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Occupational Therapy Based Guide for Caregivers of Individuals with Muscular Dystrophy

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OCCUPATIONAL THERAPY BASED GUIDE FOR CAREGIVERS OF INDIVIDUALS
WITH MUSCULAR DYSTROPHY

by

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A Scholarly Project

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This Scholarly Project Paper submitted by Chelsea Hesby and Macaila Pagel in partial fulfillment of the requirement for the Degree of Master of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

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ABSTRACT

The purpose of this scholarly project was to develop a holistic guide that could be provided by occupational therapists (OTs) to caregivers of individuals with muscular dystrophy (MD). A comprehensive literature review was conducted on the impact that caregiving for individuals with MD has on quality of life, stress management and mental health. The review of literature also explored caregivers' access to resources and common difficulties experienced.

The literature revealed that there have been recent advances in medical fields which have led to an increased lifespan for individuals with MD to an average age of 27 years old (Eagle et al., 2007). As a result, caregivers of individuals with MD are experiencing an increase in psychological and physical demands for an extended period of time. Families and caregivers have expressed the need to have access to reliable and accurate resources throughout the disease process. They have often reported feeling vulnerable, stressed and less supported as the disease progressed when they did not have access to resources (Dawson & Kristjanson, 2003). Based on the unmet needs that caregivers of MD often face, a guide, *Caring for Yourself as a Caregiver*, was created. The guide can be used to ensure caregivers have easily accessible resources to fulfill their needs as a caregiver while maintaining their own physical, emotional and mental health.

Guided by the Model of Human Occupation and the adult learning theory, this caregiver guide addresses a caregiver's volition, habituation and performance capacity to increase meaningful impact and occupational functioning. These models were also used to format the product in a way to make it easily understood by caregivers of varying educational levels. Within

the caregiver guide there are sections that focus on: roles of a caregiver, information about MD, how the disease typically progresses, common caregiver tasks, caregiver well-being, the grieving process, palliative care, and resources to look for additional information. There was also an OT manual created to serve as an intervention tool and provide guidance on how to use the caregiver guide. Through OTs providing the guide, caregivers will be able to better care for the individual with MD and find greater meaning, value and a sense of commitment from taking care of their loved one with MD. This manual was created to help caregivers get the most out of their time with their loved one by learning how to best care for themselves.

CHAPTER 1

INTRODUCTION

Rationale

Muscular dystrophy (MD) is classified as a group of diseases, which are genetic and present through muscular atrophy and weakness (Lue, Lin, Chen & Lu, 2009). While there are over 30 different types of MD, they all have three major things in common: being hereditary, causing weaknesses, and displaying a pattern of the weaknesses experienced. This skeletal weakness is often accompanied by progressive cardiac and respiratory muscular weakness (Canadian Nurse, 2012; Dawson & Kristjanson, 2003). Of the numerous types of MD, Duchenne muscular dystrophy (DMD) and Becker muscular dystrophy (BMD) are the most common discussed in literature. DMD affects approximately 28.6 out of 100,000 males and BMD affects 2.5 out of 100,000 males (Zebracki and Drotar, 2008).

While there is no present cure for MD, there have been numerous progressions in medicine related to treatments (Dawson & Kristjanson, 2003). These advancements have led to an increased lifespan for individuals with MD to an average age of 27 years old (Eagle et al., 2007). With the progressive nature of the disease, it is common for individuals with MD to become increasingly dependent on others for assistance with completion of daily tasks despite the type of MD. Thus, individuals with MD have a prolonged need for caregivers to assist with daily living tasks.

The demands placed on caregivers have especially risen since the U.S. government set the Healthy People 2010 Goal. The goal includes reducing the number of individuals aged 22 and younger living in care settings to zero. The goal has led to an increased number of caregivers needed within the home of an individual who has MD. Therefore, there has been an increased demand for family members to serve as the primary caregivers (Disability and Health, 2013).

The term caregiver may have varying meanings depending on the individual and the setting. While healthcare professionals typically assume the role of a caregiver in a hospital setting, a family member often takes on the responsibility of being a caregiver if the individual with MD is receiving home care (Venes, 2009). This scholarly project focuses on informal caregivers who are most often family members, and more specifically parents, of individuals with MD (Miller et al, 2009).

Statement of Problem

Current literature indicates that caregivers of individuals with MD often face difficulties while dealing with stress related to the individual's chronic disability and the outlook of a shortened lifespan with recovery not being an option. Caregivers may experience anxiety, depression and diminished energies and resources (Im et al., 2010; Chen & Clark, 2010). Families and caregivers have expressed the need to have access to reliable and accurate resources throughout the disease process. Families and caregivers have often reported feeling vulnerable, stressed and less supported as the disease progressed when they did not have access to resources (Dawson & Kristjanson, 2003).

Scope of OT

Occupational therapists (OTs) have the knowledge to assist with providing these resources and supports to promote improved quality of life along with health and wellness. It is

important to understand the physical, emotional and mental health of the caregiver and the individual seeking services. OTs can work with caregivers to support health and participation in life through engagement in occupations (AOTA, 2008). OTs do this by applying knowledge and skills to reduce the hardships caregivers may experience. While supporting engagement in occupation, OTs may also prepare the caregiver with therapeutic ways to cope with changes and addressing role transitions throughout the progression of the disease. OTs are trained and educated in addressing the psychological issues that a caregiver may experience throughout the disease process. OT interventions designed for caregivers have led to improved quality of life for both the care recipient and the caregiver. Caregivers who have received OT services often reported fewer declines in occupational performance, enhanced self-efficacy and well-being for themselves. Therefore, it would be in the caregiver's best interest to seek out services from an OT because the profession focuses on addressing the individual as a whole. OTs are highly qualified to work with this population due to their ability to address each aspect of life. By understanding how various aspects of life and caregiving influence each other, OTs can better evaluate how they contribute to the caregiver's quality of life and engagement in occupations (AOTA, 2008).

Theoretical Framework

The development of this project was guided by the Model of Human Occupation (MOHO). MOHO is a client-centered approach that uses a holistic point of view. Throughout the guide, the caregiver's engagement in occupations is considered and promoted. Every caregiver who is providing support for an individual with MD will be different. MOHO is a dynamic model just as each caregiver is, which strengthens the connection between this project and the theoretical base.

MOHO has three main constructs that influence the caregiver and their occupational engagement: volition, habituation and performance capacity (Turpin & Iwama, 2011). As the MD progresses, the individual's with MD abilities to perform tasks will change. As performance capacity decreases, the caregivers may need to provide a higher level of assistance with daily activities. This may also have an impact on habituation and alter how routines are carried out in daily living for the individual with MD and the caregiver. As the MD continues to progress, the caregiver's volition may also be challenged with a higher demand and dependence on them (Turpin & Iwama, 2011).

Also guiding this project was the Adult Learning Theory. The majority of individuals taking on the role of a caregiver for individuals with MD are adults. This theory uses an andragogical approach to teaching and learning styles in adult populations (Bastable & Dart, 2011). Adults have different learning styles and needs that help them understand and apply what is being taught. Throughout the guide, andragogy guided the layout of the information being provided. The intended audience will have varied backgrounds and educational levels. To make the product useful to caregivers of varying educational levels, the product was formatted in a way that is easily understood. One of the main concepts of the adult learning theory is that the adult population often uses self-direction in their motivation to learn. The handouts and activities provided within the manual allow the caregivers to use the information within the guide and apply it to their own lives (Bastable & Dart, 2011). We set up the handouts so that the caregivers would be motivated to complete them, which also connects MOHO to the Adult Learning Theory.

Importance of the Study

This scholarly project offers a guide for OTs to provide to caregivers of individuals with MD. The guide provides an outline of the roles of a caregiver, information about MD, how the disease typically progresses, common caregiver tasks, caregiver well-being, grieving processes, palliative care, and resources for additional information. As MD progresses, the caregivers' roles and responsibilities may change and increase. Caregivers are at increased risk of stress, anxiety and depression when their loved one becomes more dependent upon them. This not only influences their ability to provide care, but may also affect their quality of life, health and well-being (Dawson & Kristjanson, 2003).

As the authors were investigating literature and resources available to caregivers, there were several available, but they were often limited to one or two topics. This guide serves as a holistic resource for caregivers to decrease their feelings of vulnerability, stress and lack of support often felt as the MD progresses (Dawson & Kristjanson, 2003). The guide offers a variety of coping strategies to help them through times of transition in order to better handle challenges and interactive worksheets to allow the caregivers to integrate the personal experiences they may have with the resources provided. Included in this scholarly project is a review of literature, methodology used in developing the product, the caregiver guide, an OT manual, and a summary of the overarching scholarly project.

CHAPTER 2

LITERATURE REVIEW

This is a comprehensive review of literature that focused on caregiving and muscular dystrophy. Included in the review will be background information on the diagnosis and types of muscular dystrophy. Also, included are the roles of a caregiver as well as how they may manage stress and cope with the progression of the disease. Information regarding the caregiver's role with medical equipment and enhancing the individual's with muscular dystrophy participation in activities of daily living will be covered as well. Finally, the review includes information regarding palliative care and the grieving process that the caregiver and individual may endure.

What Is Muscular Dystrophy?

Muscular dystrophy (MD) is classified as a group of diseases which are genetic and present through muscular atrophy and weakness. The disease occurs through deficits to the X chromosome which differ depending on the type of MD (Lue, Lin, Chen & Lu, 2009). There are over 30 different types of MD which have three major things in common: being hereditary, displaying a pattern to the weaknesses experienced and causing weaknesses (Canadian Nurse, 2012; Dawson & Kristjanson, 2003). Affected individuals endure skeletal weaknesses as well as progressive cardiac and respiratory muscular weakness (Eagle et al., 2007). With the progressive nature of the disease, it is common for individuals with MD to become increasingly dependent on others for assistance with or completion of daily tasks despite the type of MD. Out of the

numerous types of MD, Duchenne Muscular Dystrophy (DMD) and Becker Muscular Dystrophy (BMD) are the two most commonly discussed in literature (Kenneson & Bobo, 2010).

Duchenne Muscular Dystrophy

The most commonly discussed type of MD in the literature is DMD which is a recessive X linked genetic disorder which affects 28.6 out of 100,000 males (Zebracki and Drotar, 2008). The average age for an individual with DMD to be diagnosed is 4.9 years old (Canadian Nurse, 2012). If a female carrier has a son, there is a 50% chance that he will inherit DMD (Canadian Nurse, 2012). The defect occurs on the Xp21 region of the X chromosome (Lue, Lin, Chen & Lu, 2009). This mutation causes the body of the individual with DMD to be unable to make the protein dystrophin which is essential for muscle contraction. The inability for muscles to contract leads to muscle deterioration and decreased muscle strength. The individual who has DMD or BMD will experience progressive weakness as a result of the replacement of muscle with fatty tissue (Davidson & Truby, 2009).

Becker Muscular Dystrophy

Another one of the commonly discussed types of MD in literature is BMD. BMD is a form of MD that is less common in prevalence than DMD and affects 2.5 out of 100,000 males (Zebracki and Drotar, 2008). BMD is similar to DMD in that muscular weakness is present, but it typically shows an onset later in life and progresses at a rate slower than that of DMD. In a study it was found that 23% of the families had two or more immediate family members with BMD. MD is genetic and can result in families having more than one individual with the disease, which may increase the task demands for the caregiver (Kenneson & Bobo, 2010). The demands for the caregiver have also been increased as the lifespan for individuals with MD is increasing.

There have been numerous progressions in medicine related to treatments which have led to an increased lifespan for individuals with neurodegenerative conditions including MD (Dawson & Kristjanson, 2003). Specifically, there are recent advances in medical fields including spinal surgeries and home mechanical ventilation. These advances have led to an increased lifespan for individuals with MD to an average age of 27 years old (Eagle et al., 2007). With an increased lifespan, individuals with MD have a prolonged need for caregivers to assist with daily living tasks. A caregiver's role and their responsibilities will vary depending on the individual they are caring for, but consistencies have been found with what a typical caregiver may experience.

Caregiving for Individuals with MD

Although caregivers value their role, it was found that caregivers of individuals with DMD may experience substantial burden from caring for their loved ones (Im, Lee, Moon, Park and Park, 2010). The definition of the term "caregiver" may vary depending on the individual. For example, Venes and Taber (2009) describes a caregiver as the individual "who provides care to a dependant or partially dependant person" (Venes & Taber, 2009, p. 373). It was found that in a hospital setting, a professional often assumes the role of the caregiver. If the individual is receiving home care than a family member often takes on the responsibility of being a caregiver (Venes & Taber, 2009). Family members and friends frequently are found to play a vital role in providing care whether that is in their own home or in a professional health care facility (Candy, Jones, Drake, Leurent & King, 2011). Miller, Condin, McKellin, Shaw, Klassen & Sheps (2009) explored the continuity of care for children with chronic health diagnoses. In their study, they found that the majority of participating caregivers were parents and more specifically the caregivers were mothers (Miller, Condin, McKellin, Shaw, Klassen & Sheps,

2009). Im et al. (2010) consistently found that many primary caregivers included in their research were also mothers of individuals with MD. One family involved in this study also included grandparents as caregivers as well. Pangalila, van den Bos, Stam, van Exel, Brouwer and Roebroek (2012) found over 90% of the caregivers included in their study were parents. Pangalila et al. (2012) also included partners, a sister and a friend that served as caregivers to adults with DMD.

The demands placed on caregivers have risen since the U.S. government set the Healthy People 2010 Goal. The goal includes reducing the number of individuals aged 22 and younger living in care settings to zero. The goal has led to an increased number of caregivers needed within the home of an individual who has DMD. Therefore, there has been an increased demand for family members to serve as the primary caregivers (Disability and Health, 2013).

