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A Reference Manual for Caregivers of Individuals with ALS

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A REFERENCE MANUAL FOR CAREGIVERS OF INDIVIDUALS WITH ALS

by

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CHAPTER 1
INTRODUCTION

Rationale

Amyotrophic Lateral Sclerosis (ALS) is a terminal neurodegenerative disease characterized by the loss of voluntary muscle control (Forwell, Copperman & Hugos, 2008). The degeneration of the motor neurons disrupts the brain's ability to send signals to contract voluntary muscles. With the inability to control muscle contractions, muscles continually weaken until muscle control is lost (PubMed Health, 2012). Additionally, the cause of ALS is unknown and once diagnosed with ALS, the average life expectancy is between three to five years (Forwell et al.; PubMed Health, 2012).

According to the ALS Association (2012), approximately 30,000 Americans are living with ALS at any given time. At the same time, it was estimated that 65.7 million people in the United States were unpaid caregivers, many of which were caring for individuals with a terminal disease (NAC & AARP, 2009). Until there is a cure for ALS, individuals with ALS will gradually become dependent on formal and informal caregivers due to their decline in physical functioning resulting in a loss of independence. Caregivers of individuals with ALS spend on average eleven hours each day caring throughout the course of the disease (Roach et al., 2009). It is not uncommon for caregivers to spend this amount of time even while they are receiving assistance from other family members or healthcare professionals (Roach et al., 2009). This scholarly project focuses on informal ALS caregivers, which are defined as individuals charged
with the principle responsibility of caring for an individual with ALS excluding healthcare professionals (Pizzi, 2010).

With an increased amount of time spent and demands on the caregiving role, caregivers are at risk for many psychological distress symptoms such as depression, anxiety, guilt, resent, anxiety, burden, and decreased social support. As the individual with ALS becomes more dependent on the caregiver, the caregiver is more likely to experience psychological distress (Goldstein et al., 2006). Nearly half of caregivers reported feeling psychologically and physically unwell (Muphy et al., 2009). In particular, one study indicated that nine percent of study participants displayed characteristics of a depressive disorder which is higher than the average population (Rabkin et al., 2005).

In one study, 30 percent of caregivers reported that they did not feel there was anything that could be done to make their caregiving tasks less difficult and stressful. It is likely that these caregivers did not know the resources that were available to them, and occupational therapists (OTs) can assist with providing these necessary resources and supports. OTs promote health and well-being through engagement in occupations during all roles of one’s life (AOTA, 2008). By empowering caregivers, the OT will be holistically promoting the caregiver’s health (Pizzi, 2010).

Theoretical Framework

The Model of Human Occupation (MOHO) was the main theory guiding the development of this scholarly project. MOHO is client centered and ultimately concerned with the caregiver’s ability to perform occupations that are familiar and adapt to new
occupations. MOHO is focused on three main constructs that affects an individual's engagement in occupation: (Kielhofner, 2009)

- Volition: the caregiver’s motivation to participate in the activities involved in the role of being a caregiver. Volition shapes the way caregiver’s view the opportunities and challenges involved with caregiving.

- Habits: ways of responding in a routine manner in familiar environments and situations. According to MOHO, a major construct of therapy is to build or rebuild habits to perform occupations related to caregiving.

- Performance Capacity: the physical and mental abilities of the caregiver.

MOHO offers a wide variety of therapeutic strategies that are beneficial to assist a caregiver in identifying and preventing psychological distress. The main therapeutic strategies used to guide this scholarly project are advising, encouraging, and validating (Kielhofner, 2009).


- Encouraging: providing reassurance and emotional support to enhance occupational performance.

- Validating: recognizing and acknowledging the caregiver’s experience and knowledge regarding their new role.

Adult learning theory was also used to guide the development of Helping Others by Helping Yourself: An ALS Caregiver’s Guide to Self-Care. The adult learning theory has multiple assumptions to guide information when addressing adult learning needs (Knowles, Holton & Swanson, 2005). The manual was created to be used by caregivers with a variety of educational backgrounds and learning styles. In order to cater to a
variety of educational styles, the manual was written in a language that would be easy to read and understand (Knowles, Holton & Swanson, 2005).

Adult learning theory indicates that the learner’s motivation determines their engagement in the learning process. Adults are more resistant to change therefore motivation is important to address in the adult learner. A learner is more likely to change if a caregiver perceives a learning experience to be meaningful. Many stressors associated with caregiving can be taxing to the ALS caregiver which can be a barrier in finding motivation. The adult learning theory suggests that learners are more likely to seek information when they feel ready with the intent to cope with life situations (Knowles, Holton & Swanson, 2005).

Statement of the Problem

Current literature indicates that ALS caregivers are at risk for psychological distress secondary to caregiving demands that impact quality of life and well-being. Current research lacks initiation of addressing and preventing the psychological symptoms experienced by an ALS caregiver and the role of OTs in addressing these needs to promote health, quality of life, and well-being. Caregiver’s demands change throughout the course of the disease which ultimately affects one’s ability to prioritize engagement in occupations as well as maintaining engagement in occupations (AOTA, 2007).

Scope and Delimitation

OTs are an important part of the treatment team for individuals with ALS and their caregivers. OTs promote health and well-being through engagement in occupations during all aspects of one’s life (AOTA, 2008). In addition to treating the affected
individuals, OT’s focus on the needs of family members and caregivers. OTs have the skills to educate caregivers, strategies to balance caregiver demands, knowledge of coping strategies, and the ability to recognize the need for additional supports. OTs can assess and address the needs of the caregiver regarding the caregiver’s well-being and support their ability to care for the individual with ALS. OTs are also trained to meet the needs of the caregiver by identifying demands that may be essential as the disease progresses (e.g. positioning), educate the caregiver early and continuously on coping with these demands, address issues of regret, and enable caregivers as well as the individual with ALS to “experience the joys and pleasures that are still available to them” (Pizzi, 2010, p. 408). By empowering the caregivers, the OT will be promoting positive emotional, social, spiritual and mental health (Pizzi, 2010).

An essential skill that OTs possess is the ability to understand and recognize the signs of caregiver burden and distress. Caregivers may feel as though they need to be strong or they are best able to perform the caregiving duties which lead them to not communicate their feelings of psychological distress (Pizzi, 2010). Therefore, an OT can monitor the signs of burden and distress throughout the entire disease process. Developing the ability to detect and recognize these signs is essential because it improves the quality of care provided to the individual with ALS as well as the quality of life of the caregiver.

Importance of the Study

This scholarly project offers a manual for an OT to provide to an ALS caregiver. The manual provides an outline of the ALS disease and prognosis, the role of each healthcare professional for an individual with ALS, frequent psychological symptoms
experienced by ALS caregivers, coping strategies, and resources for caregivers to address and prevent psychological distress symptoms. Caregiver’s experience many changes as they transition throughout their role. These changes lead to an increased risk of psychological distress which ultimately puts caregivers at risk for decreased quality of life, health, and well-being. It is essential to provide support and resources to an ALS caregiver to promote health and well-being and prevent symptoms of psychological distress from developing into severe mental illness. As the authors were investigating the resources available to caregivers for individuals with ALS, they found many different fact sheets, but these all addressed only one or two topics. This manual compiles information and resources all in one place to make access easier for caregivers.
CHAPTER II  
LITERATURE REVIEW  

A comprehensive literature review was conducted on the topic of caregiving for an individual with Amyotrophic Lateral Sclerosis (ALS) and the role of occupational therapy with this population. Specific areas of interest were quality of life, demands placed on caregivers, psychological distress, end of life care, spirituality, and the stages of grieving. Pertinent information was summarized and compiled into the following review.

What is ALS

ALS is a terminal neurodegenerative disease characterized by the loss of voluntary muscle control due to deterioration of upper motor neurons (UMN) and lower motor neurons (LMN) throughout the body (Forwell, Copperman & Hugos, 2008). The degeneration of the motor neurons disrupts the brain's ability to send signals to contract voluntary muscles. With the inability to control muscle contractions, muscles continually weaken until muscle control is lost (PubMed Health, 2012). The cause of ALS is unknown (Forwell et al., 2008). The majority of individuals diagnosed with ALS have sporadic ALS which is not hereditary (ALS Association, 2012). Genetic features of ALS have been researched and five to ten percent of ALS diagnoses are familial (ALS Association, 2012). Research indicates there is a higher incidence in men than women (Forwell et al., 2008). Onset of ALS usually occurs in later adulthood around 50 years of age however individuals as young as 20 have been
diagnosed (Forwell et al., 2008; PubMed Health, 2012). According to the ALS Association (2012), approximately 30,000 Americans are living with ALS at any given time. Once diagnosed with ALS, the average life expectancy is between three to five years (PubMed Health, 2012).

There is no single test to diagnose an individual with ALS; therefore physicians administer multiple tests to rule out other diagnoses. Physicians will acquire past medical history, and conduct physical and neurological examinations to obtain necessary information regarding symptoms and physical functioning. Many tests such as electromyography (EMG), nerve conduction velocity (NCV), magnetic resonance imaging (MRI), and blood and urine tests are completed to assist in ruling out other diagnoses (ALS Association, 2012). It is difficult to diagnose ALS due to the many symptoms individuals with ALS experience.

The rate of disease progression varies with each person diagnosed with ALS, however, symptoms such as muscle weakness and paralysis are universal (ALS Association, 2012). Individuals experience a wide variety of symptoms including muscle cramps, progressive muscle weakness leading to eventual paralysis of muscles, speech difficulty, complications with swallowing, and difficulty breathing (PubMed Health, 2012). The initial symptoms displayed may be indicators of the prognosis of the disease (Forwell et al., 2008). Symptoms can occur within UMN, LMN, and bulbar nerves. UMN damage typically causes general weakness, spasticity, and hyperreflexia. LMN damage neuron is different in that it causes weakness or muscle atrophy of the extremities rather than general weakness as in UMN damage, weakness in the cervical extensors,
fasciculations, muscles cramps and a loss of reflexes compared to hyperreflexia (Forwell et al., 2008).

Damage to bulbar nerves leads to difficulty with speech, swallowing, and breathing. Although there is a differentiation of symptoms between damage to UMNs, LMNs, and bulbar nerves, individuals with ALS will eventually exhibit a variety of symptoms of all three nerve groupings throughout the course of the disease. Individuals who exhibit initial damage to UMNs have a slightly better prognosis than those with initial damage to LMNs secondary to the severity of LMN symptoms. Those who initially exhibit damage to bulbar nerves are most likely to experience a more rapid disease course (Forwell et al., 2008).

