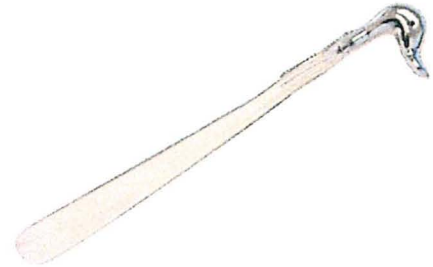
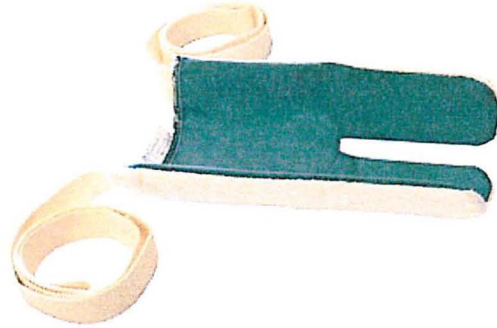
Grooming



<http://www.chronic-illness.org/blog/a-long-handle-brush-and-comb-makes-living-alone-easier> <http://www.techforlrc.org/product.aspx?id=3517>

- **Long handled hair brush allows for independent brushing without deltoid use**
- **Modified nail clipper used for individuals with decreased hand strength**

Dressing



<http://www.aidsforarthritis.com/catalog/good-grip-button-hook.html> <http://www.activeforever.com/p-255-easy-pull-sock-aid.aspx> <http://www.shoeandfootcare.com/p/107-104/product-shoe-horn-long-spoon.html>

- **Button hook allows for dressing with the use of one hand**
- **Sock aid allows for dressing with decreased lower extremity strength**
- **Shoe horn allows for ease of donning shoes for those with decreased hand strength**

Dressing Continued



<http://www.underworks.com/health/423.html>



<http://www.allegromedical.com/daily-living-aids-c519/aluminum-reacher-with-magnetic-tip-p191918.html>

<http://selfcare-solutions.com/Dressing-stick>

- **Elastic shoe laces allow for donning of shoes without the use of hands to tie laces**
- **Reacher allows for dressing with the use of one hand or decreased hand dexterity**
- **Dressing stick allows for donning/doffing clothing with the use of one hand or decreased hand dexterity**

Supplementary

AT

Grab Bars/Safety Rails



<http://www.sanliv.com/bathroom-accessories/category/safety-grab-bar/>



<http://www.safetied.org/bathsafety.aspx>

- **Grab bars and safety rails can be used throughout the house and provide additional stability for functional transfers**

Ramps



<http://www.disabilitysystems.com/ramps/modular.html>

- **Ramps provide an opportunity for wheelchair accessibility**

Stair Lifts



<http://scarlton.hubpages.com/hub/The-Up-Downs-of-Stairlift-Chairs>

- **Stair lifts provide accessibility to those in wheelchairs**

Commode



<http://www.amazon.com/Medline-MDS89664H-4-in-1-Steel-Commode/dp/B000BJEZ88>

- **Commodes provide toileting support for those who are unable to ambulate to the bathroom**
- **Additionally, can be used in the nighttime for energy conservation and to prevent falls**

C) Dependent Stage

Coordinate and consult with other disciplines to ensure all needs of the client and caregivers are being met

At this stage the client is receiving most if not all services in the home. The OT should meet with all members of the care team to ensure symptoms are relieved, the client is able to complete all ADLs with safety and assistance from caregivers, and quality of life is maintained. They family/caregivers should be encouraged to ask any questions they may have or address any problems they may be encountering with the different disciplines.



<http://www.allthingsprivatepractice.com/open-call-opportunities-for-mental-health-professionals-to-network/>

Collaborate with the client and caregivers to optimize the home circumstances

The OT should make sure the home is modified to meet the client's and caregivers' needs as much as possible. For example, the client may want someone to be with him or her at all times in case of a bathroom emergency or because they are uncomfortable being alone. A bed or cot may need to be moved into the client's bedroom to allow family members/caregivers to sleep next to the client. Respite care or hospice may be contacted to assist with daily cares and to give caregivers an opportunity to take a break. Ensure the client and family members are given opportunities to ask questions or voice concerns. Family members should be encouraged to attend support groups and take time for themselves.

Continue to coach the client to maintain sense of self and self-worth

This stage can be difficult for clients with ALS as they are completely dependent on others for all ADLs and other activities. The OT should talk with the client about the meaning of his or her life in regards to family and friends as well as other aspects of spirituality.



<http://www.fanpop.com/spots/spirituality-and-religion/images/16797009/title/hands-photo>

Collaborate with the client and caregivers to finalize end-of-life care plan

The OT should facilitate an agreement among all immediate family and the client regarding the plan for end-of-life care. This will include various forms of life support the client wishes to use or not use and a timeline of how long the life support should operate. Any changes from the previous written agreement should be added to the document and resigned if necessary.