The demand on caregivers depends on the individual with MD's physical, cognitive and mental state. The type of MD may also have an impact on the amount of assistance required by the caregiver which may impact their quality of life (Hodges & Dibb, 2010; Kenneson & Bobo, 2010). It was found that although stress or distress levels may not be affected by the form of the disease, family members of those with BMD were more likely to express satisfaction with life than caregivers of DMD. This may be due to DMD's persistent, progressive and complex nature; the diagnosis alone presents parents with substantial challenges (Hodges & Dibb, 2010; Kenneson & Bobo, 2010). It was found that if the individuals with MD were no longer ambulatory there were higher levels of caregiver demand placed on the family members than had been experienced while the individuals were still in the ambulatory phase. This increased the demands placed on the caregivers (Kenneson & Bobo, 2010).

There is a growing body of literature focusing on the benefits to caregiving. Parents have reported strong, enriching and valuable experiences that they cannot imagine living without (Pangalila et al., 2012). Caregivers have also found greater meaning, value and a sense of commitment from taking care of their loved ones with MD (Candy et al., 2011). Having positive feelings about caregiving also leads to decreased subjective burden and depression, along with better subjective health reports (Pangalila et al., 2012). Pangalila et al. (2012) also reported that caregivers of adults with DMD indicate comparable levels of happiness as the unaffected population. Although caregivers may experience their role in a positive light, they are still at risk for strain on their physical and emotional well-being due to increased stress levels (Raina et al. 2004).

Stress

Caregivers of individuals with MD face difficulties dealing with stress related to the individuals chronic disability and the outlook of a shortened lifespan with recovery not being an option; therefore, they may experience anxiety, depression and diminished energies and resources (Im et al., 2010; Chen & Clark, 2010). Some of these challenges may be psychological, physical, domestic, or economic (Candy et al., 2011). Kenneson and Bobo (2010) found that 46.4% of caregivers reported high levels of stress. An additional 11.6% of caregivers reported severe psychological distress. Depression was found in two thirds of caregivers, with nearly 30% having moderate to severe depression (Im et al., 2010). Caregivers find that it is difficult to avoid, however it is not experienced by all. When Ahlstrom and Wenneberg (2002) surveyed individuals, seven people returned the questionnaires blank because they could not identify any specific situation related to MD as stressful.

Social support has been found as an indicator for stress with higher amounts of support linked to lower stress levels (Raina et al., 2004). Nereo et al. (2003) reported that women with low levels of social support were increasingly likely to have high levels of stress and distress. Life satisfaction was also lower for those with minimal levels of social support. In addition, annual household income greater than \$50,000 played a positive role on caregiver's stress levels. These individuals reported less stress and distress, along with greater life satisfaction (Kenneson & Bobo, 2010). Additional issues have been found when the individual with MD leaves home. Parents have voiced concerns when considering their child's quality of care from another source, along with the physical separation (Pangalila et al., 2012).

Employment has also been noted as a factor that attributes to stress for caregivers of individuals with MD. According to Kennensen & Bobo (2010), caregivers are more likely to experience more negative stress if they are in a low income family. It is also more common for those caregivers to have lower life satisfaction which may be due to lower income combined with the stress of being a caregiver (Kenneson & Bobo, 2010). The expenses related to caring for an individual with MD may cause an increase in stress. The yearly average cost for an individual who has MD is \$18,930 (Canadian Nurse, 2012). If the family has stable employment then they may not experience as much stress related to finances.

Family members who are employed outside of the home experience both the positive and negative. One of the positive aspects is that individuals who are employed outside of the home experience an increased income and have family members who receive an increase in social support and social contact. The negative is that employment outside the home is linked to increased stress levels due to being away from their loved one who has special needs (Kenneson & Bobo, 2010).

There are different factors that can ease a caregiver's stress and help them maintain a healthy physical and mental wellbeing. Involving caregivers in the development of care plans may give them a sense of control, which in turn creates less caregiver stress (Chen & Clark, 2010). Learning and utilizing different coping strategies may help effectively manage stress. It was reported that persons with MD and their caregivers are already using many different coping strategies to deal with illness-related stress (Ahlstrom & Wenneberg, 2002).

Coping

Coping refers to the challenges and difficulties caregivers are faced with and figuring out a way to manage that stress (Epiphaniou, et al., 2012). Caregivers and families have taken an increasingly active role in coping and advocating for their loved one who has MD (Scorgie & Sobsey, 2000). Caregivers utilize different techniques and strategies to cope with MD and its progression (Epiphaniou et al., 2012). Some parents reported difficulty combining caregiving tasks and their own daily needs. To cope with this, Pangalila et al. (2012) emphasized the importance of taking time off due to the positive association with satisfaction in caregiving. Time off and social relief also aid in improved mental health for the caregivers (Pangalila et al., 2012)

There are two different types of coping techniques commonly utilized by caregivers and families of individuals who have MD (Ahlstrom & Wenneberg, 2002). One of the types is problem-focused coping which entails dealing directly with the stressful situation (Ahlstrom & Wenneberg, 2002). Parents and caregivers use different mechanisms within the category of problem-focused coping to manage their role as a caregiver. The mechanisms may include being overprotective and avoiding disciplining their loved one (Webb, 2005). Another mechanism is

called magical thinking in which the caregivers or families believe that the MD is progressing slower than what is typical or that the individual may recover completely (Webb, 2005).

The second type of coping is emotion-focused in which the emotions and feelings are dealt with instead of changing or adjusting the actual situation (Ahlstrom & Wenneberg, 2002). One of the techniques utilized is to watch TV as a distraction technique in order to relieve stress. Another strategy used to cope includes completing crosswords or games which focus on mental stimulation (Epiphaniou et al., 2012). Another emotion focused strategy to cope with physical strain in caregivers is energy conservation (Corcoran, 2003). Along with using coping strategies to manage stress, utilizing support from others and the community may reduce strain on caregiver.

Support

Social Support

When considering the individual with MD, Abbott (2012) found that all of the young adults included in his study had finished a full time education but were at home without employment. It was also noted that the typical adult with MD moves away from home at 24 years old and has completed 9 years of education, but seldom obtains additional education and almost never has a salaried job. Individuals with MD at this point in life often live alone with restricted social lives and have strong reliance on close family members for social interaction and social support (Abbott, 2012; Rahbek et al., 2005). The individual with muscular dystrophies difficulty with social relationships may influence the time the caregiver has for social experiences.

Caregivers who receive social support are on average four times more likely to be satisfied with life (Kenneson & Bobo, 2010). If they do not receive social support there is an

increase in caregiver stress and distress. Caregivers who reported levels of social supports higher than average tended to be caring for individuals with MD who are ambulatory. It is important that caregivers receive support from their peers when they first find out about the diagnosis and as the condition of their disease progresses (Chen & Clark, 2010). According to Kenneson & Bobo (2010), the amount of social support a caregiver receives is not associated with age, income, employment status or how many individuals with MD they are caring for. It was found that caregivers who are married reported experiencing high levels of social support. This may be due to having a consistent amount of support from their significant other (Kenneson & Bobo, 2010).

If an individual with MD reported having stress, it was commonly associated with decreased social supports and interactions, which may place higher demands on the caregiver. Also, if the individual with MD's condition has progressed to the post-ambulatory phase and the individual requires a wheelchair for mobility, there is a change in social participation due to an increase in caregiver demands. The family and individual experience decreased social support throughout the progression of the disease and an increase in social isolation (Kenneson & Bobo, 2010).

Family Support

It was identified that the development of a support program based on counseling for patients and families were one of the major goals of rehabilitation for individuals who have MD (Fujiwara, Tanabe, Uchikawa, Tsuji, Tanuma, Hase and Liu, 2010). According to Law, King, Steward & King (2002), families experience benefits from being involved in a support group to assist with coping with their loved one's disability. Such programs designed for caregivers and/or families of individuals who have MD should promote healthy living through support

(Chen & Clark, 2010). If family members receive support focused on promoting a healthy lifestyle, psychological well-being, spiritual and financial support, it may lead to an increase in their ability to adapt to the disease (Chen & Clark, 2010). Programs can help to educate caregivers on problem solving techniques throughout the progression of the disease, which is viewed as beneficial by caregivers (Hodges & Dibb, 2010). The families and caregivers develop a sense of empowerment through education to increase their ability to advocate for their loved one (Hodges & Dibb, 2010). If a family receives support from their community, it also contributes to promoting the family's health and their quality of life (Chen & Clark, 2010).

Community Resources

Families and caregivers have expressed the need to have access to reliable and accurate resources throughout the disease process (Dawson & Kristjanson, 2003). Families and caregivers have often reported feeling vulnerable, stressed and less supported as the disease progressed when they did not have access to resources. If the family is provided with resources, it is important to note that each family handles receiving information differently pertaining to the progression of the disease. According to Dawson & Kristjanson (2003), caregiver's reported that healthcare professionals waited to discuss end of life care until the family or caregiver asked for information. Other's felt that information pertaining to end of life was provided prematurely. Additionally, there are caregivers who feel that it is important to have access to information immediately after the diagnosis, throughout each stage of the progression and information pertaining to the future progression of the disease (Dawson & Kristjanson, 2003).

According to Dawson & Kristjanson (2003), caregivers prefer written information or resources on how to acquire information. Families of an individual with MD should receive resources about outside sources available such as respite care (Pangalila et al., 2012). It is

important that the resources provided are easy for the caregivers or loved ones to access and understand in order to save them time, energy, expenses, burnout and avoid confusion (Miller et al., 2009). Fundraising is something that the individual, family, loved ones and the caregiver may become involved in to advocate for the cause and raise money.

There is an annual fundraiser called the Jerry Lewis Labor Day telethon which raises money for research specific to MD. The telethon was founded in 1966 and broadcast by one NY TV station (Canadian Nurse, 2012). As of 2012, the telethon has raised \$2 billion for MD (Canadian Nurse, 2012). This event is one of many examples of how community resources may not only assist with care for individuals with MD, but can also improve quality of life.

Life Satisfaction

Life satisfaction is an additional area that is important to address for caregivers and individuals with MD. Im et al. (2010) found that caregivers play an important role in positively or negatively affecting an individual with MD's quality of life. Having a strong influence on the patient's quality of life can also impact the outcome or progress of the individual's independence. With this in mind, one must also acknowledge the caregiver's quality of life to improve that of both the patient and the caregiver. Emotional status of individuals with MD has also been linked to caregivers' quality of life, especially when patients are under the age of 18 years old. It was found that patients under the age of 18 years old are more open to expressing emotions to caregivers. As a result, there is an emphasis to focus more attention on the psychosocial aspects of the younger patients with MD and their relationship with caregivers to promote higher qualities of life (Im et al., 2010). Intensive and supportive care can also help to further improve longevity and quality of life (Dawson & Kristjanson, 2003). Im et al. (2010) suggested further exploration of various environmental or emotional interactions that may

improve quality of life. Additional research on this may assist in establishing a generalized care protocol to contribute to medical information while simultaneously avoiding caregiver burnout (Im et al., 2010). Life satisfaction may also be influenced by other factors such as independence in activities of daily living, ambulation and cognition.

Cognition

Although, individuals who have MD experience physical deficits and muscular weakness, they may also experience intellectual difficulties or deficits (Fujiwara et al., 2010). Additionally individuals with MD may experience verbal impairments and deficits in attention (Carter, Weiss, Chamberlain, Han, Abresch, Miro & Jensen, 2010). There are learning disabilities in about 1/3 of the individuals who have MD (Carter et al., 2010). Also, individuals who have MD demonstrate deterioration in linguistic functions and an overall decline in their executive functioning.

Ambulation may also be affected by the cognitive level of the individual who has MD. If the individual who has MD also has mental retardation they may lose the ability to ambulate earlier on in life (Fujiwara, 2010). It is important for caregivers and families to be aware of these deficits and consider them while assisting the individual who has MD (Carter et al., 2010).

Currently, there is a lack of research regarding interventions or treatments specifically designed for individuals who have MD and cognitive or psychosocial deficits (Carter et al., 2010). An individual's cognitive ability has the potential to impact the level of assistance required by the caregiver to complete activities of daily living (ADLs) in individuals who have MD.

Areas of Occupation

Activities of Daily Living

Due to the disease's progressive nature, individuals with MD typically experience a decrease in independence with ADLs over time (Dawson & Kristjanson, 2003; Fujiwara, 2010). ADLs are considered to be critical to living in a social world as they facilitate basic survival and well being (Christiansen & Hammecker, 2001). As the individual's functional ability lessens, the level of dependence for ADLs on caregivers increases (Chen & Clark, 2010). Due to the personal and intimate nature of many ADLs, one of the major goals of rehabilitation for individuals with MD is maintenance of ADLs (Dawson & Kristjanson, 2003; Fujiwara et al., 2010). Fujiwara et al. (2010) found that ADL tasks requiring lower body functions such as dressing lower extremities and transfers were relatively difficult for individuals with MD. Tasks using upper extremities such as eating, bathing and grooming were found to be easier. These findings may be due to the early lower extremity weakness that typically begins early in MD's course (Fujiwara et al., 2010).

Transfers

When exploring ADL structure for individuals with DMD, Fujiwara et al. (2010) found that among transfers, toilet transfers were the easiest and bed transfers were most difficult. This may be attributed to distal weakness of the lower extremities that is required for individuals to lift their feet while transferring to or from a bed, but not while completing toilet transfers (Fujiwara et al., 2010). It may be beneficial for caregivers to note the level of assistance that may be required for different transfers depending on the individual. Although the transfer may be considered easier, the bowel and bladder management portion of toileting may be more difficult.

Therapists throughout Australia often found when working with individuals who have DMD, a substantial portion of them had voiding complications (Backhouse & Harding, 2006).