Despite the nerve groupings initially affected, every muscle that is voluntarily controlled will eventually lose its ability to contract. This is especially alarming when ALS begins to affect the diaphragm. As the disease progresses, individuals lose the ability to breathe on their own, requiring ventilator support (PubMed Health, 2012). While ALS affects voluntary muscle control, eye function, bowel/bladder function and sensation are not affected by the disease (Forwell et al., 2008). Cognition on occasion is affected by ALS, however it is rare. Based on symptoms experienced by individuals with ALS, they are at an elevated risk for pneumonia, pressure sores, lung failure, weight loss, and aspiration. Individuals with ALS also have an increased risk of falls secondary to muscle weakness (Forwell et al., 2008). The changes experienced by an individual with ALS regarding physical functioning can be described in phases to explain the level of care provided and the associated risks during each phase.
To facilitate the care provided for the individual with ALS, Van Den Berg et al. (2004), described 3 phases of ALS: diagnostic phase, rehabilitation phase, and terminal phase. These phases can also be used while describing the disease process to individuals with ALS and their caregivers. During the diagnostic phase, the neurologist is responsible for providing information regarding ALS including the disease course, progression and prognosis. The rehabilitation phase consists of anticipating changes in the individual’s condition, coordinating care between the multidisciplinary team members, and most importantly informing everyone involved about the decisions regarding end-of-life care that need to be made. During the rehabilitation phase, the role of the caregiver becomes more prominent. The rehabilitation phase can be subdivided into the following three sub-phases: independent, independent with aids and appliances, and dependent. The final phase, the terminal phase, is marked by carrying out the terminal treatment plans as previously agreed upon. The terminal phase also emphasizes care being provided to the caregivers and/or family members after the individual with ALS has passed away (Van Den Berg et al., 2004). These phases will continue to be referenced throughout this scholarly project.

ALS affects many aspects of daily life including activities of daily living (ADLs), instrumental activities of daily living (IADLs), rest and sleep, education, work, play, leisure, and social participation (AOTA, 2008). Individuals with ALS experience many changes in their ability to care for themselves as the disease progresses. Due to the complications and possible risks, an individual with ALS will eventually require the assistance of a caregiver, whether formal or informal. Formal caregivers are those that are connected to the healthcare system, such as a nurse or social worker. A formal caregiver
can be either a paid or unpaid position (Pizzi, 2010). This scholarly project will focus on informal caregivers. An informal caregiver is defined as an individual that is charged with the principle responsibility of caring for an individual with ALS excluding healthcare professionals (Pizzi, 2010). In 2009, it was estimated that 65.7 million people in the United States were unpaid caregivers (NAC & AARP, 2009). It is important for caregivers to be educated on all aspects of treatment to provide the best possible care and ensure the health and safety of the individual with ALS (Forwell et al., 2008). The demands placed on an informal caregiver will depend on the caregiver’s abilities as well as the relationships between the caregiver and the individual with ALS (Pizzi, 2010).

Caregivers are faced with a great deal of psychosocial stress due to the increased economic burden and decreased physical functioning of the individual with ALS. More than 70 percent of caregivers scored below the population norm on mental health (Jenkinson et al., 2000). In particular, one study indicated that nine percent of study participants displayed characteristics of a depressive disorder; this amount is higher than the average population (Rabkin et al., 2005). Due to this, more emphasis should be placed on the needs of the caregivers. In one study, 30 percent of caregivers reported that they did not feel there was anything that could be done to make their tasks less difficult (Pizzi, 2010). It is likely that these caregivers did not know the resources that were available to them, and occupational therapists (OTs) can assist with providing these necessary resources.

Quality of Life

Numerous studies have been conducted on the topic of being a caregiver for an individual with ALS to better understand the caregiver’s quality of life (QOL).
Caregivers reported that individuals with ALS suffered from lack of interest and concerns, disinhibition, and executive dysfunction. Lack of interest and executive dysfunction experienced by an individual with ALS were key symptoms that influenced a caregiver’s psychological distress. These negative symptoms experienced by the individual with ALS impacted the caregivers QOL and increased caregiver burden (Chio et al., 2010).

Tederous et al. (2008) determined that caregivers who lived with the individual with ALS as an informal caregiver had poor rating of QOL compared to those caregivers who did not live with individuals with ALS. Another determining factor for QOL was other life events not related to caring (e.g. marriages, children being born, and changes in work); these played a significant role in the caregivers’ perceived QOL (Roach et al., 2009). Additionally, research indicated that personality, spirituality, and social relationships can play a large role in the caregivers’ perceived QOL. One factor that increased the level of burden for the caregiver and subsequently decreased QOL was the increase in the individual with ALS’ physical symptoms as the disease progressed. The researchers believed that the decreased QOL experienced by the caregivers was due in part to the increase in physical tasks required to care for the individual with ALS. Overall, the caregivers felt an impact from the increasing physical symptoms of the individual with ALS, but the caregiver’s personality and other life events were also a large factor in determining QOL (Roach et al., 2009).

Quality of Marital Relationships

Although not all informal caregivers are married to the individual with ALS, many are. Spousal caregivers that have a loved one experiencing at least one ADL
impairment are at a significantly higher risk for decreased time and willingness to take care of themselves, taking longer to recuperate from personal illness, and forgetting to take prescription medications (Acton, 2002). Roach et al. (2009) suggested that caregivers may experience a decreased QOL which can be linked to the issues stated above, but can also be due to the changing roles within the marriage. The caregivers may be affected by the sudden change from what was expected for the course of the marriage (i.e. most people do not get married expecting their spouse to be diagnosed with a terminal disease) (Roach et al., 2009).

Atkins et al. (2010) found that the perceived quality of the marital relationships between the individual with ALS and their spousal caregivers differed throughout the progression of the disease. However, the perceived quality of the relationship prior to the diagnosis of ALS was a large predictor of quality of the marital relationship during the disease progression. Individuals with ALS indicated that their functional impairment impacted the perceived quality of marital relationship negatively, and as the disease progressed, self-esteem was a predictor of perceived satisfaction with quality of the marital relationship. Spousal caregivers reported a lesser degree of satisfaction in the quality of the relationship as the disease progressed secondary to caregiver burden and functional impairment of the individual with ALS (Atkins et al., 2010). Goldstein et al. (1998) found caregiver’s perceived burden to be correlated with the perception of a loss of intimacy with the individual with ALS.

**Caregiver Demands**

Caregivers spend on average 11 hours each day caring for the individual with ALS throughout the course of the disease with females having reported providing more
hours of care as well as a higher level of care than their male caregiver counterparts (NAC & AARP, 2009; Roach et al., 2009). It is not uncommon for caregivers to spend this amount of time even while they are receiving assistance from other family members or healthcare professionals (Roach et al. 2009). Hecht et al. (2003) also found that the total number of caregivers did not increase or decrease the perceived burden of the primary caregiver.

Psychological Distress

Burden is a common form of psychological distress experienced by caregivers; other types of distress include depression, guilt, resent, and anxiety. Nearly half of caregivers reported feeling psychologically and physically unwell (Murphy et al., 2009). Among the studies that have been conducted on psychological stress, differing conclusions have been made as to the predictors of distress.

The following were found to be predictors of psychological distress: psychosocial demands of ALS, changes in the individual with ALS’ ability to control emotional responses, social support and other caring demands. These factors were predictors in the early stages of caregiving and/or subsequently in the caregiving process. As the individual with ALS becomes more dependent on the caregiver, the caregiver is more likely to experience psychological distress (Goldstein et al., 2006). Caregivers who still work, live in a rural area, or have been providing care for an extended period of time were identified as being at a higher risk for experiencing psychological distress compared to other caregivers (Pizzi, 2010).
Caregiver Burden

One of the symptoms of caregivers’ psychological distress noted in the literature was burden. Caregiver burden is described as the negative aspects and perceived stresses an individual experiences associated with caring for an ill individual (Kim, Chang, Rose, & Kim, 2012). There is increasing evidence that caregiver burden affects both caregivers and the care recipient (Pizzi, 2010). The total amount of burden perceived by the caregiver has been found to be a predictor of future issues related to caregiving (Hecht et al., 2003). The caregiver’s level of burden increased as they became more depressed, anxious, or felt their social supports declining (Pagnini et al., 2010).

In previous research, caregivers reported an increase in caregiver burden as the individual with ALS’ physical functioning declined and subsequently the individual with ALS’ ability to perform self-care tasks diminished (Hecht et al., 2003; Roach et al, 2009; Pizzi, 2010). Patient distress was also a significant factor in triggering caregivers’ experiences of burden and distress (Boemer & Mock, 2011). A positive correlation was found between the amount of burden experienced and caregivers experiencing anxiety and depression (Pagnini et al., 2010; Goldstein et al., 2010).

Depression

Among the forms of psychological distress experienced, depression was most prevalent. Research indicated that nine percent of caregivers of individuals with ALS displayed characteristics of a depressive disorder; this is higher than the average population (Rabkin et al., 2005). Caregivers that have decreased feelings of competence regarding their role are twice as likely to experience depression after the individual with ALS has passed away (Dumont, Dumont, & Mongeau, 2008).
Despite common beliefs, spirituality, relationship to the caregiver, financial status, and participation in hospice care were not determined to be risk factors for depression in the caregiver (Rabkin et al., 2005). Rabkin, Wagner, and Del Bene (2000) found depression and distress were not related to the amount of time since receiving the ALS diagnosis, manifestation of symptoms, or the progression of the illness.

*Other Symptoms of Psychological Distress*

Although burden and depression are the most common forms of psychological distress, many other symptoms exist that impact caregivers; these include guilt, resent, and anxiety. According to Centers (2001), caregiver’s psychological distress was found to be related to feelings of guilt due to perceiving themselves as not providing high enough quality care as well as being overwhelmed and experiencing resent. Feelings of resent often lead to the caregiver experiencing an increased level of guilt, which leads to a cycle of guilt and resent that is hard to disrupt (Centers, 2001). Additionally, as the individual with ALS’ symptoms increased, the caregivers experienced greater amounts of distress and anxiety (Pagnini et al., 2010).

**Social Demands**

Due to the increased risk factors for psychological distress, Centers (2001) recommended that caregivers be educated on the necessity of maintaining social relationships despite the lack of time they may perceive from their caregiving duties. It is important to note that the size of the social network does not directly correlate with the quality of social support provided (Pizzi, 2010). Goldstein et al. (2006) determined that early in the caregiving process, a restriction felt in social support and leisure opportunities influenced the caregivers’ psychological states negatively.
Caregivers that are older in age may have friends or other family members that have also been placed in the role of caregiving, which may have a positive effect on their psychological health due to their increased sense of social support (Roach et al., 2009). Another source of social support that cannot be underestimated is the encouragement offered in ALS support groups. Fine (1991) stated “Acquiring a sense of belonging to a social group or, for that matter to all of life, is a powerful way to sustain oneself in the face of death or other extremes” (p. 497). Support groups provide a point of view that cannot be provided by anyone else; the members of these groups have their own experiences in similar situations, and this knowledge should not be taken for granted (Centers, 2001).