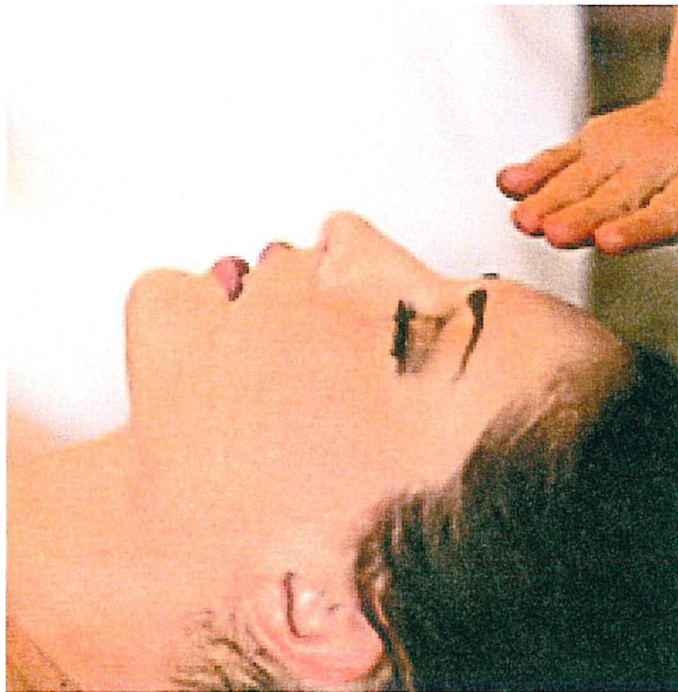


<http://www.advocate4u.net/join.aspx>

Terminal phase

Specialize in therapy techniques such as therapeutic touch for symptom management

Occupational therapists can specialize in various forms of intervention to help clients reach an enhanced quality of life. This can range from simple discussion to specialized care. Additional training may be required for different areas of specialized care. The OT can help to reduce symptoms such as pain through positioning and pressure relief techniques. The client should continue to receive coaching to increase their sense of self and self-worth through bonding with family and friends during this final stage.



<http://www.ndmh.ca/article/palliative-care-162.asp>

Continue to monitor and modify assistive technology needs

As the disease progresses, the client will lose the remaining function and control over body systems. As this process continues additional adaptive equipment may be necessary for client comfort and care. For example, a hoier lift may be utilized in the bedroom for all transfers. If the client wishes to use life sustaining devices, a PEG or mechanical ventilator will be incorporated into everyday use. The family should be included in collaboration to find the best assistive technology to meet the client's and family's needs.



<http://www.hoyerlift.info/hoyer-lift-%E2%80%93-patient-lift/>

Educate caregivers on support options once their loved one has passed

As mentioned previously, support groups are often available in urban and more populated areas. These support groups can be utilized as an outlet to express emotions and a way to tell their loved one's story. The state ALS Associations offer support groups on their websites for clients and family. The OT should encourage clients and families to contact these services and continue to advocate for additional caregiver support. Donating money and/or other resources to the ALS Association can be therapeutic as can fund research to help find a cure. In addition, attending ALS walks in the name of the family's loved one can be another form of support.



http://www.zazzle.com/als_awareness_i_wear_als_ribbon_for_my_mother_button-145551902326431285

**Send condolences to family/ Conclude and exit therapy
relationship.**

The OT should contact the family to give their condolences and thank them for the memories and time spent together. At this point the therapy relationship will end, although the OT is encouraged to stay in contact with the family.

Dear (Family's name)

I wanted to send my condolences to you and your family for the loss of _____ . I am thankful to have known and worked with him/her. I will think of _____ often and miss him/her. Thank you for allowing me to also work with you. I hope I was able to make things easier. If you have any questions or need to contact me, I can be reached at _____ .

(Therapist's signature)

Evaluate outcomes of therapy process

The OT will gather all documentation and review the client's goals for the therapy process. Although the outcome is inevitable, the OT can look for areas of improvement in function and reflect on any interventions or activities that were beneficial. The OT should evaluate the therapy process based on the client's and family's quality of life and determine what influence occupational therapy had on the overall experience.

References

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CHAPTER V

SUMMARY

The product presented within the preceding chapter is an encompassing document outlining the role of the OT working with ALS clients and their families from diagnosis to end-of-life care. This document was created in response to the lack of occupational therapy literature in ALS care as well as the increasing prevalence of the disease. In addition, throughout the literature review many articles have called for a full continuum of care, however few have described how to do so.

The product created was with the Canadian Model of Occupational Performance and Enablement's (CMOP-E) eight action points, ten enablement skills, and concept of spirituality integrated in. Examples of these include; advocating, educating, consulting, building rapport, and specializing. In addition, an assistive technology section was created to give OT's ideas for the purchase or design/build of devices to allow their clients and families to adapt both the environment and/or occupations to increase independence.

The product was designed to be implemented into acute care and rehabilitation facilities to guide OT's care when working with ALS clients and their families. It was designed to be a general guideline for practitioners and should be adapted depending on

each clients' and families' individual and unique needs. In addition, the inclusion of the family throughout the therapy process is evident throughout the product.

In order to expand upon the product, the authors suggest the following recommendations. First, additional research should be completed on the effectiveness of this product as well as the role of occupational therapy in working with clients and families affected by ALS. As this is an area of little research, it is crucial that OT's strengthen their knowledge of this disease and its impact on the client and family. Second, documentation of the product's effectiveness should be done in order to allow for modifications to be made to increase its success with other clients and families.

The document is in its premature stage and additional student projects may be beneficial in order to increase its effectiveness in the clinical setting. Ideas for expanding its contents include adding in additional sections related to leisure participation, work exploration and performance, and the product could also be adapted to include the OT's role in working with other terminal illnesses. As the document is a general guideline for occupational therapy use, it would be effective in working with other clients and families affected by various terminal illnesses.

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