Voiding

Many factors have been reported that attribute to difficulties with bowel and bladder management. The functional ability of the digestive and urinary tracts in individuals with DMD is not typically affected until later stages of the disease or potentially as a result of surgery or scoliosis (Backhouse & Harding, 2006). Atrophy and fibrosis of an individual's intestinal muscles may be a contributing factor for reports of constipation and diarrhea associated with MD (Backhouse & Harding, 2006). Dysfunctional bowel evacuation has been noted to be a problem for individuals with neuromuscular disorders, primarily in the non-ambulant phase. Due to this, caregivers may need to address bowel and bladder management more frequently. Additional problems experienced may include urinary urgency, daytime bowel urgency, bowel pain, and voiding postponement for more than 6 hours. Backhouse and Harding (2006) found that children younger than 9 years reported no bowel problems other than diarrhea and individuals 12 years and older reported to have experienced urinary hesitancy.

After losing the ability to ambulate, most individuals develop scoliosis and require a spinal fusion, which helps manage deformity. The majority of those with bladder wall sensitivity and problems with sphincter control, which often lead to urinary incontinence, had received a spinal fusion (Backhouse & Harding, 2006). It was found that caregivers stress the importance of proper positioning and use of equipment to help prevent urinary hesitancy. Several individuals found reclining the chair to widen the hip angle to be an effective way to overcome urinary hesitancy. Another way children with urinary incontinence typically relieve the urge to urinate is by squatting. This strategy may not always be utilized by children with DMD due to their limited

capability to squat from muscle weakness (Backhouse & Harding, 2006; Chen & Clark, 2010). Once the individuals are no longer able to ambulate and are wheelchair bound, they experience increased embarrassment when asking for assistance for toileting, along with needing additional time, proper equipment and space. The increased complexity may mean that they may delay voiding, which consequently may lead to urgency and hesitancy during bowel and bladder management (Backhouse & Harding, 2006). Caregivers may need to demonstrate increased patience and empathy during these times to help comfort the individual with MD.

Along with the embarrassment that may be experienced, another potential cause for increased reports of bowel problems for individuals with MD may be due to increased levels of anxiety (Backhouse & Harding, 2006). Anxiety or mental discomfort can be brought on by increased dependence with toileting and inability to wipe oneself of urine or fecal matter after urinating or defecating (Backhouse & Harding, 2006). There were instances reported by caregivers that school staff at times would call them from work or home for assistance with their child for toileting, most often with bowel movements (Backhouse & Harding, 2006). These instances may be reduced by integration of holistic care addressing bowel and bladder management in all contexts.

Holistic care that also includes dietary consultation and referral for medical examination and follow up are recommended for young individuals with DMD who experience bowel and bladder difficulties. The holistic care should also include support within the home and at school, in regards to toileting routines, as well as fitting of the appropriate equipment (Backhouse & Harding, 2006).

Sexuality

Among ADL's, the least discussed topic for individuals with MD was that of sexuality. There was limited research available covering how individuals with MD's sexuality may be affected by the presence and progression of their disease. According to Rahbek et al. (2005) 80% of individuals with MD were not satisfied with their sexual life. Discussing sexuality may be a sensitive topic for individuals with MD, especially when focusing on sexual experiences. The typical adult male with MD has sexual difficulties and by the time he reaches mid 20's, he has likely had sexual experiences with a prostitute (Rahbek et al., 2005). There were varying remarks about experiences with prostitutes ranging from nervousness, perceiving the experience with a prostitute as helpful, having mixed feelings, and not having particularly good experiences (Rahbek et al., 2005). More often, the answers to inquiries on sexual life include a forthright need for love from a significant other. As individuals with MD get older their outlook on love changes from finding oneself unattractive and perseverating on the absence of love, to giving up the hope for a significant other and love (Rahbek et al., 2005). Rahbek et al. (2005) suggests that caregivers, parents and professionals must anticipate and properly equip those with DMD with the competencies necessary for adult social life, including love and sex.

Eating

Eating is another ADL that individuals with MD may experience difficulty. Fujiwara et al. (2009) reported that 40% of the individuals included in their study were independent in eating. Of these, only 7.8% of those 15 years and older remained independent in eating (Fujiwara et al., 2009). These findings were consistent with Carter et al. (2010) and Backhouse and Harding (2006) who also noted that individuals in the advanced stages of DMD were experiencing severe malnutrition. In contrast, while malnutrition is seen more often in

individuals with MD 15 years or older, obesity is experienced by 44% of males with MD under the age of 15 (Backhouse and Harding, 2006). This may be an area where caregivers should receive education from dietary services to tailor to the needs of their loved one. It was found that there were high incidences of picky eating and limited variety of foods consumed by individuals with MD (Backhouse & Harding, 2009). Around the time that individuals with MD lose the ability to self-feed, respiratory complications are also present. Unfortunately, when severe respiratory compromise is present, the increased effort put into breathing may significantly increase the caloric needs of the individual (Carter et al., 2010). Carter et al. (2010) emphasized the importance of proper dietary requirements and assessments by a nutritionist for all MD patients experiencing forced vital capacity of less than the predicted 50%. At this time, a variety of assistive technology/equipment may be introduced to be of assistance to the caregiver and the individual with MD.

Equipment for Individuals with MD

If caregivers assist the individual who has MD with utilizing proper equipment within their daily lives it has the potential to improve their quality of life (Carter et al., 2010). Equipment can be utilized with individuals who are ambulatory or nonambulatory (Carter et al., 2010). Individuals who have MD typically reach their early developmental milestones, but motor and speech may be delayed depending on the individual's condition (Backhouse & Harding, 2006). Abnormal gait patterns such as difficulties with running, quick movements, climbing, walking on toes and being clumsy or frequently falling may lead to an earlier clinical diagnosis (Backhouse & Harding, 2006). As the condition progresses, an individual's gait or ambulatory rate slows (Backhouse & Harding, 2006). Additionally, there may be safety concerns due to increasing fatigue levels and higher frequency of falls. Caregivers may assist in this by

encouraging use of energy conservation techniques and equipment (Backhouse and Harding, 2006).

Due to recent advances in healthcare and the positive effects of prescribed corticosteroids, the time period at which an individual's ambulatory phase ends has been extended (Backhouse & Harding, 2006). According to Eagle et al., (2007) an individual who does not receive interventions or corticosteroids typically loses the ability to ambulate independently by the age of 13. After the individual loses this ability they are at risk of developing scoliosis, cardiomyopathy and respiratory failure (Eagle et al., 2007). Also, a decrease in an individual's ambulation and functional mobility leads to an increase in their dependence on the caregiver to complete daily activities (Backhouse & Harding, 2006).

Wheelchairs

Individuals with MD enter a phase in life where they are able to ambulate with the use of specific assistive devices such as a walker or cane to prevent falls. After an individual's condition progresses past the ambulatory stage, there are different types of wheelchairs to consider (Carter et al., 2010). On average individuals who have MD begin using a wheelchair at age 14 (Canadian Nurse, 2012). A wheelchair needs to be selected specifically for the individual depending on the size, seat type, height, supports and cushioning. Individuals who have MD can be evaluated for a proper wheelchair by a healthcare professional such as an occupational or physical therapist. Depending on the progression of their disease, individuals often transition to a manual wheelchair initially. When they no longer have the upper body strength to propel the manual wheelchair independently, there is the option of a power wheelchair. The individual will need to be reevaluated by an occupational or physical therapist for the power wheelchair to ensure that it fits properly and they can operate it safely. The therapists can provide education for

the caregiver in regards to wheelchairs and home modifications that may need to be implemented.

Depending on the progression of the patient's muscular weakness they may require a cervical collar for extra support. Holding the head up is strenuous especially for weak neck muscles; if not taken care of appropriately it may lead to neck pain and muscle spasms. There are different types of cervical collars available which will be evaluated and determined by the occupational or physical therapist while being fitted for the power wheelchair (Carter et al., 2010). Along with wheelchairs and cervical collars individuals may require additional equipment such as home mechanical ventilation.

Home Mechanical Ventilation

Individuals who require home mechanical ventilation (HMV) are described in the professional setting as a vulnerable population (Stuart & Weinrich, 2001). There are two different types of mechanical ventilation: noninvasive and invasive. According to Rahbek et al. (2005); individuals who have MD in Denmark typically start using noninvasive mechanical ventilation around 16-19 years of age, depending on progression of the disease and the individual (Rahbek et al., 2005). It was found in a study that a key factor in determining when individuals start utilizing HMV is whether or not they endured a spinal surgery. For the individuals with MD who endured spinal surgery it was common for them to be introduced to HMV around the age of 17. Individuals who did not endure spinal surgery were on average introduced to HMV a year later (Eagle et al., 2007).

As the individual's breathing capacity deteriorates, they begin the invasive home mechanical ventilation during the night which may add additional stress or strain to the caregiver (Rahbek et al., 2005). It was found in a study that participants who have experienced both types

of ventilation preferred the invasive ventilation over the noninvasive ventilation. The noninvasive type of mechanical ventilation is a mask or BiPAP type, which has been known to be noisy. Patients reported that the face masked leaked, itched, and the machine woke them up throughout the night (Dreyer, Steffensen & Pedersen, 2010).

Invasive mechanical ventilation is a tube that goes down the individual's throat. Participants reported they prefer this type because it controls their breathing rather than support it which is the focus of the noninvasive type. They also reported that utilizing a ventilator was not more restricting to completing their daily activities than a wheelchair. Having controlled breathing is representative of "normal breathing" because it is a non-voluntary action and does not require conscious thought (Dreyer, Steffensen & Pedersen, 2010). Individuals who utilized the ventilator reported it not only expanded their lives and the ability to breathe; but it improved their quality of life (Ballangrud, Bogsti & Johansson, 2009).

There is currently a lack of evidence regarding when to initiate home mechanical ventilation for individuals with MD (Laub, Berg & Midgren, 2006). Participants reported that they had difficulty deciding when to begin utilizing the invasive type of mechanical ventilation. Once started, they were able to put on a healthy amount of weight and developed the ability to speak without tiring. Some of the participants in the study reported they change their own tubing and others go into the clinic to have a health care professional change their ventilation tubing for them. Caregivers can receive education regarding ventilator care so they are competent and can assist their loved one as needed.

An individual who has MD may need to suction themselves or be suctioned in order to open up their airway. The amount or degree to which the individual needs to be suctioned depends on the individual. They may need just the opening of their airway suctioned or might

require being suctioned all the way down to their bronchi. A caregiver may need to assist the individual with MD if their physical abilities limit them from performing the task independently.

Unfortunately, a ventilator is a type of machine and has the possibility of failing which can be life threatening for the individual who has MD. Caregiver stress may be increased when ventilators are introduced because of this risk. It is crucial that depending on the physical and vital state of the individual, they have a call button or alarm to alert their caregiver if something goes wrong while utilizing the ventilator. It is important for health care professionals and caregivers to be aware that care needs associated with mechanical ventilation need to be altered and modified depending on the individual's home accessibility, available equipment and their daily activities (Dreyer, Steffensen & Pedersen, 2010).

HMV is most often not used until the individual with MD's capacity to breathe independently is compromised. As HMV is introduced to the individual and family, other services may be offered as well. These services may include home nursing, respite and palliative care.

Palliative Care

There is evidence that palliative care is currently offered to individuals who have motor neuron disease (MND), but it has not yet been recognized as a typical plan of care for individuals who have MD (Dawson & Kristjanson, 2003). Palliative means to ease and/or alleviate symptoms or pain from an uncomfortable condition. Therefore, palliative care is a treatment used to relieve an individual with a disease rather than cure it (Venes & Taber, 2009). Palliative care is not only geared towards individuals facing end of life, but their family and friends as well (Dumont, Dumont & Mongeau, 2008). Typically, palliative care is not considered until all treatments have been exhausted or completed (Dawson & Kristjanson, 2003). Home nursing

services and respite care may be brought in at this time or prior to palliative care. Both home nursing and respite services assist with the needs of the individual with MD and can provide the caregivers with relief of their duties, both physically and emotionally.

According to Dawson & Kristjanson, (2003) families or caregivers of individuals who have MD have reported that they feel discussing end of life care or the option of DNR means that they have given up which then begins the process of grief prior to the death of their loved one. The grieving process occurs throughout the progression of the disease as the individual goes through different stages of ambulation and non-ambulation. However, discussion and preparation for end of life care may increase feelings of grief and bereavement.

Grieving

Grieving includes reflecting on the progression of the disease and the stages that the individual who has MD has endured. It also includes the effect that the loved ones or caregivers feel as a result of the individual's disease progression. It was found that individuals with MD reported experiencing loss on a daily basis. The individuals with MD reported that they often fear the worst and that they may be nearing the end of their life (Dawson & Kristjanson, 2003). Concerns have been noted for difficulties experienced by the caregivers and the consequences the difficulties may have on psychological health long term, especially during bereavement. Some of the factors that influence bereavement outcomes include the following: caregivers overall health status, relation to patient, perceived social support, circumstances of patient's health status and burden experienced from caregiving (Dumont, Dumont & Mongeau, 2008).

Depending on the perception of caregiving, family members may have more ease or difficulty with the loss of their loved one. Individuals who viewed their role as a caregiver as a chance for growth and reward adjusted better to bereavement than those who felt caregiving was

a disruption to their daily lives. Positive amounts of social and professional support with caregiving have been shown to decrease anxiety and stress, along with positively influencing how grieving is experienced. In the circumstance where a loved one passes away, it is viewed as a difficult time for family members and caregivers. The caregivers and family members may be emotionally charged which is common during the grieving process after a loved one passes. The patient's departure is also experienced as the end of the caregiving process and the key point in end-of-life care (Dumont, Dumont & Mongeau, 2008).

Theoretical Framework

The Model of Human Occupation (MOHO) guided the development of this project. MOHO is centered around a holistic point of view that focuses on engagement in occupations. Each caregiver for an individual with MD is different and changing, which is addressed through the dynamic aspect of MOHO. As the disease progresses, the individual with MD's ability to perform tasks changes. As performance capacity decreases, there is a higher level of assistance needed from caregivers to engage in daily activities. Changed performance capacity may alter habituation and how routines are carried out in daily living for the individual with MD and the caregiver. As the disease continues to progress, the caregivers volition may be challenged due to increased demand (Turpin & Iwama, 2011).