Finding Meaning

The role of caregiving can be experienced in many different ways. Caregivers have the choice to either view their caregiver role as an opportunity for personal growth and bravery or as disruptive and time consuming (Dumont et al., 2008). Although caregivers may experience an increase in perceived burden, this burden has been found to be positively correlated with finding meaning in the caregiving process (Roach et al., 2009). In a study by Roach et al. (2009), caregivers reported immediately having a hard time finding meaning within the ALS diagnosis. However, the caregivers subsequently reported an increased ability to find meaning followed by eventually feeling an even higher level of well-being than prior to the diagnosis. Although caregivers may struggle with their new role, many will use the ALS diagnosis as an opportunity to embrace their situation and grow personally from their experiences. Mock and Boerner (2010) found that as the individual with ALS’ symptoms become more severe, increased feelings of
support from others can lead caregivers to have more positive thoughts about caregiving and the situation at hand (Boemer & Mock, 2011).

Rabkin et al. (2000) found a positive correlation between perceived burden and finding meaning is caring for their loved one, suggesting that finding meaning was used as a way to cope. The caregivers with a positive outlook were found to have the highest overall QOL and lowest incidence of psychological distress (Murphy et al., 2009).

Center (2001) suggested that until a cure for ALS is discovered, anyone in the role of a caregiver should take their new role as an opportunity provided to them and find the positives that may arise from the situation. The diagnosis, although terminal, provides individuals affected with the chance to contemplate his or her own hopes, beliefs, desires, regrets, and fears.

Occupational Therapist’s Role with Psychological Distress

OTs are an important part of the healthcare team for individuals with ALS. OTs promote health and well-being through engagement in occupations during all aspects of one’s life (AOTA, 2008). In addition to treating the affected individuals, OTs have the skills to educate caregivers, strategies to balance caregivers’ demands, knowledge of coping strategies, and the ability to recognize the need for additional supports. OTs can assess and address the needs of the caregiver regarding the caregivers’ well-being and support their ability to care for the individual with ALS. By empowering caregivers, OTs can promote positive emotional, social, spiritual and mental health (Pizzi, 2010).

One important issue for an OTs to address is providing the caregiver with permission to not always be strong. Recognizing the caregiver’s need to “grieve” the diagnosis of ALS enables them to seek out help for themselves (Pizzi, 2010). Other interventions suggested by Pizzi (2010) include identifying demands that may be essential as the disease progresses (e.g.
positioning), educating the caregiver early and continuously on coping with these demands, address issues of regret, and enabling caregivers as well as the individual with ALS to “experience the joys and pleasures that are still available to them” (Pizzi, 2010, p. 408).

An essential skill for OTs is to be able to understand and recognize the signs of caregiver burden and distress. Although these signs and symptoms may be difficult and uncomfortable to address with a caregiver, it is likely that a caregiver will experience many of these. Caregivers may feel as though they need to be strong or are best able to perform the caregiving duties which lead them to not communicate their feelings of psychological distress directly (Pizzi, 2010). Therefore, OTs can monitor the signs of burden and distress throughout the entire disease process. Developing the ability to detect and recognize these signs are essential for OTs because it improves the quality of care provided to the individual with ALS as well as the QOL of the caregiver.

End of Life Care

The most common cause of death for an individual diagnosed with ALS is respiratory failure due to restrictive lung disease (Munroe et al., 2007). Other terminal symptoms include difficulty with eating, swallowing, and a high occurrence of shortness of breath (Goy, Carter, & Ganzini, 2008). Although ALS is terminal, individuals have many options to delay death such as invasive mechanical ventilation, noninvasive ventilation measures, and gastric feeding tubes. There is also a single prescription drug, Riluzole, which has been found to extend an individual’s life by a few months (Roach et al., 2009).

ALS typically has a disease course that is gradual, which allows the individual to discuss end-of-life options with their caregivers. Researchers suggested that these measures should be discussed with the individual with ALS, family members, and
caregivers as soon as a definitive diagnosis is determined due to the unpredictability of the disease course. However, there is little consensus as to which health care team member should discuss the end-of-life measures (Blackhall, 2012). Many individuals with ALS are interested in more information on dying, but most feel that it is the physician’s job to initiate the conversation or they do not know where to look for further information (Blackhall, 2012; Munroe, 2012). Health care professionals need to provide factual information regarding the course of treatment.

Centers (2001), an OT and former caregiver for a family member with ALS, suggests that one of the most important aspects of working with the caregiver and the individual with ALS is for the clinician to be truthful. Being truthful gives the necessary information and control for the individual with ALS and the caregiver to make the best decisions for themselves. At the same time, the provider needs to be careful not to overwhelm them with too much information at one time. The healthcare provider’s job is to fully educate the caregiver and individual with ALS on the pros and cons of any decision, but ultimately the decisions needs to be left up to the individual with ALS and their caregiver. A second important piece of advice from Centers (2001) is to focus on the present situation. There is no cure for ALS, therefore it is necessary to help the individual with ALS and caregiver to focus on the life they are living now because it is the only life they are given. Some individuals use spirituality as a means to cope and stay focused on the current situation.

Spirituality and Quality of Life of Caregivers

Moreira-Almeida & Koenig (2006) define spirituality as “the personal quest for understanding answers to ultimate questions about life…” (as cited in AOTA, 2008,
p.633). This is the definition used in the *OT Practice Framework*. Inherent within this definition is the fact that spirituality does not only encompass one’s religious practices. Individuals who do not describe themselves as being religious or affiliating to a certain belief system will likely still have spiritual needs (Udell & Chandler, 2000). Spirituality can encompass many facets including one’s values and beliefs or occupations that give a person a sense of meaning or comfort (AOTA, 2008). For these reasons, spirituality has been found to be necessary when providing the highest quality of care. One study found that 88 percent of caregivers ranked spirituality as being especially important for answering questions about the meaning of life (Kaye & Robinson, 1994).

Spirituality has been found to be a predictor of perception of QOL for both the caregiver and the individual with ALS (Pagnini et al., 2010; Calvo et al., 2011; Murphy et al., 2009). Pagnini et al. (2010) found that individuals with ALS who had higher levels of spirituality had caregivers with a lesser degree of depression, anxiety, and caregiver burden (Pagnini et al., 2010; Calvo et al., 2011). In their research, Calvo et al. (2011) found religiousness to be the second highest predictor of QOL for the caregiver, which indicates the importance of this topic when working with caregivers (Calvo et al., 2011). One reason for these results may be due to caregivers using spirituality as a coping strategy (Kaye & Robinson, 1994). Based on these results, healthcare professionals should take time to address spirituality needs with both the individual with ALS and caregivers. With OTs knowledge regarding spirituality, OTs are one of the health care professionals that could address this topic.

When spirituality is not addressed, caregivers may experience spiritual distress, anger directed to a higher being or others, suffering, and a decreased ability to find
meaning. Udell and Chandler (2000) described three levels of spirituality for addressing the wide range of spiritual needs encountered by an OT: practical spiritual needs, acknowledgment of the spirituality of the individual, and spiritual counseling. Practical spiritual needs are the most straightforward and can be addressed through interventions similar to other needs. Acknowledgement of spirituality includes the need for space, dignity, respect, and someone to speak with. The final level of spirituality, counseling, was deemed as not being within an OTs scope of practice (Udell & Chandler, 2000).

Grieving Process

The five stages of grief can be used as a tool to help people understand the emotions they are experiencing during the grieving process, and it is within an OTs scope of practice to educate caregivers and individuals with ALS on these stages (Kubler-Ross & Kessler, 2006). The five stages of grief are: denial, anger, bargaining, depression, and acceptance. These stages are meant to assist a person in coping with loss. Not everyone will go through these stages, nor will they go through the stages in a specific order. In the case of a caregiver for an individual with ALS, the caregiver will inevitably grieve multiple times including after the individual receives the ALS diagnosis and when the individual passes away (Kubler-Ross & Kessler, 2006).

Denial

Denial is the first of the five stages of grief. Denial is not meant in the literal sense; instead it describes the feelings that one has when they simply cannot believe their current situation. Denial is encompassed with emotions such as feeling shock, numbness, and paralysis. Denial is a coping strategy and protective mechanism because the person experiencing grief is not psychologically ready for the other emotions that follow grief.
Denial is a form of survival within the grieving process. As a person proceeds through this stage and onto the other stages, all the feelings that were being denied start flooding back to the person (Kubler-Ross & Kessler, 2006).

**Anger**

Anger is an emotion that is commonly avoided or minimized. At this stage in the grieving process, anger should be felt. The more an individual allows themselves to feel anger, the more one can heal. Anger is a sign of love for the individual with ALS. The importance of this emotion should not be diminished or minimized. At this stage, the caregiver should not be criticized because anger is felt at a time when a person is feeling safe enough to know that they will be able to survive during the disease course of ALS and the loss of the individual with ALS (Kubler-Ross & Kessler, 2006).

Anger may come in many forms. A caregiver may feel angry because he or she feels they did not do enough to care for the individual with ALS. Anger can also be directed at health care professionals for not being able to stop their loved one from dying. Anger may be directed towards the individual with ALS for dying despite them not choosing to be diagnosed with ALS (Kubler-Ross & Kessler, 2006).

**Bargaining**

Bargaining is the third stage of the grieving process. This stage of the grieving process is a transitional stage that exists between periods of strong emotions. Bargaining allows the caregiver time to process and adjust to the situation. After receiving the diagnosis of ALS, chaos may ensue, and the bargaining stage will be a time for order to be restored. Overtime, the things the caregiver bargains for will likely change. In the beginning, the person grieving may wish for their loved one not to die. However, by the
end, the caregiver may hope that the individual with ALS dies peacefully while experiencing as little pain as possible (Kubler-Ross & Kessler, 2006).

**Depression**

Depression is typically the longest lasting and hardest of the five stages. Experiencing depression does not automatically mean a person has a mental illness; this common misconception often leads a person to hide their sadness and not allow themselves to fully experience this stage. However, depression needs to be experienced as it is part of the healing process. Depression allows the caregiver to adapt to their situation. It also gives the caregiver time to slow down and fully understand their situation. Depression is a time of rebuilding. At this point in the stages of grief, the caregiver will be thankful for support systems that allow them to experience the depression without trying to change their mood or feelings. Thus, a support system that is available for the caregiver, yet allows them to experience depression is essential (Kubler-Ross & Kessler, 2006).

**Acceptance**

Acceptance does not necessarily mean that the caregiver welcomes the ALS diagnosis. Instead, this stage consists of recognizing that ALS is a reality as is the eventual loss of the individual with ALS. This does not mean that the caregiver likes this reality; they have simply accepted it. At this point, the caregiver will not necessarily be done with the other stages. Instead, they may start to have more good days than bad days. There are many difficult aspects of being a caregiver that may be difficult, including passing through the stages of grieving many times. However, a caregiver should take
their time of being a caregiver as a blessing, as there is no cure for ALS and time is limited.

Summary

ALS is a terminal disease with an average life expectancy of about three to five years. It is characterized by the degeneration of motor nerves resulting in an individual with an inability to move limbs, breath, swallow, and talk independently (Pub Med Health, 2012). As the disease progresses, an individual diagnosed with ALS will require assistance from a caregiver, most commonly a family member or a friend. A caregiver is expected to provide assistance in every aspect of the individual with ALS’ life to make sure every need is met (Pizzi, 2010). Caregiving tasks can occupy multiple hours a day, which affects a caregivers established routines, roles, and physical and mental health (Roach et al., 2009). With the transition into a caregiving role, a caregiver is at risk for psychological distress which impacts one's ability to complete caregiving demands and maintain QOL and well-being (Chio et al., 2010; Jenkins et al., 2000). Negative symptoms commonly experienced by caregivers are depression, anxiety, decreased QOL and well-being, guilt, resent, and limited social support. Although being a caregiver can have many negative symptoms, caregiving can also be a meaningful experience and an opportunity for personal growth. OTs are a resource in assisting caregivers to find meaning and encouraging personal growth to promote QOL and well-being.

OTs have the knowledge and skills to address the needs of an ALS caregiver to endorse their physical and mental health, as their needs may be overlooked in the treatment of an individual with ALS. This makes an OT a great candidate for creating and implementing the manual created in this scholarly project. An OT can provide family-
centered care which can include education, strategies to cope with difficult experiences, preventative strategies and knowledge of resources for support. OTs can use strategies to encourage, validate, and advise ALS caregivers to find purpose, meaning, and motivation in their role as a caregiver.

In summary, the authors created this product to address the psychological aspects of being a caregiver for an individual with ALS and to promote caregivers’ health and well-being as a caregivers’ needs are not always addressed in healthcare. Many caregivers have described that their caregiving role can be a burden which can lead to stress, anxiety, depression, guilt, and resentment which in turn affects their ability to care for an individual with ALS. The product, Helping Others by Helping Yourself: An ALS Caregiver’s Guide to Self-Care, is to be used as a reference manual for caregivers to seek information about taking care of themselves.

Being a caregiver for an individual with ALS may not have been a planned life experience, especially when a caregiver is providing care to a loved one. It is difficult for a caregiver to watch a loved one experience hardships and difficulties as the disease progresses, which can ultimately hinder the caregiver. As the disease progresses, a caregiver will be expected to provide a greater level of assistance, which can lead to mental and physical exhaustion from providing care for many hours each day.

The benefits a caregiver will obtain from this manual will be to gain the ability to identify their feelings, to learn strategies to cope with experiences, and to gain resources to promote QOL, well-being, and support. By addressing these needs, it is proposed that a caregiver will better their ability to complete their caregiver duties with satisfaction while maintaining their QOL and well-being.
CHAPTER III

METHODOLOGY

This product, *Helping Others by Helping Yourself: An ALS Caregiver’s Guide to Self-Care*, is intended for ALS caregivers to use as a reference manual to reduce psychological stress and increase quality of life and well-being. Within the manual there are detailed sections describing common mental health symptoms experienced by ALS caregivers, the grieving process, coping strategies, and resources to prevent the undesirable symptoms that may occur.

The Model of Human Occupation (MOHO) was chosen to guide the development of this manual because MOHO focuses on a client-centered and holistic approach to address caregivers’ abilities to perform occupations. Adult learning theory was a second theory used to guide the development process. Adult learning theory was used to assist in making the reference manual user-friendly for the caregivers and to address adult learners’ needs.

The initial phase of developing this product included locating current literature regarding ALS, caregiver role in ALS, ALS impacts on caregiver demands, burden of caregiving, coping with caregiving, caregiver quality of life, caregiver relationships, finding purpose in caregiving, benefits of spirituality when caregiving, role of an interdisciplinary team, end of life care, and occupational therapists (OTs) role in addressing caregivers. To locate literature, multiple search engines were utilized to retrieve information such as CINAHL, PubMed, PsychInfo, Google Scholar, AJOT, and
OT Search. Other information regarding assisting caregivers was obtained from textbooks and through the ALS Association website. Assistance was given by the reference librarian in the Harley E. French Library and contacts within the ALS association. The authors were in contact with members of Minnesota/North Dakota/South Dakota chapters of the ALS Association as well as an OT that works in an ALS clinic, all of whom provided valuable information.

With an extensive amount of literature reviewed on this topic, the authors reduced the information obtained into a thorough analysis as represented in the literature review and final product. Through analyzing the literature reviewed the authors identified common barriers that affect ALS caregivers. ALS caregivers are at risk for psychological distress due to physical and mental demands they experience during their caregiving role. Through analysis and evaluation of current literature of the impact psychological distress has on caregivers, the researchers identified that the psychological needs are currently not being addressed. These unmet needs led to the development of the reference manual to meet the psychological needs of an ALS caregiver.
CHAPTER IV

PRODUCT

Purpose

A review of literature found that caregivers for individuals with ALS are at an increased risk for psychological distress and a decline in quality of life compared to the general population. In response to these findings, the authors developed two manuals focused on improving the lives of these caregivers.

The ALS caregiver manual, *Helping Others by Helping Yourself: An ALS Caregiver’s Guide to Self-Care*, was designed to address the unmet needs of an ALS caregiver regarding their physical and mental health by providing information, resources and tools to help caregivers focus on caring for themselves. This manual was created as a reference manual to allow the caregiver to learn strategies to manage their stresses and schedules, identify feelings and experiences, and maintain engagement in occupations.

The second manual, *OT Guidelines for the ALS Caregiver Manual “Helping Others by Helping Yourself: An ALS Caregiver Guide to Self-Care”* was created to educate OTs on the use of ALS caregiver manual. This guide contains the purpose of the caregiver manual, a brief description of the contents, timing for distribution, and follow up suggestions.
Model

The Model of Human Occupation (MOHO) was the theory guiding the research and development of the manuals. MOHO’s main concepts of volition, habituation, and performance capacity were used to guide the development of the manuals. Guidance of MOHO helped the authors to focus on the main concepts of the model to promote engagement in occupations that are familiar and to assist an ALS caregiver to adapt to new situations and occupations. MOHO incorporates therapeutic strategies to guide the therapy process; these strategies include advising, encouraging, and validating and allow for an ALS caregiver to identify feelings as well as provide guidance for engaging in occupations and managing psychological distress. These strategies were also incorporated into OT Guidelines for the ALS Caregiver Manual “Helping Others by Helping Yourself: An ALS Caregiver Guide to Self-Care” as suggestions for guiding the therapy process (Kielhofner, 2009).

Adult learning theory was also used to guide the development of the product. The adult learning theory has multiple assumptions to address the needs of adult learners. First, adult learning theory indicates that the learner’s motivation determines their engagement in the learning process. Since, adults are more resistant to change due to established beliefs, values, and routines, motivation is a necessary topic to address and to incorporate into the product. Additionally, many stressors associated with caregiving can be taxing on the ALS caregiver and a barrier for motivation. Secondly, a learner is more likely to change if a perceived learning experience is through to be meaningful. Thus the
manual is focused on assisting an ALS caregiver in determining and finding meaning through establishing schedules, engaging in occupations, and maintaining roles and responsibilities. The content within the manual is directed towards applying multiple strategies into daily life to facilitate and support engagement in occupations. Finally, adult learning theory suggests that learners are more likely to seek information when they feel ready with the intent to cope with life situations (Knowles, Holton & Swanson, 2005). The OT is able to monitor readiness for learning and assist the ALS caregiver in coping when the caregiver is willing. The caregiver manual was created to be used by caregivers with a variety of educational backgrounds, learning styles, and needs. Accordingly, the manual is designed to be easy to read and understand.
Helping Others by Helping Yourself: An ALS Caregiver’s Guide to Self-Care
Introduction

As a caregiver you may have multiple stressors on a daily basis. This manual is focused on giving you the information, resources, and tools needed to maintain your physical and mental health as well as ways you can care for yourself.

Additionally, this manual will provide information on ALS. An individual with ALS will have multiple healthcare professionals caring for them. You may not understand their job, thus, each healthcare professional's role is also described.

Lastly, mental health symptoms are felt by ALS caregivers, the most common symptoms are described in detail as a reference. This manual also contains multiple questions for you to answer to help you to begin identifying your thoughts, concerns, and experiences. Prevention and coping techniques for common mental health issues are discussed to provide ways to address your needs and promote your health and well-being.
An occupational therapist and former caregiver for a family member diagnosed with ALS suggested that until a cure for ALS is discovered, anyone in the role of a caregiver should take their new role as an opportunity given to them and find the positives that may come from the situation. An ALS diagnosis is fatal and difficult to accept but this situation provides individuals affected with the chance to contemplate his or her own hopes, beliefs, desires, regrets, and fears.

Being a caregiver can be felt in many ways. You have the choice to either view your caregiver role as an opportunity for personal growth and bravery or as disruptive and time consuming. Now is the time to decide how you will make the best out of the situation you are dealing with.
Amyotrophic Lateral Sclerosis

Amyotrophic Lateral Sclerosis (ALS) is a terminal disease defined by the loss of voluntary muscle control due to motor neuron deterioration throughout the body. Motor neurons are nerves in the body that carry signals from the brain to the muscles to produce movements. The breakdown of neurons that happens in ALS interrupts the brain’s ability to send signals to move a person's arms, legs, and body. This eventually leads to muscles getting weaker.

- The cause of ALS is unknown.
- Symptoms of ALS usually start later in adulthood.
- Approximately 30,000 Americans are living with ALS at any given time.
- Average life expectancy after the diagnosis is between 3 to 5 years.
- No single test can diagnose an individual with ALS.

Symptoms of ALS

The rate of disease progression varies with each person diagnosed, however, symptoms such as muscle weakness and paralysis are universal. Individuals may experience a wide variety of symptoms including:

- Muscle cramps
- Muscle twitching
- Loss of reflexes
- Difficulty speaking
- Trouble swallowing
- Difficulty breathing
- Progressive muscle weakness leading to eventual paralysis of one's arms, legs, and body

(Forwell et al., 2008)
Course of ALS

Every muscle that an individual can choose to move will eventually lose its ability to contract. This is very alarming when ALS begins to affect the diaphragm which are muscles that assist with breathing. In this case, individuals lose the ability to breathe on their own, requiring the support of a machine (a ventilator) to help with breathing. ALS will not change the individual’s eyes, bowel, and bladder functioning. Cognition, the way a person thinks, does not normally change, but in rare case this is possible. Based on the symptoms, the individual with ALS will be at an increased risk for pneumonia, pressure sores, lung failure, weight loss, and choking. As the symptoms get worse, safety with walking and other movements becomes harder because muscle strength decreases. Thankfully, there are many options to increase safety and reduce risks.