Another theoretical framework that guided the development of this project was the Adult Learning Theory. The theory uses an andragogical approach to teaching and learning styles in adult populations as the majority of individuals who assume the caregiving role for individuals with MD are adults. Adult caregivers have different learning styles that assist with the understanding and application of what is being taught. One of the key concepts in the Adult Learning Theory is that the use of self-direction is prominent in adult populations. Adult learners

are typically self-directed in obtaining and using the information provided in the caregiver guide (Bastable & Dart, 2011).

Summary

Muscular dystrophy is a progressive genetic disease primarily in males that presents through muscular atrophy and weakness and is typically diagnosed around the age of five years old (Lue, Lin, Chen & Lu, 2009). The two main types mentioned throughout this review are DMD and BMD (Kenneson & Bobo, 2012; Canadian Nurse, 2012). There has been recent medical advances causing an increased lifespan for individuals who have MD (Eagle et al., 2007). As a result there is a prolonged need for caregivers to assist with daily living tasks. The role of a caregiver is most often assumed by parents or more specifically the mother of the individual. However, a caregiver may be a family member, friend or a professional.

The demands the caregiver experiences depend on the physical, emotional and mental state of the individual. This affects the caregiver's quality of life and stress levels and as a result, may influence their need to utilize coping strategies (Hodges & Dibb, 2010; Kenneson & Bobo, 2010). Lower levels of social support have been linked to high levels of stress and distress in caregivers (Raina et al., 2004). While, caregivers may experience increased levels of depression and anxiety, there is also a growth in literature which displays the positive aspects that caregivers may experience. It has been found that caregivers who reported greater meaning and value in taking care of their loved one had greater life satisfaction and decreased subjective burden (Pangalila et al., 2012).

There are different strategies that have been found to be effective in coping with the diagnosis of MD and the progression of the disease (Epiphaniou et al., 2012). Various forms of support including social, community and family may increase life satisfaction and ability to cope

for the caregiver. The use of support groups and reliance on community resources may be viewed as beneficial by the caregivers (Hodges & Dibb, 2010).

Cognitive deficits, functional decreases, linguistic challenges may impact the amount of assistance the individual with MD requires from the caregiver (Carter et al., 2010). Another important aspect is that as the individual's functional ability lessens the level of dependence for ADLs on caregivers increases (Chen & Clark, 2010). The caregiver may assist through encouraging the individual by utilizing energy conservation techniques, assistive devices and equipment. As the individual with MD's breathing capacity deteriorates, they may begin the use of HMV during the night which may be additional strain or stress for the caregiver (Rahbeck et al., 2005). Grieving occurs throughout the entire disease process in the individual, caregiver and family. Towards the end stages of the disease, palliative care is typically introduced to the caregiver, individual and the family (Dumont, Dumont & Mongeau, 2008).

With improvements in technology and an increased lifespan, individuals with MD are experiencing a longer period of dependency on caregivers. This also means that caregivers are providing assistance in all aspects of life, which can be physically, psychologically and socially wearing on the individual. All of these factors demonstrate an increased need to maintain quality of life for both the individual with MD and the caregiver (Dawson & Kristjanson, 2003).

CHAPTER III

METHODOLOGY

The product, *Caring for Yourself as a Caregiver*, was developed for caregivers to use as a resource that is easily accessible. Having all of their resources in one location may decrease the amount of stress and demands that a caregiver experiences, positively influencing their life satisfaction. Within the caregiver guide, there are sections that focus on: roles of a caregiver, information about MD, how the disease typically progresses, common caregiver tasks, caregiver well-being, the grieving processes, palliative care and resources to seek out additional information. Within the *OT Manual for Caregivers of Individuals with MD: Carrying for Yourself as a Caregiver*, there is an introduction to the product, theoretical influences that guided development, the purpose of the caregiver guide, application to OT, and when to provide the guide to caregivers.

The Model of Human Occupation (MOHO) was used to develop the caregiver guide and OT manual. This model was selected because it is a client-centered approach utilizing a holistic point of view. The caregiver and their occupational engagement are influenced by the three main constructs of MOHO: volition, habituation and performance capacity (Turpin & Iwama, 2011). The adult learning theory was also used to guide the development of the product. This theory uses an andragogical approach to teaching and learning styles in adult populations (Bastable &

Dart, 2011). Each caregiver will have a different learning style which may influence how they understand and apply what is being taught.

There were different phases that led to the development of the product. The first phase of development focused on locating and finding literature using the following search terms: muscular dystrophy, muscular dystrophy progression, caregiving for MD, caregiver stress, depression in caregivers, coping skills, support for caregivers, activities of daily living, caregiving for terminal illness, mechanical ventilation for MD, ambulation with MD, caregiver quality of life, transitioning for caregivers, caregiver resources, parent resources, palliative care, and grieving. The research was found using various search engines including PubMed, CINAHL, OT Search, AJOT and Google Scholar. Additional information was obtained through educational websites about MD, the Muscular Dystrophy Association and textbooks.

The next phase in the development of the product involved creating a caregiver guide and OT manual. The information included within those two resources was founded on the literature review. The caregiver guide includes information on MD, challenges often faced by caregivers, ideas and strategies to cope with stressors, additional resources to increase support, and worksheets that can be completed. The OT manual was created to educate the OT about the purpose of the caregiver guide. It is important that the OT encourages the caregiver to fill out the worksheets located within the guide. This provides the caregiver an opportunity to integrate the personal experiences they may have with the resources provided. It also provides the caregiver with an area to self-reflect and gather an insider's point of view into the matter.

Caring for Yourself as a Caregiver:

A Guide for Caregivers of Individuals with MD

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Introduction

As a caregiver, you may have times where you feel like life is going at a fast pace and you have a difficult time keeping up with everything. This guide will serve as a resource for you to ensure that you are keeping yourself happy and healthy, and in turn allow you to give care to the best of your ability.

Included in this manual is information about MD and what the progression, may typically look like. It is the authors' hopes that having this information will help you anticipate transitions and challenges that may arise.

Also included in this manual is information on mental wellness and difficulties that caregivers often experience, in consideration of their own health. If you find yourself relating to any or all of these areas, there are also strategies about how to cope therapeutically. While these strategies may be very useful during difficult time, you may also find it helpful to bring them into your everyday life and routines to promote wellbeing.

Introduction

Lastly, we have provided a variety of resources that you may find helpful when caring for an individual with MD. It is the authors' hopes that the information, resources and tools that we provided will help you maintain your physical, mental and emotional health to the best of your ability.

As a caregiver for an individual with MD, you may view your experience as rewarding and valuable or as challenging and stressful. Having positive feelings about care giving also leads to less burden and depression, along with better health reports. With the use of this manual, it is the authors' hopes that this experience may help you find greater meaning, value and a sense of commitment from taking care of your loved one. Another hope is that the information included may renew your motivation to provide the best possible care for your loved one.

“There are four kinds of people in the world:
Those who have been caregivers;
Those who are currently caregivers,
Those who will be caregivers, and
Those who will need caregivers.”

- Rosalynn Carter
Helping Yourself Help Others

What It Means To Be a Caregiver

The definition of a caregiver may vary from person to person. How you define yourself may depend on your duties and responsibilities when providing assistance for another person. Since MD is progressive in nature, you will find that your role as a caregiver will change over time to better accommodate your loved one's abilities and needs. At the beginning, you may primarily provide emotional support and assistance only when asked.

As time goes on, you will likely need to provide more assistance with daily physical tasks such as bathing, dressing, moving around, and often in learning how to operate new types of medical equipment. You may feel as though your role as a caregiver becomes more complex and challenging as time passes. Throughout time, you will become accustomed to methods that are effective for assisting your loved one.

(Venes, 2009)

Roles of a Caregiver

As a caregiver, you may also have the roles of a:

Parent

“Being a parent means providing for protecting and teaching your child. It also means that you are now the most important role model that child will ever have.”

- Candice Carlson

Sibling

“An older sibling is a friend and defender - a listener, conspirator, a counselor and a sharer of delights and sorrows too. “

- Pam Brown

Worker/Employee

“ A person who works for another person or for a company for wages or a salary.”

- Merriam-Webster Dictionary

Family Member

“Family is the group of people who love us and whip us back into shape and mold us with knowledge. Family members are the ones we tell all our stories to and share events and fun with.”

- Janice Evans

Spouse

“The word spouse refers to a person's partner in marriage. It can denote either the husband or the wife. You may call this person your better half, mate, or life partner.”

- Unknown

Friend

“Friendship improves happiness and shares misery by the doubling of our joy and the dividing of our grief.”

(Brown, n.d.; Employee, n.d.;
Evans, 2013; First Covers, 2011;
Pangalila, 2012)

Roles of a Caregiver

Important Characteristics for Caregivers

As a caregiver, there is a variety of characteristics to have that may simplify your job. You may feel that you already have these characteristics, but strengthening them may benefit you and the individual. A few of these characteristics include but are not limited to; assertiveness, advocating, empathy, dependability, patience and flexibility

Assertive

Definition: Confident in behavior and style.

Example for a caregiver: If you want people to listen to your ideas, thoughts or concerns, you need to be assertive.

Advocating

Definition: A person who supports or argues for a cause, individual or policy.

Example for a caregiver: Advocating for the individual you are caring for may include seeking out resources through communicating with medical staff.

Empathetic

Definition: Feeling and/or expressing that you understand and share another person's feelings and/or experiences.

Example for a caregiver: Empathy as a caregiver is if you try to understand what they are going through by putting yourself in their shoes.

(Assertive, n.d.; Advocate, n.d.;
Empathetic, n.d.)

Dependable

Definition: Being trustworthy and reliable to others.

Example for a caregiver: The individual you are caring for must feel that you are dependable to be satisfied with the care provided to them.

Patient

Definition: The ability to be even tempered when confronted with difficult situations.

Example for a caregiver: As a caregiver you will need to be patient when confronted with difficult situations.

Flexible

Definition: Ability to adjust or adapt to change.

Example for a caregiver: There will be changes throughout the progression of the disease and you will need to be flexible.

(Dependable, n.d.; Patient, n.d.;
Flexible, n.d.)

For caregivers, developing empathy can begin with recognizing boundaries. It also coincides with understanding what things can be changed. As well as what things concerning the individual with MD cannot be changed. This is a guide for caregivers to utilize when beginning to understand and heighten the characteristic of empathy. This may also be used as a tool for developing a caregiver's role in advocacy for the individual and recognizing in which areas, they can make a difference.

As a caregiver while filling this out please take the time to reflect about each comment. Write down things from your job as a caregiver and your personal life that fit within each category. Take the time to review these things and change your answers accordingly throughout the progression of the disease.

Grant me the SERENITY to accept the things I cannot change...

COURAGE to change the things that I can...

And the WISDOM to know the difference.



(Microsoft Office, 2013)

Communication Strategies

As a caregiver, it is important to be aware of the different forms of communication. This worksheet includes examples of individuals with the three different forms: Aggressive, assertive and passive.

As a caregiver please take the time to circle or identify the comments that describe you. Then go back through and circle in a different color the areas that do not describe you currently, but you would like them to.

Aggressive:

I am loud, bossy and pushy.

I dominate and intimidate people.

I violate the rights of others.

I get my way and it does not matter who I hurt or offend.

I instantly react and do not process what I am going to say prior to saying it.

Assertive:

I am direct, honest and firm.

I respect the rights of others.

I recognize the importance of having my needs and rights respected.

I process what I am going to say prior to saying it.

I have the right and ability to make choices and change.

I am confident in who I am as a caregiver and as an individual.

I speak clearly to articulate my point.

FYI: If a caregiver is respectful and assertive when advocating for an individual to health care professionals, they are going to be perceived in a positive manner.



(Microsoft Office, 2013)

Passive:

I am unable to speak up for my own rights.

My opinions end up being overlooked.

I am mild mannered and often viewed by others as weak.

I am very accommodating to others needs or wants.

Please take the time to answer the following questions after reading the examples of each communication style listed above. Filling out the questions is a form of self-reflection and can be used as a guide for you as a caregiver to take charge of your communication style.

What form of communication do you currently use when advocating for the individual you are caring for?

In what way do you think you can improve your ability to care for that individual through adapting your communication style?

What areas did you identify to describe you in the future?

How are you going to achieve that?

As a caregiver, I have the right and ability to **change** a situation.

Take the time to fill out the following worksheet. It is beneficial to you as a caregiver because it provides you with an area to reflect and consider your options. Please write down a situation that you currently are unhappy with or feel that the individual you are caring is not receiving the best possible care. Then identify ways that are you are to change that circumstance.

For example, a situation may include that an individual is not receiving financial support for medical equipment. One change that a caregiver may identify is going to local programs that loan medical equipment such as the Goodwill Easter Seals Program.

Situation:

Change:

A.

B.

C.

Situation:

Change:

A.

B.

C.

Situation:

Change:

A.

B.

C.

I will explore different options and respect my personal choices and decisions!

Listening skills

Listening is a major part of a healthy communication process and is an important skill to have as a caregiver. Having effective listening skills will help to ensure you are providing your loved one with the best possible care. It will make your job easier as caregiver if you listen to their needs, as it may increase their satisfaction with the care provided. This is a guide to see how you would rate your listening skills when talking to the individual and then to health care professionals. Please circle the following answers that apply to you as a caregiver.

When listening to the **individual who has MD**, how often do you...

Put aside what you are doing and devote your full attention to them?

Always Sometimes Never

Focus your eyes on the individual when they are speaking?

Always Sometimes Never

Think about what they are really saying?

Always Sometimes Never

Avoid interrupting them?

Always Sometimes Never

Show interest through nonverbal such as gestures or facial expressions?