ALS will impact nearly every aspect of one’s life, therefore to ensure health and safety, a caregiver is needed. Individuals with ALS will experience many declines in their ability to care for themselves. Individuals will eventually need assistance with self-care tasks, preparing meals, taking care of children, driving, and leisure activities. An occupational therapist can assist in determining the tools and equipment needed as muscles begin to weaken. These tools, known as adaptive equipment, are designed to help with many aspects of life including dressing, toileting, bathing, meal preparation, hygiene, cooking, and eating. Adaptive equipment is used for safety and improving the individual with ALS’s ability to complete common tasks.

(Forwell et al., 2008; PubMed Health, 2012)
Stages of ALS

There are three phases of ALS that can help you as a caregiver understand how ALS affects an individual. These phases can also be used to describe the disease process to a family member or a friend.

1. **Diagnostic Phase**: Information will be provided regarding ALS including the disease course, progression and possible outcomes. Treatment will begin as soon as possible after the diagnosis is confirmed.

2. **Rehabilitation Phase**: consists of anticipating changes in your loved one’s condition, coordinating care between the multidisciplinary team members, and importantly, informing everyone involved about the decisions regarding end of life care that need to be made. During the rehabilitation phase, the role of the caregiver is very important. The rehabilitation phase can be subdivided into the following three sub-phases.
   
   A. **Independent**: focused on exploring possible treatment options and setting treatment goals; team members will be introduced.
   
   B. **Independent with Aids and Appliances**: focused on choosing and learning the use of tools and equipment that will help your loved one to be as independent as possible. Management and acceptance of the tools and equipment is also addressed. Treatment options are discussed to prepare for the possibility of a rapid decline in function.
   
   C. **Dependent Stage**: focused on allowing your loved one to stay at home as long as possible. He or she is provided the necessary tools and equipment. The tools and equipment are checked more frequently in order to make sure they are still the best option at the current level of physical functioning. This stage of treatment also focuses on you, the caregiver, and supporting your needs because the individual with ALS will be relying more and more on your assistance.

3. **Terminal Phase**: marked by carrying out the end of life treatment plans as previously agreed upon. The terminal phase also emphasizes care being provided to the caregivers and/or family members after the individual with ALS has passed away.

(Van Den Berg et al., 2004)
Treatment for ALS

As there is no cure for ALS, treatment is focused on minimizing symptoms, maintaining independence, and improving quality of life. Treatment options should be discussed with healthcare professionals immediately, as the course of ALS is unknown. Healthcare professionals that may be involved in the individual with ALS’s treatment are discussed in the next section called “Role of Healthcare Professionals.” Additionally, the Food and Drug Administration has approved a prescription drug called Riluzole which has been found to extend an individual’s life by a few months. Along with Riluzole, there are many treatment options which may include but are not limited to:

• Tools and equipment used as muscles begin to weaken

• Tube feeding used when swallowing becomes too difficult

• Communication devices for assistance with speaking

• Ventilator for assistance with breathing

(Van Den Berg et al., 2004)
Role of Healthcare Professionals

There will be multiple healthcare professionals working with you and the individual with ALS throughout the disease process. Each healthcare professional has a specific role in providing care and educating an individual with ALS, their family, and caregivers. You are encouraged to ask any healthcare professional questions and bring up concerns you have regarding the care provided and additional options for care. An overview of the role of each healthcare member is provided below.

- **Neurologist**: specializes in the ALS diagnosis, evaluation, and treatment options and can prescribe medications.

- **Nurse**: focuses on providing overall care to the individual.

- **Pharmacist**: educates an individual on taking medications properly and the side effects of medications.

- **Dietitian**: educates and assists in planning meals for adequate nutrition; collaborates frequently with a speech pathologist regarding intake of fluids and food; provides education on nutritional changes needed and often seen with individuals who have ALS.

- **Social Worker**: assists the individual with ALS in obtaining necessary medical equipment, financial planning, knowledge regarding insurance and locating community resources for support.

(Emory Healthcare, 2013; National Institute of Neurological Disorders and Stroke, 2012)
Role of Healthcare Professionals

- **Speech Therapist**: assists in managing speaking as it becomes difficult; collaborates with a dietitian to monitor swallowing in an individual with ALS and to ensure adequate food and fluid intake.

- **Occupational Therapist**: implements evaluations, treatments, and home evaluations to enhance independence; assists with engagement in meaningful tasks that support health, recommends adaptive equipment to support independence; focuses on dressing, bathing, feeding, eating, toileting, grooming, hygiene, meal preparation, and alternative communication devices; is a resource for coping, stress reduction, and balancing a healthy lifestyle.

- **Physical Therapist**: implements evaluation, treatment, and home evaluations to enhance independence; assists with maintaining independence and safety with walking at home and in the community; implements light exercise programs to increase strength and movement of limbs.

- **Respiratory Therapist**: assists in maintaining the ability to breathe independently and educates the individual with ALS, their family, and caregivers on expected changes; monitors an individual with ALS’ muscle strength for breathing; monitors changes in breathing capacity and provides education on alternative options.

(AOTA, 2008b; Emory Healthcare, 2013; National Institute of Neurological Disorders and Stroke, 2012)
Grieving Process

As a caregiver, you may experience grief many times. The first time may occur after the individual receives the ALS diagnosis, then throughout caring, and again at the time when the individual you are caring for passes away.

There are five stages of grief which include denial, anger, bargaining, depression, and acceptance. The grieving stages are meant to assist a person in recognizing the feelings that are common when coping with loss and sadness. None of the stages are described as good or bad, they simply are feelings that will likely be felt by you at some point when caregiving.

(Kubler-Ross & Kessler, 2006; Microsoft, 2010)
Grieving Process

Denial

Denial is the first stage of grief. Denial is described as feeling as if you may not be able to believe that you are going through the experience. Denial may occur throughout caregiving, for example when your loved one has been diagnosed with ALS and later when your loved one has passed away.

Denial includes emotions such as feeling shock, numbness, and as if a weight has been placed on you. Denial may be felt when you are not ready to experience other emotions. As a person proceeds through this stage and onto other stages, all the feelings that were being denied start flooding back to the person, which can be difficult to deal with.

Anger

Anger is an emotion that is commonly avoided or minimized. At this stage in the grieving process, anger should be felt. The more you allow yourself to feel anger, the more you can heal. Anger, along with the other stages, is a sign of love for the individual with ALS. The importance of this emotion should not be minimized. Do not let anyone criticize you for feeling angry. Anger will be felt when you are feeling safe enough to know that you will survive.

Anger appears in many forms. You may be angry because you feel you are not doing enough to care for the individual with ALS. Anger can also be directed at the health care workers for not being able to stop their loved one from dying. Anger can be directed towards the individual with ALS for dying as well, despite them not choosing to be diagnosed with the disease. It is healthy to grieve and be angry as the feelings are part of the healing process. But you have to be able to work through it.

(Kubler-Ross & Kessler, 2006)
Grieving Process

Bargaining

Bargaining is described as identifying an alternative to a situation. Bargaining happens between periods of strong emotions. Bargaining allows you time to think about and adjust to the situation. Overtime, the things you bargain for will likely change. In the beginning, you may wish for your loved one not to die. As the disease progresses, you may hope that the individual with ALS dies peacefully.

Depression

Depression typically lasts the longest and is the hardest of the five stages. Experiencing depression does not mean you have a mental illness. This misunderstanding often leads a person to hide their sadness and not allow themselves to fully experience the emotions that are part of the healing process. Depression allows you to adapt to the situation which, at the time, might feel impossible to handle. It also gives you time to slow down and fully understand the loss.

At this point in the stages of grief, you will be able to think about your life and the life of your loved one. You should start thinking about the support systems that allow you to experience the depression without trying to change your mood or feelings about the situation. Remember that a support system that is available for you, yet allows you to experience depression is essential.
Grieving Process

Acceptance

Acceptance does not necessarily mean that you are all right with the ALS diagnosis. Most people will never fully be okay with losing their loved one to ALS. Instead, this stage consists of recognizing that ALS is a reality. This does not mean that you like this reality; you are simply at peace and can cherish the time you have with your loved one. This stage is a time for transformation and renewal. It may mean that you start to have more good days than bad days.

The grieving process helps you understand the emotions that may be felt while caregiving. The grieving process is different for each person. You may move back and forth between stages many times while providing care and also after the individual with ALS has passed away. It is important for you to be able to recognize, express, and feel these emotions because it is an important part of the healing process.

• How are you going to empower yourself to feel each of these emotions?

__________________________________________________________________________________________

__________________________________________________________________________________________

__________________________________________________________________________________________

__________________________________________________________________________________________

(Kubler-Ross & Kessler, 2006)
Talking to Someone Who is Grieving

When an individual is grieving, many people will want to make them feel better. However, if a person isn’t careful they can easily hurt the feelings of the one they are trying to comfort. This section may be helpful to read when talking to others about your role as caregiver. This section can be shared with friends and family to help them understand what you are experiencing.

Here are some ideas to keep in mind to best support an individual who is grieving.

• Recognize the loss (avoiding the subject will make the situation harder)
• Be supportive!
• Acknowledge the individual’s feelings
• Don’t tell the person what to do or how to grieve
• Don’t try to change the feelings experienced
• Don’t try to limit the grieving process to a certain time frame

(Kubler-Ross & Kessler, 2006; Microsoft, 2010)
Talking to Someone Who is Grieving

Here are some ideas of what to avoid while talking to an individual who is grieving. This information can be shared with your friends and family to help them better understand what you are experiencing.

- Don’t try to rationalize or explain the loss
- Don’t try to “fix” anything; there is nothing to be fixed
- Don’t be judgmental
- Don’t compare situations (everyone is unique in their grieving process)

With these tips in mind, you will be less likely to offend the individual who is grieving. It is important to have open communication with others so you can discuss concerns that you may have. It is also important to talk about the positive aspects of caregiving.

- Who are the supports in your life that you may want to share this information with?

___________________________________________
___________________________________________
___________________________________________

(Kubler-Ross & Kessler, 2006)
Finding Meaning

At first, you might have a hard time understanding why you have been put in the role of being a caregiver. Although you may struggle with your new role in the beginning, many caregivers have used the ALS diagnosis as a chance to embrace their new role and grow personally from their experiences. The caregivers with a positive view have the highest overall happiness and lowest rate of distress.

Questions to think about:

• Do you feel you are able to look at the positive side of caregiving?

• What are some the positives that you have found while being a caregiver?

• Do you feel comfortable talking about your feelings with the individual you are caring for?

(Muphy et al., 2009)
Finding Meaning

Questions to Answer:

• Write a list of things you find meaningful

_____________________________________________
_____________________________________________
_____________________________________________

• What motivates you to be a caregiver?

_____________________________________________
_____________________________________________
_____________________________________________

• How can you remind yourself to focus on positives in your life?

_____________________________________________
_____________________________________________
_____________________________________________
Common Feelings Among ALS Caregivers

Caregiving tasks as well as maintaining your habits and daily routines can be stressful and difficult to complete while caring for others. Caregiving tasks can lead to an imbalance in life and disruption in one’s daily routines. Many psychological symptoms are experienced by caregivers that can decrease quality of life.

Psychological distress symptoms include feelings of burden, depression, guilt, resent, and anxiety. All of the symptoms are commonly experienced among caregivers. By recognizing these feelings you can begin to utilize strategies to prevent and cope with them.

The following were found to be predictors of psychological distress:

- Changes in the individual with ALS’ emotional responses
- Changes in social support
- Other demands besides caregiving

These factors were predictors of psychological distress in the early stages of caregiving and/or during the caregiving process.

(Goldstein et al., 2006)
Caregivers have expressed 5 areas of concern that have impacted their mental health when caring for an individual with ALS. These include:

• Concerns about one’s own personal health
• Taking on a new role while putting one’s life on hold
• Feeling guilty
• Limited amount of support from and time with family and friends
• Lack of time to take care of one’s self

These are normal feelings expressed by caregivers and they may impact you negatively and additional help may be needed.

• How do you take care of your personal health and well-being?

• Do you feel you are putting your life on hold because you have too many demands to complete? Explain your feelings.
Depression

Being a caregiver puts you at a higher risk of developing depression. Depression can be experienced in many forms. Symptoms of depression can make it difficult to get out of bed, to enjoy activities that you once found joyful, and to find motivation to complete daily tasks.

Depression is characterized by:

- Feelings of sadness or feeling empty
- Having diminished interest in activities
- Tiredness
- Lack of energy to complete tasks
- Problems sleeping or sleeping too much
- Thoughts about death

(Microsoft, 2010; Rabkin, Wagner, & Del Bene, 2005; Sadock & Sadock, 2008b)
Questions to think about:

• Do you feel sad and empty?

• Do you have problems sleeping at night or are you sleeping too much?

• Do you feel like you don’t have enough energy to complete tasks on daily basis?

• Do you feel like you don’t enjoy things like you used to?

• Do you have thoughts or feelings about killing yourself?

Question to answer:

• From the previous page, identify one or two symptoms from the symptoms list you are having. How often do you experience these symptoms? (For example, do you experience this symptom every day, in the evenings, or once a week, etc.)
Common Feelings Among ALS Caregivers

Anxiety

Anxiety is a response or feeling that can be beneficial in certain situations. For example, feeling anxious before a job interview is okay. But when anxiety begins to disrupts your ability to complete routines and desired tasks, assistance is needed. Research has shown that caregivers are at risk for developing anxiety, which can begin from experiencing stress.

Anxiety is characterized by:

- Feelings of uneasiness
- Sweating
- Feeling nervous
- Increased heart rate
- Trouble controlling your level of worrying
- Difficulty sleeping because you are thinking too much
- Having a difficult time concentrating on daily tasks

(Pagnini et al., 2012; Sadock & Sadock, 2008a)
Questions to answer:

• What physical signs of anxiety such as uneasiness, sweating, increased heart rate, or difficulty sleeping have you experienced?

• What other symptoms of anxiety have you experienced such as trouble controlling your level of worrying or difficulty concentrating?

• How often do you have these feelings?

• Describe a situation that makes you feel very anxious or worried?

• What are the symptoms that you experience in this situation or similar situations?
Common Feelings Among ALS Caregivers

Caregiver Burden

Caregiver burden is described as the negative aspects and perceived stress you experience while caring for an ill person. It is common for caregiver burden to increase as the individual with ALS begins to need more physical assistance to perform self-care tasks.

Questions to think about:
- Are you experiencing stress related to caregiving responsibilities?
- If you are feeling stressed, do you think the stress is impacting your ability to provide care to the individual with ALS?
- Do you feel like additional assistance is needed to help care for the individual with ALS?
- Have you talked about your feelings to other people?

(Hecht et al., 2003; Kim et al., 2012; Microsoft, 2010; Pizzi, 2010; Roach et al., 2009)
Caregiver burden affects both you and the individual you are caring for. Negative feelings and stress may affect your ability to complete caring tasks as well as your ability to cope with current issues related to caring. Therefore it is important for you to begin to cope with the negative experiences and stressors that occur.

**Questions to answer:**

- What are sources of your stress?
  
  ______________________________________________________________________________________
  ______________________________________________________________________________________
  ______________________________________________________________________________________

- What do you do to relieve stress? What else would you like to try?
  
  ______________________________________________________________________________________
  ______________________________________________________________________________________
  ______________________________________________________________________________________

- What feelings are you currently experiencing?
  
  ______________________________________________________________________________________
  ______________________________________________________________________________________
  ______________________________________________________________________________________

(Hecht et al., 2003; Pizzi, 2010)
Guilt and Resent

Guilt and resent are described as a person feeling sorry or upset with themselves because of real or imagined responsibility for a situation.

It is common for caregivers to have feelings of guilt due to caregivers viewing themselves as not providing high enough quality care as well as being overwhelmed. Feelings of resent often lead you to experience more guilt, which leads to a cycle of guilt and resent that is hard to stop.

If you are beginning to feel symptoms of resent and guilt, start taking time for yourself to do something you enjoy and consider talking to a family member, friend, or healthcare professional. You are only able to provide the care that you are physically and emotionally able to do. This experience is not easy, but there are tools you can use to prevent and deal with the feelings of guilt and resent. First you need to be able to identify these feelings.
Common Feelings Among ALS Caregivers

Questions to answer:

• Do you ever feel you should be giving better care?

• What makes you feel you could provide better care?

• How can you reassure yourself that you are doing the best you can?

• Take time to talk truthfully with the loved one you are caring for. Do they feel you could improve on your caregiving? Write down their response.

• If yes, make a plan for improving the areas necessary, in order for you to both feel satisfied.
Social Demands

As a caregiver, you may feel that your time is limited outside of caregiving duties. You may feel that you are isolated from family and friends because you feel that you need to attend to the needs of the individual with ALS. Many caregivers feel a restriction in social support and leisure opportunities that negatively impacts their health. Balancing your time and finding social supports is important for your mental and physical health.

Questions to think about:

• Are you able to maintain relationships with friends and/or family?

• Do you have a person to talk about to about challenges you may be having?

• Do you have a person to talk to about the positive and cheerful aspects of your day?

• How well do you feel others provide support for you?

(Goldstein et al., 2006; Microsoft, 2010; Pizzi, 2010)
Common Feelings Among ALS Caregivers

One source of social support that cannot be underestimated is the encouragement offered in ALS support groups. Developing a sense of belonging to a social group can be inspiring and offers a support that you may feel few can understand. These groups provide a point of view that cannot be provided by anyone else, the members of these groups have their own experiences in similar situations, and this knowledge should not be taken for granted. A list of support groups can be located in the resources section of this manual.

• Who do you consider to be part of your support system?

________________________________________________
________________________________________________
________________________________________________

• What type of additional support would you like?

________________________________________________
________________________________________________
________________________________________________

• How can you tell someone you need additional support and help?

________________________________________________
________________________________________________
________________________________________________

(Centers, 2001; Fine, 1991)
Prevention and Coping

In the previous section, common feelings and experiences were discussed. The next step is to learn strategies to decrease negative feelings and experiences that you may have. This section is intended to help rebuild a lifestyle that allows you to handle stress in a positive manner as well as supporting your abilities to be a caregiver.

Prevention is described as a strategy an individual uses to stop the onset of an unhealthy condition or disability. This section of the manual focuses on strategies to prevent psychological distress symptoms by having you engage in meaningful activities to improve your quality of life and well-being.

Coping can be described as a strategy for taking control of your emotions or a situation once it has already began. These strategies teach you how to handle the symptoms in the moment.

The most important thing to remember with all of the skills taught in this section, is that practicing the skills before you need them helps to create a habit. Forming the skills into a habit makes it easier to remember to use the skill when you actually need it.
Taking Time for Yourself

Taking time for yourself does not mean taking a break once a week; taking time for yourself means that you are willingly to take a break each day. Taking time for you does not need to be a long process, it can be simple things that bring joy to you and something that will bring a smile to your face.

One way to begin taking time for yourself is to begin a self-care routine that allows you to feel good about yourself. When you begin to take time for yourself you may start to feel more relaxed and feel you are able to take on challenges that occur throughout the day. By feeling relaxed and grounded it will be easier for you to provide the necessary care needed for an individual with ALS.

Quick ways to take care of yourself, relax, and smile right away in the morning:

• When you wake up, take 5 minutes to stretch and breathe
• Think of one positive characteristic about yourself each day and write it down somewhere where you will see it often
• Reminisce on a positive memory you have with the individual with ALS
• Look at photographs that makes you smile
Prevention and Coping

Respite Care
Respite care is very helpful for caregivers because it allows you to take a break from caregiving demands.

Respite care can be from a trained professional who will take care of the individual with ALS within your home or in a facility to allow you time for yourself. Another informal way to obtain time for yourself is to ask a friend or family member to stay with the one you are caring for while you take time for yourself. Whichever option you choose, taking time for yourself is needed to prevent psychological distress and burden.

With choosing to use respite care, remember to take the time to do something for yourself! This time is just for you and you can choose how you would like to spend your time.
Prevention and Coping

Questions to think about:
• Do you make time for yourself?
• Do you feel guilty about taking time for yourself?

Questions to answer:
• List activities that you find meaningful

______________________________________________
______________________________________________
______________________________________________
______________________________________________

• How can you incorporate taking time for yourself into each day?

______________________________________________
______________________________________________
______________________________________________
______________________________________________
In the next few pages, there are lists of activities that you can engage in. You may feel that taking time for yourself is just one more thing to add on your list of things to do, but you should try these suggestions to see how you may benefit from them. The activities listed are going to give you simple ideas of ways to help you relax, have fun, smile, engage in the community, and enjoy time with friends and family.

Try these relaxing activities:

• Exercise to melt away stress and boost mood
• Go for a walk outside and enjoy the fresh air
• Get a massage and relax
• Take a nap to get rest
• Do yoga to find relaxation and peace of mind
• Meditate
• Sit at a park and observe nature
• Go for a swim and soak up the sun
• Paint or draw a picture
Prevention and Coping

Try these fun activities:

• Go to the grocery store and buy items to make your favorite meal

• Go shopping and splurge on something you like

• Read a book for fun

• See a musical or movie

• Listen to your favorite band or song
Prevention and Coping

Try these social activities:

• Go to church

• Volunteer at an animal shelter

• Go to a sporting event with a friend

• Attend a support group and push yourself to discuss a problem you may be experiencing

• Go to dinner with friends or family
This checklist can be used to help you remember the strategies that you have already used, and the strategies that you would like to use in the future. If you have already tried one of the strategies listed, make a note of how you felt about it. For example, in the “I already use this strategy” column for relaxation strategies you could write “I used this and I felt calmer after, but I had some trouble concentrating while I was trying to relax.”