Always Sometimes Never

Respond in a non-judgmental way?

Always Sometimes Never

Ask questions that demonstrate you are interested?

Always Sometimes Never



(Korb-Khalsa, & Leutenberg, 1996;
Microsoft Office, 2013)

When listening to a **healthcare professional**, how often do you:

Put aside what you are doing and devote your full attention to them?

Always Sometimes Never

Focus your eyes on the individual when they are speaking?

Always Sometimes Never

Think about what they are really saying?

Always Sometimes Never

Avoid interrupting them?

Always Sometimes Never

Show interest through nonverbal such as gestures or facial expressions?

Always Sometimes Never

Respond in a non-judgmental way?

Always Sometimes Never

Ask questions that demonstrate you are interested?

Always Sometimes Never

Avoid making it about you and bringing in too many personal examples

Always Sometimes Never

Looking at the areas circled above which are you best at as a listener?

Which areas do you feel that you can work on?

(Korb-Khalsa, & Leutenberg, 1996)

Muscular Dystrophy

Muscular Dystrophy

MD is classified as a group of progressive diseases, which are genetic. Below are some of the common symptoms or signs of MD but the possibilities are not limited to that list.

Common symptoms or signs of MD:

Muscular atrophy

Weakness: skeletal, cardiac and respiratory

Difficulty with ambulation

Learning disability

Abnormal muscle appearance

Cause: The disease is a result to deficits on the X chromosome. These deficits differ depending on the type of MD an individual has.

Types of MD:

There are over 30 different types of MD. All of the differing types have three major things in common: being hereditary, displaying a pattern to the weaknesses experienced, and causing weaknesses.

Duchenne Muscular Dystrophy (DMD) and Becker Muscular Dystrophy (BMD) are two of the most common.

(Davidson & Truby, 2009;
Zebracki & Drotar, 2008;
Lue, Lin, Chen & Lu, 2009)

Common facts of DMD:

- The type that is most prevalent and commonly discussed in literature.
- 4.9 years old is the average age individuals are diagnosed with DMD.
- If a female carrier has a son, there is a 50% chance he will inherit DMD.
- The mutation or deficit on the X chromosome causes the individual's body to be unable to make a protein called dystrophin. This protein is essential for muscular contraction.
- The muscular deterioration and decreased muscle strength leads to progressive muscle weakness

Common Facts of BMD:

- BMD is not as prevalent as DMD but is one of the most commonly discussed types of MD in literature.
- Progressive muscular weakness is present in BMD but typically begins later in life.
- BMD progresses at a slower rate than that of DMD.
- This is a genetic disease and families can have more than one individual who is affected by BMD.

(Davidson & Truby, 2009; Zebracki & Drotar, 2008; Lue, Lin, Chen & Lu, 2009; Canadian Nurse, 2012; Eagle et al., 2007; Kennesen & Bobo, 2010)

MD Progression

Depending on the type of MD the individual has, progression throughout the disease may happen at different rates. There are stages of MD that may help you as a caregiver understand how it affects an individual. These stages are termed by ability to ambulate because it is most often the biggest indicator to the amount of assistance and care giving that may be needed. It is important to plan ahead in order to enhance the life of the individual you are caring for. As a caregiver you can enhance their ability to be as independent as possible, despite all of the opportunities and challenges that the individual with MD may endure.

Presymptomatic

- Most individuals with MD are not diagnosed at this stage unless there is a family history of the condition or elevated CK (Creatine Kinase) levels are found during blood tests.
- Symptoms of delayed walking or delayed speech may be present but are typically subtle.

Early Ambulatory (Walking)

- Boys will be showing what are considered “classical” signs of DMD.
 - Gower’s maneuver (the individual needs to support themselves with hands on thighs as they get up from the floor).
 - Waddling type walking, walking on their toes, running, quick movement, being clumsy and frequently falling.
- Can still climb stairs, but typically will bring the second foot up to join the first rather than going foot over foot.



(Microsoft Office, 2013)

Late Ambulatory

- Walking becomes increasingly difficult and there are more problems with climbing stairs and getting up from the floor, which leads to increased fatigue and higher frequency of falls.
- The individual is likely to be diagnosed by this stage unless delayed for other reasons.
- Orthopedic specialists may be consulted at this stage for appropriate assistive devices such as a walker or cane.

Early Non-Ambulatory

- The individual will need a wheelchair at this phase. Typically will begin with a manual wheelchair in which the individual self propels the chair independently and typically still has good posture.
- Spinal curvature (scoliosis) will need to be monitored after loss of ambulation, along with risks for cardiomyopathy and respiratory failure.
- Orthopedic input may be needed to monitor foot posture, which may cause pain and discomfort.
- Respiratory function is likely to begin declining after loss of ambulation. Respiratory interventions may be introduced at this stage.

Late Non-Ambulatory

- The individual will typically use an electric wheelchair at this stage.
- Upper limb function and maintenance of good posture is increasingly difficult.
- Adaptations may be needed to assist with activities such as eating, drinking, toileting and transferring to and from bed.
- A cervical collar may be needed to help support the head and neck.

(Backhouse & Harding, 2006;
Bushby et al., 2009)

Talking about the Diagnosis and Progression of MD

It is important to obtain consent from the individual who has MD prior to disclosing information to others. It may be difficult for a caregiver to discuss and disclose information regarding MD. There are times when it is appropriate to discuss the diagnosis as well as there are occasions and circumstances when it is viewed as inappropriate. Discussing the diagnosis with others can be therapeutic especially if the caregiver is a family member, friend or loved one to the individual.

Following are some guidelines and questions to discuss with the individual prior to disclosing information regarding their diagnosis.

- Who is it okay to be completely open and honest with?
- Who or in what circumstances/situations should I be more discreet and disclose a minimal amount of information?
- How much information is considered a minimal amount?
- Who should I avoid disclosing ANY information with and keep the situation completely private?
- Do I have permission and consent regarding the above questions?

After obtaining consent from the individual about disclosing information it is beneficial to think about what you might say if these situations arise.

(Korb-Khalsa, & Leutenberg. 2000)

Grieving

As a caregiver, you may find that grieving will commonly happen throughout the disease progression for you and your loved one with MD. The first time that you may begin the grieving process will be after the individual receives the MD diagnosis. As a caregiver, you may experience the stages of grief several times throughout your loved ones life, which is to be expected and normal. Grieving is a normal response to the challenges that may lie ahead and when learning how to face these challenges.

Every person will deal with grief in his or her own dynamic way. Do not be alarmed if the way that you are grieving is different from your family members or friends. The most important thing is that you allow yourself to experience grief so that you are able to move past it. Moving through and past the stages of grief will allow you to enjoy the time you have with your loved one with MD and begin living again.

On the next page, you will find a poem that describes what it is like to have a child with some degree of disability. This poem may show you a new way to view your experience. You may also better understand the motivators and rewards that other caregivers have experienced through taking care of their loved one.

Welcome To Holland

by Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

(Kingsley, 1987)

Role of Healthcare Professionals

Throughout your journey, you may work with a variety of healthcare professionals while managing the progression of MD. Living a full life for both you and the individual with MD may involve a variety of healthcare providers. Through different health care professionals, working together in order to address the different needs of the individual will provide the best outcome.

Each professional has a specific role in providing care and education to the individual with MD, family and caregivers. Communication is important with each of the professionals, as they will be able to provide you the best care if they know what is going on. We encourage you to have open communication with each of your providers and bring up concerns or other options for care.

We have included an overview of each healthcare professional you may encounter throughout the progression of MD. There is a place for you to write the healthcare members information for the individual you're caring for.

Primary Care Physician (PCP):

- Manages day to day medical care.
- Arranges referrals to specialist clinics and centers.

PCP's Contact Information

Nurse:

- Focuses on providing overall care to the individual.
- May assist in a formal healthcare setting or within the home.
- Administers medications.

Nurse's Contact Information

Occupational Therapist:

- Implements evaluations, treatments, and home evaluations to enhance independence.
- Provides information on managing daily living activities and assessments for equipment and housing adaptations.
- Focuses on dressing, bathing, feeding, eating, toileting, grooming, hygiene, meal preparation, and alternative communication devices.
- Educates on strategies for coping, stress management, balancing a healthy lifestyle and social support.

OT's Contact Information

Physical Therapist:

- Implements evaluations, treatments, and home evaluations to enhance independence.
- Advises on exercise and stretching to maintain mobility and comfort.
- Educates on handling techniques, posture, preventing contractures and breathing exercises.

PT's Contact Information



(Microsoft Office, 2013)

Speech Therapist:

- Assists in speech and language difficulties.
- Advises on chewing, swallowing and eating issues.
- Collaborates with dietician to monitor ability to swallow.

Speech Therapist's Contact Information

Respiratory Therapist:

- Implements assessments and interventions to enhance maximum respiratory function.
- Instructs and educates individual about respiratory management that may include the use of assisted cough and nocturnal ventilation.
- Initiates and manages non-invasive ventilation and associated techniques.

Respiratory Therapist's Contact Information

Cardiac Care:

- Early detection and treatment of deterioration of heart muscle function that commonly occurs.
- Surveillance and proactive management.

Cardiac Care Contact Information

Dietician/Nutritionist:

- Counsels and assesses nutritional status.
- Educates and assists in meal planning for adequate nutrition.
- Advises on weight control, special diets, and alternative feeding methods.

Dietician’s Contact Information:

Social Worker:

- Assists the individual with MD in obtaining necessary medical equipment, financial planning.
- Information regarding insurance and locating community resources and programs for support.
- Assesses and provides for social care needs such as respite care.

Social Worker’s Contact Information

Pharmacist:

- Provides knowledge and care relating to medications and their management.
- Identifies, resolves and prevents drug-related problems.
- Educates an individual on the side effects of medications.

Pharmacist’s Contact Information

Neurologist:

- Specializes in MD diagnosis, evaluation, and treatment options.
- Can prescribe pharmacotherapeutic medications.

Neurologist's Contact Information

Clinical Geneticist:

- Specializes in the inheritance patterns of MD.
- Provides information and genetic counseling.
- Helps identify family members at risk.

Clinical Geneticist's Contact Information

(Muscular Dystrophy Awareness, n.d.;
University of British Columbia, n.d.)

Common Caregiver Tasks: Safety

Safety Inside Your Home

Accidents occur more frequently in the home than elsewhere. It is important to be educated about situations within the home that may require safety awareness. Caregivers can develop the skills and knowledge to maintain the safety of the individual who has MD.

General Safety Inside the Home

- Be sure emergency phone numbers are visible by every phone or listed as contacts in a cell phone.
- Post a medication schedule developed by the caregiver, individual, occupational therapist and nurse.
- Discard old prescriptions/medications.
- Keep current medications out of reach of children and pets.
- Make everyone who provides assistance to the individual is educated on assistive equipment.
- Assistive equipment needs to be easily accessible.
- Make sure that floors, hallways and counters are free of obstacles or cleared off.
- Be aware that there may be additional safety concerns specific to your individual.

(Korb-Khalsa, Azok, & Leutenberg, 1991)

Fall Prevention

Starting in the early stages of the disease, individuals are at risk for falls. Falls can occur as a result of tripping, leg or full body weakness and loss of balance for the individual. Additional reasons falls can occur is due to lack of coordination, changes in an individual's gait pattern, medications, pain, and environmental obstacles. Caregivers can assist in preventing the occurrence of falls and injury through obtaining education or information regarding preventative techniques.

Techniques

Have an occupational therapist conduct a home evaluation to make modifications to ensure safety for the individual with MD. Some of the changes the occupational therapist may suggest include:

- Removing throw rugs
- Rearrange furniture so there is a clear path for ambulation or mobility
- Reducing clutter or obstacles on the floor
- Installing grab bars in the bathroom near the sink, toilet and in the bathtub/shower
- Place a non-slip rubber mat on floor in shower or bathtub
- Installing adequate lighting through the home
- If there are stairs, it may be beneficial to have a railing on two sides.
- Ensure items in kitchen are located within reach of the individual to prevent the use of a step stool

Depending on the individual's diagnosis there are assistive devices that may be recommended by the occupational therapist including:

- Ankle/leg brace
- Cane
- Walker
- Scooter
- Cane
- Manual wheelchair
- Electric wheelchair

(Center for Disease Control and Prevention, 2008)

Transfer Techniques

As MD progresses, your loved one may require more assistance moving around and with daily activities. To do this you might have to help them transfer to and from different surfaces. You can ask your occupational therapist to educate you and your loved one about proper transfer techniques. Those techniques include different strategies for transferring the individual from bed, chairs, toilet, bathtub, shower bench and wheelchair.

A few general tips to remember while transferring include:

- Wear stable shoes to ensure that your feet won't slip
- Bend your knees throughout the transfer to protect your back
- Keep your back straight
- Lift with your legs
- Feet should be placed at least shoulder width apart.
- Set up the place you're transferring to prior to starting the transfer
- Communicate with the individual

(Transfers and positioning, 2011)

Cognition

As a caregiver, it is important to be aware of the level of cognition that the individual you're caring for has. Safety may be a larger concern if the individual with MD has a cognitive impairment because they may not always be able to understand risks in situations. The cognition of the individual with MD may affect the amount of assistance they require to complete daily tasks. If your loved one with MD has a cognitive impairment, extra precautions may be taken to ensure their safety as well as yours.

Individuals with MD may experience:

- Verbal impairments or linguistic dysfunction
- Deficits in attention
- Intellectual deficits
- Decline in executive functioning (higher functioning tasks)
- Learning disabilities (prevalent in 1/3 of individuals who have MD)
- Impairments in ambulatory abilities (if mental retardation is present)

(Carter et al., 2010; Fujiwara et al., 2009)

**Common Caregiver Tasks:
Activities of Daily Living (ADL's)**

Activities of Daily Living (ADL's)

The individual you are caring for may experience decreases in their independence in participating in ADL's. This may result as an increase in the level of physical assistance you need to provide to the individual. ADL's are self-care activities that are typically completed on a daily basis.