<table>
<thead>
<tr>
<th>Strategy</th>
<th>I have used this strategy</th>
<th>I would like to use this strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Talking to someone</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Using relaxation strategies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(See page 44)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Using positive-self talk</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participating in religious service or other spiritual exercises</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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## Strategies for Coping with Stress Checklist

<table>
<thead>
<tr>
<th>Strategy</th>
<th>I have used this strategy</th>
<th>I would like to try this strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Going for a walk outside</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Getting a massage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reading a book for fun</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attending a support group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Volunteering at an animal shelter</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exercising</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Painting or drawing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sitting at a park</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Going to a sporting event</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Leisure

Taking time for yourself is very important. Here is a checklist to help you reflect on the activities that you have participated in and the ones you would like to participate in.

<table>
<thead>
<tr>
<th>Activity</th>
<th>I have done this within the past 1-2 months</th>
<th>I would like to do this more</th>
</tr>
</thead>
<tbody>
<tr>
<td>Crafts</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outdoors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Music</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cooking and Baking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Games</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gardening</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sports</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Learning</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Art</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Leisure

• What do you like doing for fun?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

• What do you need to spend more time doing?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

• In the categories marked “I would like to do this more”, how will you plan the activities into your schedule?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

(Microsoft, 2010)
Healthy Life Balance

It is important to find a healthy life balance between many aspects in your life to support health.

This exercise is to assist you in identifying areas that have poor health and areas that have good health. On the next page is a chart with identified areas for you to reflect on.

1. For each area identify whether it is poor, average, or good.
   a. Poor= You feel that this area could use more work to promote health and happiness
   b. Average= You feel this area is not good or poor but it is okay for your health and happiness
   c. Good= You feel this area is a beneficial way to promote health and happiness

2. For each area identified as “poor” write a list of strategies to increase the area in promoting health and happiness within your life.
Healthy Life Balance
Journaling

Journaling can be a fun way to reflect on your thoughts, feelings, joys, and experiences. Journaling can be completed every day or whenever you choose. You can choose the topics you would like to journal about.

Here is a list of ideas to journal about:

• Your daily activities and feelings
• A joke you heard
• A positive saying that you heard
• Advice you would give to a teenager
• A difficult situation in which you overcame
• Positive characteristic about yourself
• Describe your most valuable possession
• How others describe you
• What makes you laugh

(Microsoft, 2010)
Relaxation Strategies

Relaxation strategies are a great way to decrease the anxiety that you are feeling and to create a feeling of calm. This manual describes 3 strategies that can be used: imagining a peaceful scene, muscle relaxation, and relaxed breathing. All of these strategies will take practice to be good at, so don’t be disappointed if you find it hard to relax or concentrate the first few times you try these strategies. Keep practicing and incorporating your favorite strategies into your daily routine.

(Microsoft, 2010; U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, 2009)
Relaxation Strategies

Imagining a Peaceful Scene

The goal of this strategy is to “take yourself away” into a different situation where you can relax and picture yourself in a more calm and relaxing place. You can imagine a peaceful scene anywhere that is quiet as long as you have a few minutes to concentrate on this exercise.

1. Pick a scene that you find peaceful and relaxing. Here are some examples:
   - The beach
   - A meadow
   - A waterfall
   - A farm
   - By a fireplace

2. Now that you’ve chosen a scene, think about as many details as possible, including all of your senses (sight, hearing, touch, taste, and smell).

3. Allow at least 5 minutes for this practice

4. Try to push away any stressful thoughts while imagining your peaceful scene

(Microsoft, 2010; U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, 2009)
Relaxation Strategies

Muscle Relaxation

Muscle relaxation stretches muscles gently to decrease any stiffness and tension you may be feeling. The goal is to start at your head and work down to your feet. This will be most relaxing while sitting in a chair or lying in bed.

1. Shoulder Shrugs: Lift both shoulders toward your ears. Let your shoulders drop and relax completely after each shrug. Repeat 3 to 5 times.

2. Overhead Arm Stretches: Raise both of your arms over your head or out in front of you, keeping your hands together. Repeat 3 to 5 times.

3. Stomach Tension: Pull your stomach muscles toward your back as tight as you can. Feel the tension in your stomach and hold it for 10 seconds or as long as you can. Let your stomach relax. Repeat 10 times.

4. Knee Raises: Reach down and grab your right leg with one or both of your hands and raise it towards your chest. Hold your knee in this position for a few seconds. Place your right foot back on the floor. Repeat the same step with your left leg. Repeat the whole sequence 3-5 times.

5. Foot and Ankle Rolls: Lift your feet up and stretch out your legs. Rotate you ankles and feet in one direction 3-5 times. Switch directions and rotate your feet and ankles in the other direction 3-5 times.

(Microsoft, 2010; U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, 2009)
Relaxed Breathing

Relaxed breathing is meant to slow down your breathing which may increase as stress increases. Relaxed breathing can be done whether you are sitting, standing or lying down. The nice thing about this strategy is that you can take this strategy with you anywhere. For example, this one is good to use while sitting at a doctor’s office waiting for an appointment or while waiting in line at the grocery store.

1. Choose a word that you associate with relaxation. Here are some examples:
   • Calm
   • Peace
   • Relax
   • Love

2. Take a deep breath in through your nose.

3. Breathe out through your mouth, saying the relaxing word you have chosen. Say your word slowly, like this:
   “C-a-a-a-l-l-l-m-m-m”

4. Repeat this entire breathing sequence 10 to 15 times.

(Microsoft, 2010; U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, 2009)
Caregiver Resources

There are many resources that you can take advantage of in order to provide the best care for your loved one and to take care of your health and wellness. The following section is a listing of the many resources available to you. While this list does not include every resource available, you can use these resources to look for more resources. You can also talk to others who have had similar experiences to find resources that are not listed here.
Caregiver Resources

ALS Association

The ALS Association is a national organization that provides resources for individuals with ALS, their caregivers, health professionals, and researchers. The ALS Association has a network of chapters nationwide that work to provide assistance for people with ALS. This association works to search for new treatments and possibly a cure for ALS. The national website is: www.alsa.org.

On their website, the ALS Association has a specific link for caregivers. In the caregiving section, the ALS Association offers resources such as:

- **Tips and hints**
- **ALS Association Care Connection** - a network of volunteers in the individual with ALS’ community that are available to help the person with ALS and to give caregivers time for themselves
- **Respite Care** - this is specifically meant for caregivers. Respite care provides the caregiver with time to take care of themselves while the individual with ALS is cared for by skilled professionals
- **Coping with Burnout** - this section describes symptoms of burnout, causes, and how to deal with burnout
- **From One Caregiver to Another** - this section is a place for caregivers to share their stories and to connect with other caregivers
- **When a Loved One Has ALS** - this is a brochure available for caregivers of individuals with ALS

(ALS Association, 2012)
Five Wishes

This is a legal document put together by Aging with Dignity. Aging with Dignity is a non-profit group that works to protect and support individuals that are aging and/or are close to death. One of the resources that Aging with Dignity offers is *Five Wishes*. This is a legal document that was written in everyday language that assists adults with planning how they would like to be cared for. This living will addresses a person’s medical, personal, emotional, and spiritual needs.

*Five Wishes* is $5 and can be purchased at: http://www.agingwithdignity.org/five-wishes.php
Caregiver Resources

Caregiver Action Network

The Caregiver Action Network is a national non-profit organization that works to provide education, peer support, and resources to caregivers. On their website, caregiveraction.org, Caregiver Action Network has multiple resources including:

- **Peer Network**- a network of volunteers throughout the nation that provide education and support to caregivers; these volunteers can also serve as advocates for caregivers and their family members
- **Story Project**- a place for caregivers to share their experiences and to read stories that have been written by other caregivers
- **Family Caregiver Toolbox**- a listing of outside resources for caregivers
- **Family Caregiver Forum**- an online discussion board that allows caregivers to share their stories and offer assistance to other caregivers that may be going through similar situations
- **10 Tips for Family Caregivers**- tips for caregiving as well as links to assist with following these tips
- **Agencies and Organizations**- a listing of outside agencies and organizations that offer support and information for caregivers, whether formal or informal

(Caregiver Action Network, 2013)
National Family Caregiver Support Program

The National Family Caregiver Support Program is focused on providing support to family caregivers. This program is designed for family caregivers who are providing care to an individual with physical and/or cognitive limitations. This program is available in each state with a variation of specific services provided. Local programs can be found at http://www.aoa.gov.

The services in each state are:

- Information to caregivers about existing services within the community
- Helping caregivers acquire access to existing services
- Respite care

To be eligible for these services a family caregiver must meet one of these criteria:

- The family caregiver must be 18 years and older and providing care to an individual 60 years of age or older
- The family caregiver is providing care to individuals with Alzheimer’s disease

(Administration on Aging, 2012)
National Alliance on Mental Illness

The National Alliance on Mental Illness (NAMI) is one of the largest mental health organizations in the United States. NAMI works to provide education, support, and advocacy for individuals and family members of individuals with mental illness. Although this website is not directed towards caregivers specifically, there are resources on the website: www.nami.org which you may find helpful.

- Information about mental illness including symptoms, coping, and prevention strategies
- Support groups in your area for people like yourself who are experiencing similar symptoms
- Online discussion boards offering a similar support group, but these members don’t meet face to face like a support group would
- Events that are happening in your area
Closing

Being a caregiver can be rewarding, stressful, and life changing. This manual was put together with caregivers just like you in mind, to address your needs. The main goal is to establish a healthy and happy life.

The caregivers with a positive view have the highest overall happiness and lowest rate of distress. Refer to the checklists in the manual as often as you would like to identify changes in experiences and feeling within your daily life. It is important to remember that the strategies described within the manual take time and practice to learn the skills. By using this manual you will be able to recognize your feelings and determine strategies to reduce unwanted feelings and challenges that are common among caregivers.

This manual was created by occupational therapists who understand and are able to educate on the topics covered. Now that you have been given information, tools, and resources to increase your ability to perform your role as a caregiver, this is the time to take advantage of the time you have left with your loved one. But, don't forget to take care of yourself along the way.
References


References


References


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References


OT Guidelines for the ALS Caregiver Manual

“Helping Others by Helping Yourself: An ALS Caregiver’s Guide to Self-Care”
**Nature of the Problem**

The needs of an ALS caregiver are not currently being met by the healthcare team. Throughout the course of ALS, a caregiver will need to adapt to changing roles and responsibilities. As the individual with ALS becomes more dependent on the caregiver, the caregiver is more likely to experience psychological distress (Goldstein et al., 2006). Caregivers are at risk for many psychological distress symptoms such as depression, anxiety, guilt, resent, burden, and decreased social support. Nearly half of caregivers reported feeling psychologically and physically unwell (Muphy et al., 2009). In particular, one study indicated that nine percent of study participants displayed characteristics of a depressive disorder, which is higher than the average population (Rabkin et al., 2005).

Current literature indicates that ALS caregivers are at risk for psychological distress secondary to caregiving demands that impact quality of life and well-being. Caregiver demands change throughout the course of the disease which ultimately affects one’s ability to prioritize engagement in occupations as well as maintaining engagement in occupations (AOTA, 2007). Current research lacks initiation of addressing and preventing the psychological symptoms experienced by an ALS caregiver and the role of OTs in addressing these needs to promote health, quality of life, and well-being.

**Purpose of the ALS Caregiver Manual**

The purpose of the ALS Caregiver manual is to assist ALS caregivers in learning strategies to address their mental and physical health needs. Caregivers experience many changes as they transition into their new role. These changes lead to an increased risk of psychological distress which ultimately puts caregivers at risk for decreased quality of
life, health, and well-being. It is essential to provide support and resources to an ALS caregiver to promote their health and well-being and prevent symptoms of psychological distress from developing into severe mental illness and poor quality of life.

By addressing ALS caregivers’ physical and mental health needs, the ALS caregiver will be able to manage stressors related to caregiving and promote health, quality of life, and well-being. The caregiver manual is divided into sections addressing:

- **ALS disease course and prognosis**: In this section is a basic description of ALS including symptoms that may be experienced, a description of the disease course, and possible treatment options.
- **Role of the healthcare professionals involved in ALS care**: There are many healthcare professionals involved in the care of an individual with ALS. The following healthcare professionals are described: neurologist, nurse, pharmacist, dietician, social work, speech language pathologist, occupational therapist, physical therapist, and respiratory therapist.
- **Grieving process**: The five stages of grieving (denial, anger, bargaining, depression, and acceptance) are discussed. Tips for talking to someone who is grieving, which can be shared with family and friends, is included as well.
- **Frequent psychological symptoms experienced by ALS caregivers**: The types of psychological distress which caregivers are at risk for (depression, anxiety, burden, guilt, and resent) are described. The importance of maintaining social relationships is also included.
- **Prevention and coping strategies:** Caregivers are encouraged to take time for themselves on a daily basis. A brief description of respite care is discussed and caregivers are encouraged to take advantage of this as coping and prevention strategy. Ideas of fun, relaxing, and/or social activities are described to help caregivers plan ways for taking care of themselves.

- **Resources for caregivers:** There are many resources available for caregivers, and the authors described the following resources: ALS Association, *Five Wishes*, Caregiver Action Network, National Family Caregiver Support Program, and National Alliance on Mental Illness.

Throughout the manual there are checklists and questions for the caregiver to reflect on and complete. Questions are focused on the caregiver identifying specific feelings related to psychological symptoms, supports and perceived effectiveness of social supports, roles, hobbies, and strategies utilized to cope.

In the prevention and coping section, the caregivers are educated on the importance of taking time for oneself, relaxations strategies, respite care, occupations to promote health and wellness, and checklists for identifying occurrence of leisure activities. Specific relaxation strategies include imagining a peaceful scene, muscle relaxation, and relaxed breathing.

Finally, resources are included in the manual that describe potential supports for an ALS caregiver. The resources within the manual include the ALS association website, information and an outline for writing a will, and supportive groups for caregivers. The
resources outlined within the manual are located on the internet therefore caregivers may have limited access to the suggested resources. However as an OT, additional resources can be provided are available that may be offered within the facility or community organizations.

Guiding Theory of the Manual

The development of *Help Others by Helping Yourself: An ALS Caregiver’s Guide to Self-Care* was guided by the Model of Human Occupation (MOHO). MOHO is client-centered and ultimately concerned with the caregiver’s ability to perform occupations that are familiar and adapt to new occupations. MOHO is focused on three main constructs that affect an individual's engagement in occupation: (Kielhofner, 2009)

- **Volition**: the caregiver’s motivation to participate in the activities involved in the role of being a caregiver. Volition shapes the way caregiver’s view the opportunities and challenges involved with caregiving.
- **Habits**: ways of responding in a routine manner in familiar environments and situations. According to MOHO, a major construct of therapy is to build or rebuild habits to perform occupations related to caregiving.
- **Performance Capacity**: the physical and mental abilities of the caregiver.

MOHO offers a wide variety of therapeutic strategies that are beneficial to assist a caregiver in identifying and preventing psychological distress. The main therapeutic strategies used to guide the creation of the manual are advising, encouraging, and validating (Kielhofner, 2009).

- **Advising**: making recommendations for occupational performance.
• **Encouraging:** providing reassurance and emotional support to enhance occupational performance.

• **Validating:** recognizing and acknowledging the caregiver’s experience and knowledge regarding their new role.

By utilizing MOHO as the foundation of providing care to an ALS caregiver, an OT can use its main concepts to determine the process of incorporating a caregiver into therapy. An OT needs to have foundational knowledge of MOHO to utilize the product while addressing ALS caregivers as this model provides multiple guidelines and focus areas to best meet the needs of caregivers.

**Importance of an Occupational Therapist to Address ALS Caregivers**

OTs focus on the needs of a patient, family members, and caregivers to provide holistic and client-centered care. OTs possess the skills to educate caregivers, strategies to balance caregiver demands, knowledge of coping strategies, and the ability to recognize the need for additional supports. OTs can assess and address the needs of the caregiver regarding the caregivers’ well-being and support their ability to care for the individual with ALS. OTs are also trained to meet the needs of the caregiver by identifying demands that may be essential as the disease progresses (e.g. positioning), educating the caregiver early and continuously on coping with these demands, addressing issues of regret, and enabling caregivers as well as the individual with ALS to “experience the joys and pleasures that are still available to them” (Pizzi, 2010, p. 408). By empowering the caregivers, the OT will be promoting positive emotional, social, spiritual and mental health (Pizzi, 2010).
OTs can monitor the signs of burden and distress throughout the entire disease process. Developing the ability to detect and recognize psychological distress symptoms is essential because it improves the quality of care provided to the individual with ALS as well as the quality of life of the caregiver.

**When to Give the Manual to an ALS Caregiver**

The OT should give the manual to an ALS caregiver once the diagnosis has been confirmed. When giving the manual to a caregiver, the OT needs to describe the purpose of the manual and tell the caregiver that an OT is available to talk about concerns the caregiver may have. The OT should describe the reasons why an OT can assist with the caregiver managing roles, stress, schedules, and coping. The OT should also include the caregiver in treatment sessions as much as possible for educational purposes and training.

**OT Follow Up**

The OT should follow up with the caregiver as often as the individual with ALS receives OT services. Individual treatment sessions for the caregiver could be implemented on an as needed basis. As the disease progresses for the individual with ALS, an OT should follow up more frequently. The OT and the caregiver should collaborate about concerns, feelings, and experiences. The OT can encourage the ALS caregiver to look at the checklists in the manual to determine if psychological distress symptoms are occurring, identify if the caregiver needs more support, if there is a need for a schedule, and if caregivers are continuing engaging in desired occupations.
References


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CHAPTER V

SUMMARY

This scholarly project outlines the psychological distress caregivers of individuals with ALS face as well as the importance of occupational therapists (OTs) being involved in their care. This project was created in response to the lack of literature directed at self-care of caregivers for individuals with ALS. The research that was available indicated that individuals with ALS often receive care from OTs throughout the course of the disease; however, their caregivers often do not receive any care and are unlikely to seek out care for themselves. Thus, caregivers are at an elevated risk of experiencing psychological distress including depression, anxiety, guilt, resent, and perceived social isolation. The impact psychological distress has on ALS caregivers negatively affects their quality of life, well-being, and capacity to tend to another. The product of this scholarly project was fashioned to be a tool in the education of caregivers on the importance of taking care of themselves to promote quality of life and well-being.

The product was prepared as an informative reference manual directed toward the caregivers of individuals with ALS. It provides a detailed outline of the ALS disease and prognosis, the role of each healthcare professional for an individual with ALS, frequent psychological symptoms experienced by ALS caregivers, coping strategies, and resources to address and prevent psychological distress symptoms. Coping strategies recommended in the manual were directed at caregivers taking time for themselves through reflective checklists and participating in strategies such as taking a few minutes to stretch in the
mornings or going shopping with a friend. The final section of the manual includes resources for further information on ALS, coping strategies, and support groups.

MOHO was the main theory guiding the research and development of this scholarly project. MOHO’s main concepts of volition, habituation, and performance capacity were used to guide the development of the product. MOHO incorporates therapeutic strategies to guide the therapy process; these strategies include advising, encouraging, and validating.

Adult learning theory was also used to guide the development of the product. The adult learning theory has multiple assumptions to address the needs of adult learners. The manual was created to be used by caregivers with a variety of educational backgrounds, learning styles, and needs.

The authors of this scholarly project were in contact with members of the Minnesota/North Dakota/South Dakota chapter of the ALS association during the development of this project. They also contacted an OT that is involved at an ALS clinic through an area hospital. The authors plan on sharing this project with these contacts and local hospitals.

To continue developing this product further, there are a few limitations that should be addressed. One of the limitations of this scholarly project is the lack of research that has been conducted specifically on being a caregiver of an individual with ALS and specific strategies to meet the needs of ALS caregivers. The information that was used in creating this manual incorporated being a caregiver for individuals with motor neuron
diseases, cancer, and caregiving in general. A second limitation is that research has not been conducted on the effectiveness of the manual. Further research can support the effectiveness of the manual and guide OTs’ roles in providing effective care to ALS caregivers.

The following are recommendations for further action to promote this scholarly project and most importantly, the product. Qualitative and quantitative research would assist in providing data to improve the manual to make it as effective as possible. Additionally, further research should be conducted on the role occupational therapy plays in providing care to caregivers to strengthen the knowledge base of and provide a comprehensive evaluation of caregivers’ needs. Research should be conducted on the relationship of support between the individual with ALS and their caregiver to determine the dynamics of the relationship and further promote the coping strategies of a caregiver. Also, this manual could be used to guide the development and implementation of support groups for caregivers of individuals with ALS within a hospital or a community setting.

This manual will be a resource for ALS caregivers to utilize in the prevention of psychological distress which is common within this population. The information within the manual is focused to meet the ALS caregivers’ mental and physical health needs that are currently not being met. Caregiving can be a difficult and stressful role when caregiving for an individual with ALS, therefore, this manual is intended to provide motivation and meaning as well as aiding the caregiver to be reflective and identify feelings to support quality of life, health, and well-being.
REFERENCES


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