ADL's:

- Bathing/showering
- Toileting
- Eating
- Feeding
- Personal device care
- Sexual activity
- Functional mobility
- Dressing
- Personal hygiene and grooming



It is important to note that deficits in these areas may also occur as a result of a decrease in mental wellbeing. For example if a caregiver is stressed out or anxious, he/she may not feel as though they have time to shower.



(AOTA, 2008; Microsoft Office, 2013)

Grooming and Hygiene Checklist

This is a guide for caregivers to use to ensure that the individual they are caring for are completing their hygiene and grooming tasks effectively.

	Sun	Mon	Tues	Wed	Thurs	Fri	Sat
Bath or Shower							
Shampoo hair							
Wash body							
Brush Teeth							
Clean face and hands							
Apply deodorant							
Clean/ trim/ cut nails							
Clothing is neat and clean							
Use of powder/lotion /aftershave /makeup							
Shave							

What areas do you need to provide assistance currently while the individual is completing their hygiene and grooming activities?

How much assistance do you provide?

Discussing Difficult Topics

As a caregiver you may have to address different topics with the individual you are caring for.

Examples of difficult topics:

Sexuality
Ambulation loss or changes
Transitioning to college or work
Death and dying
Palliative care
Toileting

The difficult topics may include but are not limited to the items listed above. It may be beneficial to consult with a healthcare professional when approached with identifying difficult topics. Here are some tips to keep in mind while faced with discussing different topics.

Helpful tips:

Utilize effective listening
Demonstrate open mindedness
Provide respect towards the individual
Demonstrate empathy
Be considerate of the individual's feelings
Show support

Caregiver Well Being: Emotional Wellness

Stress Statistics

Caregivers of individuals with MD face difficulties when dealing with stress related to the chronic disability and outlook of a shortened lifespan with recovery not being an option; therefore you may experience anxiety, depression, diminished family energies and resources.

- Stress has been reported by caregivers as difficult to avoid
- Nearly 50% of caregivers report high levels of stress
- 12% of caregiver reported severe psychological distress
- Stress levels are lower if the caregivers have strong social supports
- Household income and socioeconomic status can play a factor in stress levels
- Stress may not be experienced by all caregivers

There are a variety of things to do in order to assist in controlling stress levels. Becoming involved in treatment/intervention planning with health care professionals can help to provide a sense of control, which in turn creates less stress related specifically to care giving. It is effective to utilize different coping strategies to manage stress. Included in this manual are worksheets you can complete to assist with controlling and managing your level of stress.



(Im et al., 2010; Chen & Clark, 2010; Microsoft Office, 2013; Raina et al., 2004)

Are you Under Stress?

Symptoms to know that you are under stress:

- Cry more than usual
- Sleeping more or less than usual
- Eating more or less than usual
- Irritability or frustration
- Using alcohol and/or drugs more than usual
- Difficulty concentrating or focusing
- Feeling overly sensitive
- Lack of motivation



(Korb-Khalsa, Azok & Leutenberg, 1993;
Microsoft Office, 2013)

Being on Top of Stress

As a caregiver you may be experiencing stress, and one way to cope is to make a plan. This is a guide that you as a caregiver can utilize to control the level of stress that you have.

Please complete the following sentences as your job as a caregiver. Then take the time to fill out the actions you are going to do in order to change or cope with that certain stressor in your life.

Example:

When I see that I am losing sleep and becoming more irritable,

I will practice relaxation strategies to help relieve stress.

1. When I see that I... (Symptom of stress)

I will (What you are going to do to cope)

2. When I see that I... (Symptom of stress)

I will (What you are going to do to cope)

3. When I see that I... (Symptom of stress)

I will (What you are going to do to cope)

(Korb-Khalsa, Azok & Leutenberg, 1993)

Anxiety

You may find yourself stressing over whether you are adequately caring for your loved one and plagued by doubts about your ability to really help them in their time of need. The progressive nature of MD also often leaves caregivers with anxiety and fear about the future. Anxiety may be brought and experienced in a variety of ways. Caregivers often feel anxiety about facing another day and what the future holds. One of the questions you may find yourself asking is, “What happens when my child needs more care than I can provide?”

Anxiety is characterized by:

- Feelings of uneasiness
- Uncontrollable worrying
- Having trouble concentrating or focusing on what you are doing
- Feelings of restlessness and inability to relax
- Increased heart rate
- Tense muscles, which might make your hands shaky or give you pains in your muscles
- Sweating



(Microsoft Office, 2013;
World Federation for Mental Health, n.d.)

Depression

Caregiving is often physically and emotionally stressful. In an effort to provide the best care possible, you may put your loved one's needs before your own. At times you can develop feelings of sadness, anger, and loneliness, which can also trigger depression.

People experience depression in different ways; the type and degree of symptoms vary by individuals and can change over time. The following symptoms are characteristics of depression if experienced for more than two consecutive weeks:

- A change in eating habits leading to unwanted weight gain or loss
- Difficulty sleeping or sleeping too much
- Loss of interest in people or activities you enjoyed
- Becoming easily irritated or angered
- Feelings of sadness or feeling empty
- Thoughts about death
- Aches and pains with no physical cause
- Lack of ability to think clearly- difficulty concentrating, remembering or making decisions

To manage depression, it is important to know ways to make your life run smoother.

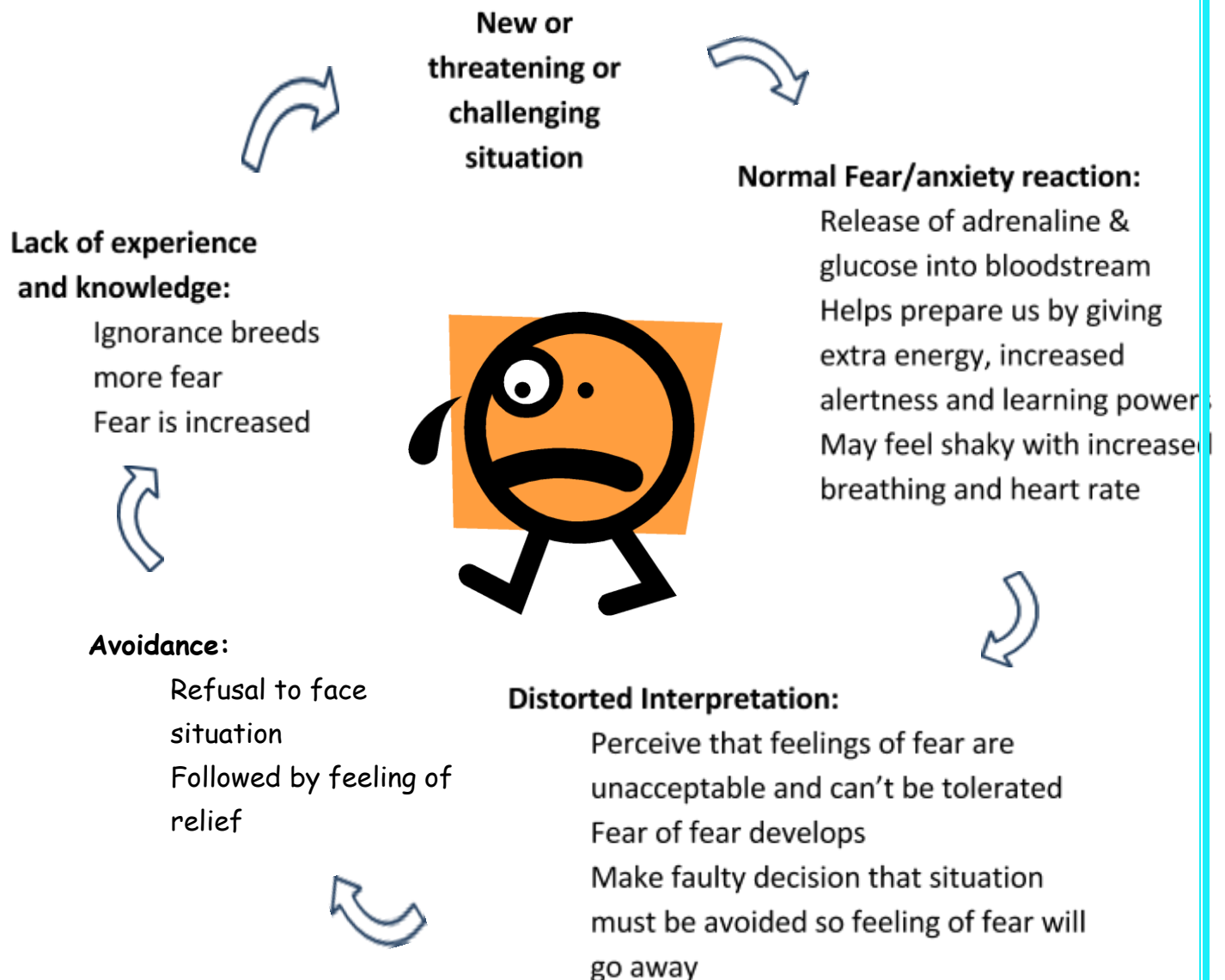
What are some ways you either know now, or would like to learn?



(Korb-Khalsa, & Leutenberg, 1996;
Family Caregiver Alliance, 2002;
Microsoft Office, 2013)

Are you stuck in the cycle of fear & anxiety?

The picture below shows some of the things that may happen when you are stuck in the cycle of fear and anxiety. This type of cycle is often hard to break out of and often leads to burnout, especially for caregivers.



(Microsoft Office, 2013)

When looking at the cycle of fear and anxiety, you may notice some parts that you can relate to. It is important to identify if you are in the cycle of fear and anxiety, and ways you can help yourself get out or stay out. Below are some questions you might find helpful to answer in order to identify any fear or anxiety you might have.

Questions to Consider:

What am I avoiding because of my fear?

What other factors may be adding to my fear?

What small step could I take to work through my fear?

How is fear or anxiety affecting my ability to keep myself and the person I am caring for healthy?

Caregiver Burnout

As a caregiver, you may have several responsibilities and tasks that can keep you busy. You may feel overwhelmed at times and potentially burnt out. Burnout is a state of emotional, mental, and physical exhaustion caused by excessive and prolonged stress. You are at higher risk for burnout due to the demands that may be placed on you. There are several signs to watch for and strategies to use to prevent or reduce burnout.

Some warning signs and symptoms to look for

- Feelings of depression
- Fatigue
- Decrease in interests
- No longer participating in social events
- Feeling helpless and overwhelmed

Prevention and Reduction

- Stay involved; continue to do what you love
- Participate in a support network if possible
- Consult with professionals
- Rotate responsibilities with others
- Establish alone time
- Laugh about something every day
- Get sufficient exercise and rest

(Seligson, 2009; Helpguide.org, 2009)

Caregiver Well Being:
Managing Stress and Anxiety

Balancing a Healthy Life

When preventing or reducing burnout, it may also be helpful for you to evaluate the balance in your life. Adopting a balanced lifestyle is important because it can have immediate and long-term effects on your health and well-being. Maintaining a balanced lifestyle also increases your chances of living a significantly more fulfilling and happier life. This will also allow you to better care for your loved one as you will be healthier and happier.

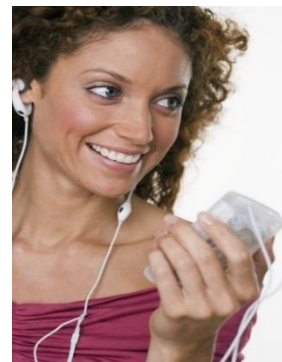
To check how well you balance your life, answer these questions:

- What do I want more of in my life?

- What boundaries can I set in my daily schedule to create more balance?

- What am I not paying enough attention to in my life right now?

- What is the easiest first step I can take now in the direction of what I want?



(Microsoft Office, 2013)

Components of a Balanced Life

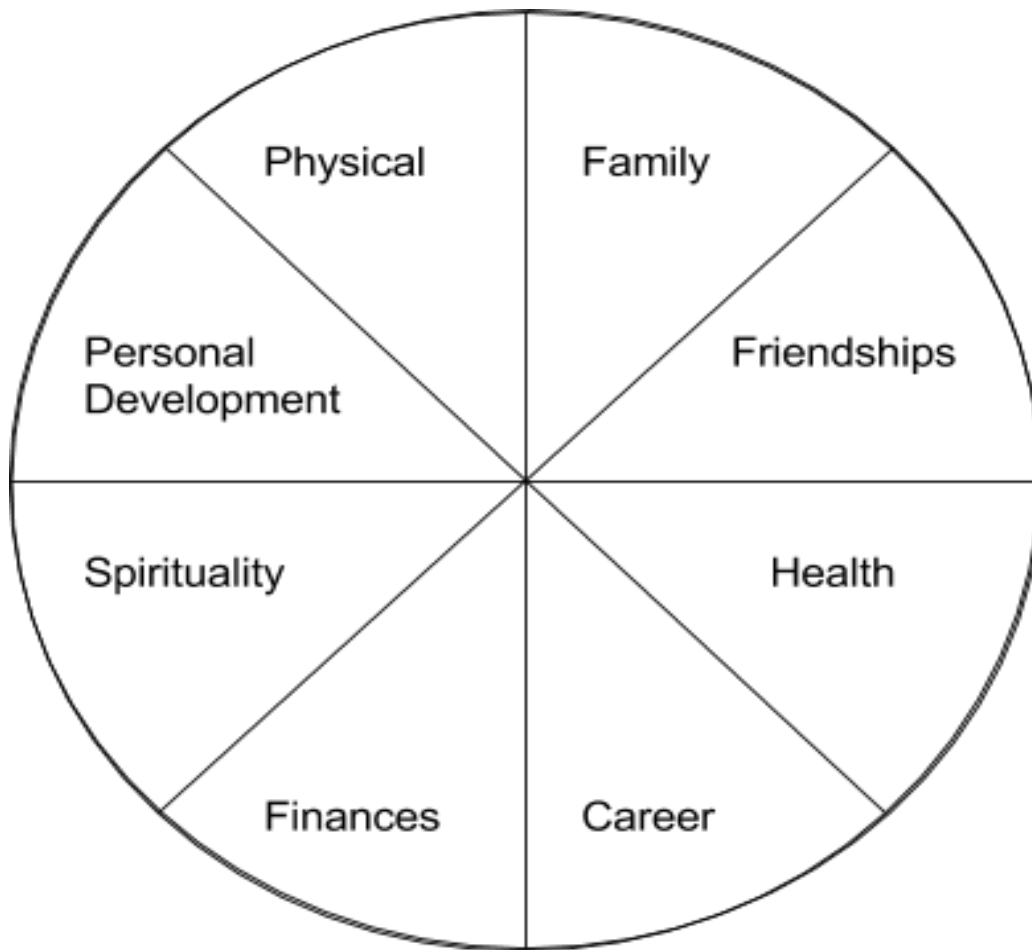


Figure 2. Each part of the circle represents an important aspect of your life. As you can see, each part is the same size to promote balance in your life. As a caregiver, you may not always find having a balanced life as an easy task. This figure will be helpful to reference if you are ever feeling as though your life is out of balance. This resource may be used to see which areas of your life may need more attention.

Caring for Yourself

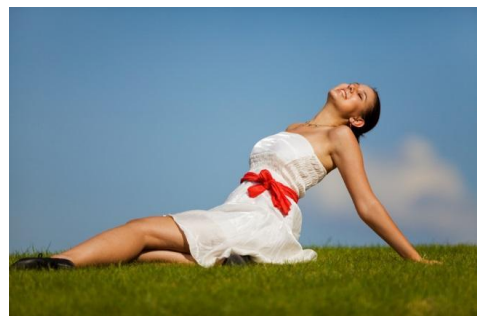
Coping

Coping refers to addressing the challenges and difficulties caregivers are faced with and figuring out how to manage these stresses. Caregivers and families take an increasingly active role in coping and advocating for their loved one who has MD. Caregivers utilize different techniques and strategies to cope with MD and its progression. Time off from work or care giving and social relief also aid in improved mental health for the caregivers.

There are two different types of coping techniques that are commonly utilized by caregivers and families of individuals who have MD. One of the types is problem-focused coping, which entails dealing directly with the stressful situation. Parents and caregivers use different mechanisms within the category of problem-focused coping to manage their role as a caregiver. The mechanisms include being overprotective and avoiding disciplining their loved one. Another mechanism is called magical thinking in which the caregivers or families felt the MD was progressing slower than what is typical or will recover completely. Another type of coping is emotion-focused in which the emotions and feelings are dealt with instead of changing or adjusting the actual situation. One of the techniques utilized was to watch TV as a distraction technique in order to relieve stress. Another strategy used to cope includes completing crosswords or games, which focus on mental stimulation. Energy conservation may also be a useful strategy to cope with the physical strain you may experience. Along with using coping strategies to manage stress, utilizing support from others and the community may reduce strain on caregiver.

Additional strategies for coping include

- Relaxed breathing (p. 55)
- Muscle relaxation (p. 56)
- Visual imagery (p. 57)



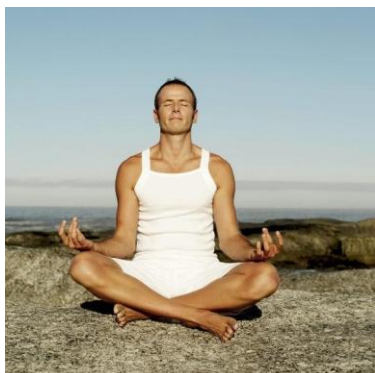
(Ahlstrom & Wenneberg, 2002; Epiphaniou et al., 2012; Microsoft Office, 2013; Pangalila et al., 2012; Scorgie & Sobsey, 2000; Webb, 2005)

Relaxed Breathing

Using a relaxation strategy, such as relaxed breathing, can help you manage stress effectively. Relaxed breathing is a strategy that you can use in almost any situation at any place. The goal of this exercise is to slow down your breathing, especially exhaling. As a caregiver, you may find relaxed breathing a helpful tool when dealing with difficult situations or during stressful times. This is a technique that you may also use in combination with other coping or relaxation strategies.

Steps for Relaxed Breathing:

1. Choose a word that you associate with relaxation such as:
 - CALM
 - RELAX
 - PEACE
1. Inhale through your nose and exhale slowly through your mouth. Take deep breaths so that you can feel your stomach go out with each inhale and in with each exhale
2. While you exhale, say the relaxing word you have chosen. Say it very slowly, like this, “c-a-a-a-a-l-m” or “r-e-e-l-a-a-a-x.”
3. Pause after exhaling before taking your next breath. If it’s not too distracting, count to four before inhaling each new breath.
4. Repeat all the steps at least 10-15 times, or until you become more relaxed.



(Microsoft Office, 2013;
U.S. Department of Health and Human Services,
Substance Abuse and Mental Health
Services Administration, 2009)

Muscle Relaxation

The goal of muscle relaxation is to gently stretch your muscles so that you feel less stiffness and tension. Your role as a caregiver not only requires emotional and mental strength, but physical strength as well. Muscle relaxation may not only be helpful early on in your loved one's life, but also as the MD progresses and requires more physical assistance. The exercises start at your head and work down to your feet. You can do these exercises while sitting in a chair or by trying other positions that are more comfortable for you.

Steps for Muscle Relaxation:

1. Shoulder Shrugs: Lift both shoulders in a shrugging motion. Try to touch your ears with your shoulders. Let your shoulders drop down slowly after each shrug. Repeat 3-5 times
2. Overhead Arm Stretches: Raise both arms straight above your head. Interlace your fingers, like you are making a basket, with your palms facing down (towards the floor). Stretch your arms towards the ceiling or reach them out in front of you. Slowly bring them down. Repeat 3-5 times.
3. Stomach Tension: Pull your stomach muscles toward your back as tight as you can tolerate. Feel the tension and hold for ten seconds. Then let go of the muscles and slowly let your stomach relax, further and further. Feel the heavy yet comfortable sensation in your stomach. Repeat 3-5 times.
4. Knee Raises: Reach down and grab your right knee with one or both hands. Pull your knee up towards your chest (as close to your chest as comfortable). Hold your knee there for a few seconds, before returning your foot to the floor. Reach down and grab your left knee with one or both hands and bring it up towards your chest. Hold it there for a few seconds. Repeat the sequence 3-5 times.
5. Foot and Ankle Rolls: Lift your feet off the ground and stretch your legs out. Slowly rotate your ankles and feet, 3-5 times in one direction, then 3-5 times in the other direction.

(U.S. Department of Health and Human Services,
Substance Abuse and Mental Health
Services Administration, 2009)

Imagining a Peaceful Scene

Imagining a peaceful scene is a helpful relaxation technique to “take yourself away” from stress and picture yourself in a more relaxed, calm situation. You may at times feel overwhelmed by your role as a caregiver or when facing difficult transitions with the individual with MD. This strategy works best if you are in a quiet environment where you feel comfortable. Playing quiet, calming music in the background may help you become more relaxed during this exercise.

Try to disregard any stressful thoughts by refocusing your attention on your peaceful scene when you find yourself distracted.

Steps to Imagining a Peaceful Scene:

1. Choose a scene that you find peaceful, calm and restful. If you have trouble thinking of a scene consider the following:
 - At the beach
 - In a meadow
 - Riding a bicycle
 - On a mountain top
 - Next to a waterfall
 - In a high rise apartment overlooking a large city
 - On a farm

2. After choosing a peaceful scene, imagine as many details as possible, using all of your senses:
 - What does your scene look like?
 - What sounds do you hear?
 - What can you feel with your sense of touch?
 - What smells are there?
 - What tastes might you be experiencing?

3. Allow at least five minutes for this relaxation technique

(U.S. Department of Health and Human Services,
Substance Abuse and Mental Health
Services Administration, 2009)

Activities to Reduce Stress

Things at home:

- Listen to music
- Take a bath
- Watch a favorite TV show
- Play with a pet
- Utilize relaxation techniques
- Read a book or magazine
- Express yourself in a journal or letter



Things to do in nature:

- Go for a walk
- Go for a bike ride
- Yoga
- Have lunch by a beach or river
- Play a game
- Meditation
- Walk a dog
- Take a nap in the warm sun

Social activities:

- Talk to a friend, family member, therapist or doctor
- Retail therapy
- Exercise
- Complete a project or craft
- Change the situation that is causing stress

There are additional techniques that can be utilized to reduce stress within this caregiver guide.

(Korb-Khalsa, & Leutenberg, 2000;
Microsoft Office, 2013)

Conserving Your Energy

Like most types of energy, your personal energy has limits. Energy conservation principles may take time to bring into your daily routine, but there are substantial benefits. This section will discuss energy conservation strategies that can be used by either the caregiver, care recipient, or both.

Pacing

- Plan your work before you do it to allow yourself to complete many jobs while remaining in one place.
- Pace yourself; do not rush to fit everything in.
- Spread out heavy and light work so you do not do all the heavy work at once.
- Split your work into small pieces or steps and rest between steps.

Use your body efficiently

- Sit instead of standing.
- Try not to lift or hold heavy things- use a cart or ask for help.
- Try not to reach or bend- move your work to be within your reach.
- Keep supplies or items that you use a lot in an easily accessible area.
- Use good posture so your core does the majority of the work.
- Avoid twisting motions when holding a heavy load.
- Support your elbows on a table or firm surface while performing a task to avoid tiring your arms.
- Keep your arms straight and close to your body while carrying objects and spread the load between both arms at the same time.

(Corcoran, 2003)

Healthy Sleeping Habits

Sleep is a necessity to live; however is often a low priority in a caregiver's lifestyle. Whether you are providing care twenty four hours a day or care giving from a distance, you are susceptible to caregiver fatigue. As an adult, your body needs six to nine hours of sleep per night. Lack of sleep contributes to an increased vulnerability to illness and can affect your emotional health as well. Fatigue and sleep deprivation can strongly impact your ability to provide the best possible care to your loved one.

Fortunately, there are many things that can help you to decrease weariness and promote a good night's sleep:

- Regular exercise can improve sleeping habits, as well as decrease stress, depression and anxiety.
- Try to maintain a daily routine for naps and sleep so that your body can adjust.
- Listen to positive sounds to promote relaxation before sleep such as music or nature sounds to soothe your soul.
- Meditation, prayer, and deep breathing exercises may help calm your mind and body so that you can sleep.
- Try drinking warm milk, taking a relaxing bath, reading something pleasant or journaling some thoughts before bedtime.
- If your sleeping difficulties are persistent, discuss alternative options such as medication with a physician.



(Dreyer, Steffensen, & Pedersen, 2010;
Dwyer, 2006; Microsoft Office, 2013)

Life satisfaction

As a caregiver it is important to maintain your life satisfaction. There are certain things that occur in life that may get in the way of enhancing your life satisfaction.

Inhibitors to life satisfaction:

- Stress
- Anxiety
- Depression
- Loneliness
- little to no use of coping strategies

Included within the guide are ways that you as a caregiver can enhance your life satisfaction.

Enhancers to life satisfaction:

- Coping strategies
- Relaxation techniques
- Activities to decrease stress
- Resources
- Ways to increase balance in your life



(Im et al., 2010;
Microsoft Office, 2013;)

Palliative Care

Palliative care

Palliative care is a service to help improve the quality of life for the affected individuals and their families when facing life-threatening illness. Typically, palliative care is not considered until all treatments have been exhausted; however, this is not always the case when dealing with children.

Palliative care may be introduced when the disease is diagnosed and continued regardless of the treatment your loved one with MD receives. This can benefit the individual with MD, your family and the medical team by helping you make decisions about the management of the condition throughout life. Being introduced to a palliative team early on may also help you develop a relationship of trust. This type of care is aimed to alleviate the individual with MD's physical, psychological and social distress.

Who may be included in your palliative care team:

- Primary Health Practitioner
 - Directs the individual's care
- Nurse
 - Assess the individual's comfort care needs and coordinates care
- Pharmacist
 - Assists with symptom management
- Spiritual Care Provider
 - Supports your family spirituality
- Social worker
 - Identifies community services and assists with decision making

(Doyle & Woodruff, 2013)

Grieving Process

Grieving Process

As a caregiver, you may find that grieving will commonly happen throughout the disease progression for you and your loved one with MD. The first time that you may begin the grieving process will be after the individual receives the MD diagnosis.

Grieving includes responses to loss that many people have, but there is no typical response to loss. Loss may include losing a hope for the future, when your loved one with MD loses ability to ambulate, when independence is lost, or when an individual passes away. It is important to remember that grief is a normal and natural response to loss. Grief is as unique as you are.

There are 5 stages of grief, which include denial, anger, bargaining, depression and acceptance. You may spend different lengths of time working through each step and express each stage more or less intensely. It is helpful to look at the stages as guides in the grieving process. This may help you understand and put into context where you are. You may not experience each of the stages in this order and will often move between stages before achieving a more peaceful acceptance of the diagnosis.



(Axelrod, 2006; Microsoft Office, 2013)

Denial

The first reaction to learning of a terminal illness or death of a loved one is often to deny the reality of the situation. It is a typical reaction to rationalize overwhelming emotions. Denial is often seen as a defense mechanism that helps buffer the immediate shock. You may find yourself blocking out the words and hiding from the facts.

During this time, you may also find yourself isolating from family members or friends. This is a temporary response that helps carry you through the first wave of pain. As a caregiver, you may have feelings of shock, numbness, and as if heavy weight has been placed upon you.

When experiencing denial, you may find yourself saying things such as:

- “My child can’t have MD, they looks just fine.”
- “Our doctor must be wrong.”
- “I can’t believe this is happening, things will never be the same.”

(Axelrod, 2006)

Anger

As the effects of denial and isolation begin to wear off, reality and the pain of it may re-emerge. You may not feel ready. As this intense emotion begins to surface, it may be redirected and expressed instead as anger. Your anger may be aimed at inanimate objects, strangers, friends, family or yourself. Anger may fall upon your medical team or a higher power. The anger may also be directed at your loved one with MD despite them not choosing to be diagnosed with the disease. Rationally, you know the person is not to be blamed, but emotionally you may resent the person for causing pain. Later, you may feel guilty for being angry which makes you more angry.

To help you better understand options available to you, you may want to ask your doctor to give you extra time when explaining the details of your loved one's MD. This may also help to rationalize the anger. It is okay to feel angry as this is a sign of healing; however, you must be able to work through the anger in order to continuing the healing process.

When experiencing angry, you may find yourself saying things such as:

- "Why is this happening to me/us?"
- "We don't deserve this."
- "I resent the doctors who told us this."

(Axelrod, 2006)

Bargaining

The normal reaction to feelings of helplessness and vulnerability is the desire to regain control. During this stage, you may find yourself trying to make a deal with God or a higher power in an attempt to postpone the inevitable. As time goes on, you may find that the things you bargain for will change. In the beginning, you may wish for your loved one to not have MD. As the disease progresses, you may hope that the individual with MD lives a fulfilling life and does not suffer painfully. This is a weaker line of defense to protect us from the painful reality.

When experiencing bargaining, you may find yourself saying things such as:

- “If only we had sought medical attention sooner.”
- “If only we had gotten a second opinion from another doctor.”
- “Please let me trade places with my child.”
- “What can I do to make my child better?”

(Axelrod, 2006)

Depression

Depression associated with grief may come in two different forms. This may also be the longest and most difficult of the five stages. The first form of depression is a reaction to a practical implications relating to the disease progression and/or loss. Sadness and regret often are noticed most with this type of depression. You may worry about costs, altering your home and other stressful events. You may also worry, that in your grief, you have spent less time with others that depend on you. You may find the depression eased by simple clarification and reassurance.

The second type of depression is more subtle and at times, more private. It may be your quiet preparation to separate and to bid your loved one goodbye. Depression allows you to adapt to the situation, which may feel at possible at the time. At this time, you may find that all you really need is a hug. Remember that you have a support system to help you through this, yet they will allow you to cope in your own way.

When experiencing depression, you may find yourself saying things such as:

- “I have no energy to do anything.”
- “I feel so helpless in helping my child.”
- “If there is a higher power, they must have given up on us.”

(Axelrod, 2006)

Acceptance

Reaching this stage of grieving is a gift that is not afforded to everyone. You may start to accept the MD diagnosis only to find yourself taking a step back to one of the other stages of grief. This may happen several times before you finally reach a point where you can accept your loved one's diagnosis as reality and move forward. Acceptance does not mean you like this reality; you are simply at peace and can cherish the time you have with your loved one. Acceptance may also be experienced after your loved one with MD has passed away.

You may not be able to change what you are being faced with, whether that is learning about the diagnosis of MD, coping with limitations or the passing away of the individuals with MD, but with acceptance you will be able to change how you live. You will begin to live again, but not until you have given grief its time. Always remember, your grief is as unique as you are.

When experiencing acceptance, you may find yourself saying things such as:

- “We are going to get past this and live life to its fullest.”
- “I am going to cherish the moments we have together.”
- “It feels good to laugh again.”

(Axelrod, 2006)

Resources

Resources

Families and caregivers have expressed the need to have access to reliable and accurate resources throughout the disease process. They have often reported feeling vulnerable, stressed and less supported as the disease progressed when they did not have access to assistive resources.

There are caregivers who feel that it is important to have access to information and assistance immediately after the diagnosis, throughout each stage of the progression and information pertaining to the future progression of the disease. It is important that the resources are easy for the caregivers or loved ones to access and understand in order to save time and money.

Resources

Supportive Relationships

Having a strong support system is useful while being a caregiver because it may become stressful. Caregivers who receive social support are on average four times more likely to be satisfied with life. If they do not receive social support, caregivers experience elevated stress and distress. It is important for family members and caregivers to receive support from their peers when they first find out about the diagnosis and throughout the progression of the disease. Unfortunately, most families, caregivers and individuals with MD experience a decrease in social support throughout the progression of the disease and an increase in social isolation.

Characteristics of supportive relationships

- Prevent the feeling of loneliness
- They offer approval
- Honest
- Give support
- Provide strength during hard times
- Optimistic
- Encourage holding head high
- Effective listeners

(Chen & Clark, 2010; Kennesen & Bobo, 2010)

Resources

Muscular Dystrophy Association (MDA)

The MDA is a nonprofit health agency dedicated to finding treatments and cures for MD, ALS and other neuromuscular diseases. This association serves as a valuable reference for individuals with MD, their caregivers, health professionals, and researchers. The MDA funds research throughout the world and provides comprehensive health care services and support to families affected by MD. The national website is: www.mda.org.

On their website, the MDA has a specific link for caregivers. To provide families and caregivers with support, the following are available under Help:

Through Services section:

- Your MDA Clinic- a national network of 200 medical clinics staffed by experts in neuromuscular diseases, including more than 40 clinics designated as MDA/ALS centers.
- Finding Support- local support groups and events for individuals and families and online opportunities to connect, share and learn through online communities, social media, care coordination and webinars.
- Equipment Assistance- assistance locating, obtaining, and repairing needed durable medical equipment.
- Caregivers- this is specifically meant to provide caregivers resources, information and support.
- Transitional Services- supports and resources that assist youth with MD to prepare for adulthood, while also transitioning from pediatric to adult medical care.
- Emergency Resources for Families- this is a section full of resources in the case of an emergency where shelter may be needed, if there are power outages during a storm, or in the event where the individual with MD has to go to the emergency room.



(Muscular Dystrophy Association, 2013a)

Resources

MDA's National Equipment Program

MDA's national equipment program is open to anyone - regardless of age, employment or insurance coverage- for whom medical equipment has been recommended and prescribed by an MDA clinic doctor in relation to an MD diagnosis.

In addition to MDA's equipment program, many federal, state and local resources are available to assist you with equipment purchases. You are encouraged to contact your local MDA office for more information on accessing equipment and to learn about other options in your community.

Minnesota

- MDA Office phone number- (952)832-5517
- MDA Clinic phone numbers
 - The Duluth Clinic, Ltd - (218)786-8364
 - Fairview Maple Grove Clinic- (763)898-1000
 - Fairview University Medical Center- (612)365-1000
 - Gillette Children's Specialty Healthcare- (651)312-3176

North Dakota

- MDA Office phone number- (701)235-1988
- MDA Clinic phone number
 - Sanford Clinic Fargo Region- (701)234-6600

For other MDA office or clinic locations, go to www.mda.org/locate

(Muscular Dystrophy Association, 2013b)

Resources

Caregiver Action Network (CAN)

This is available to all individuals who are providing care or support to another individual. The purpose of the network is to increase the life satisfaction of caregivers. This is a non-profit organization that provides free services.

Free services:

- education about support and resources
- support from peers or networking to connect you with other caregivers.
- resources for caregivers to utilize to enhance their life satisfactions.

To find additional information about the CAN

In order to reach a member of the staff of the CAN,

- Send an email to
info@thefamilycaregiver.org
- Send mail to
2000 M St. NW, Suite 400
Washington, DC 20036
- Call
Phone: 202-772-5050



(Caregiver Action Network, 2013)

Resources

National Alliance of Mental Illness

National Alliance of Mental Illness (NAMI) is one of the nation's largest mental health organizations dedicated to building better lives for Americans affected by mental illness. NAMI works hard to advocate for access to services, treatment, supports and research for individuals and family members of individuals with mental illness.

As a caregiver, you may often put your own mental health as a low priority or notice declines in the individual with MD's mental health. You may find NAMI as a helpful resource for yourself, the individual with MD, or other family members that you think may benefit. Some of the features of NAMI's website that you may find helpful include:

- Information on mental illness including symptoms, treatments, coping strategies and prevention.
- A variety of support and education programs for people that may be experiencing similar things to you.
- Information on the HelpLine NAMI runs to provide information and referrals for individuals seeking help.
- Local events that may include advocacy or social events with support groups

The national website is: www.nami.org

NAMI Information Helpline: 1(800) 950-NAMI (6264)



(National Alliance on Mental Illness, 2013)

Resources

Goodwill Easter Seals Medical Loan Program



GOODWILL · EASTER SEALS
MINNESOTA

This is a Minnesota program that lends medical assistant devices to anyone in need. As a caregiver it may be beneficial to try out medical equipment as a loan prior to purchasing it to be confident that you are buying the device that best suits the needs of the individual you are caring for. Additionally, the individual may only be utilizing the device for a short while due to the progression of the disease. If that is the case, then the loan program may be beneficial because it is a temporary program.

Examples of some of the equipment offered

- o Commode chair
- o Shower bench
- o Walker
- o Crutch
- o Cane

If you are interested in loaning medical equipment listed below are a few of the locations where you can pick it up.

Minnesota

St. Paul

553 Fairview Ave. N.
St. Paul, MN 55104
651-379-5922

St. Cloud

50 South 2nd Ave.
Waite Park, MN 56387
320-654-9527

Willmar

100 19th Ave. SW
Willmar, MN 56201
320-214-9239

Rochester

239 28th St. S.E.
Rochester, MN 55904
507-287-8699

(Goodwill Easter Seals, n.d.)

Closing

Being a caregiver for an individual with MD may be a challenging, yet rewarding, experience. It is the authors' hope that you find greater meaning, value and a sense of commitment from taking care of your loved one with MD. We have created this manual to help you get the most out of your time with your loved one by learning how to best care for them and yourself.

You are encouraged to refer to this manual early and often throughout your journey as a caregiver and use the worksheets provided to better understand how these tools can be brought into your own life. By maintaining your own physical, emotional and mental health, you will be able to better care for the individual with MD.

This manual was created by occupational therapists to educate you on the many aspects that may influence your role as a caregiver. The information and tools are now yours to use in a way that best fits your individual needs.

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CHAPTER V

SUMMARY

The purpose of this scholarly project was to develop a guide that could be provided by OTs to caregivers of individuals with MD. The guide can be used by a caregiver to ensure they have easily accessible resources. There are recent advances in medical fields which have led to an increased lifespan for individuals with MD to an average age of 27 years old (Eagle et al., 2007). As a result, caregivers of individuals with MD are experiencing an increase in psychological and physical demands for an extended period of time. Currently there is a lack of literature which focuses on caregiving for adults with MD, leaving those caregivers with continued demands and limited resources. Within the caregiver guide, there are sections that focus on: roles of a caregiver, information about MD, how the disease typically progresses, common caregiver tasks, caregiver well-being, the grieving process, palliative care, and resources to look for additional information. The OT that is providing services to the individual with MD will provide the guide to the caregiver. The guide can be provided during the diagnosis phase or throughout any of the stages of disease progression.

Another part of the scholarly project was the development of the OT manual. This is a manual specifically developed for OTs to educate caregivers about what is included within the guide. Included within the OT manual is an introduction to the product, theoretical influences that guided its development, the purpose of the caregiver guide, its application to OT, and when

to provide the guide to caregivers with educational resources specifically developed for the caregiver.

While in professional and graduate school programs, OT students receive education about physical rehabilitation and working with individuals who are experiencing physical disabilities. Within course work focusing on physical rehabilitation, OT students are provided a basic understanding about musculoskeletal disorders. Students also receive education regarding the obstacles that caregivers encounter while caring for others as it is important to understand the physical, emotional and mental health of the caregiver and the individual seeking services. Thus, OTs are trained and educated in addressing the psychological issues that a caregiver may experience throughout the disease process. Therefore, it would be in the caregiver's best interest to seek out services from an OT because the profession uses a holistic point of view when addressing patients. The caregiver product includes educational information and worksheets addressing all aspects of the individual. The guide provides the caregiver an opportunity to integrate the personal experiences they may have with the resources provided. It also provides the caregiver with an area to self-reflect and gather an insider's point of view into the matter.

Throughout the development of the scholarly project, the authors encountered various limitations. Communication with outside sources served as one of the limitations. The authors attempted to contact a variety sources for information regarding MD and caregiving. Due to limited time frames and lack of responses, there was minimal information received from those sources. It would have been beneficial for the development of the product if the amount of communication and information obtained was increased. Another limitation was a lack of literature which focuses on caregiving for individuals with MD and more so caregiving for adults with MD.

One of the authors' recommendations for continued action in the development of this product is being aware of events related to advocating about MD. Having prior awareness of national MD month and fundraising events within the local communities could have provided the authors with an opportunity to speak with caregivers about their experiences. The caregivers at those events may have helpful strategies, advice or additional topics to address in the guide that would be of benefit to other caregivers. These events may also provide an opportunity to advocate for and potentially distribute the product, *Caring for Yourself as a Caregiver*. Another recommendation for further action with development of the product is to increase communication with professionals who have experience working with individuals who have MD. This may include OTs, individuals from the MD association or contacting resources from websites that focus on MD or caregiving. Through increasing the communication with professionals, additional clinical insight and caregiver experiences would be utilized.

One of the potential barriers to implementation of the product is reaching practicing OTs to educate them about the product. It may be of benefit to contact the American Occupational Therapy Association to include information regarding the caregiver guide and OT manual on the national website. Another potential barrier would be reaching caregivers who are not currently receiving OT services. The authors may contact informational websites that advocate for individuals affected by MD and ask them to include information regarding the product. This way information about the product would reach those who are not receiving.

To seek out feedback, the authors would develop a survey for practicing OTs so that the product's usefulness or outcomes be measured annually. Included in the survey would be questions regarding the effectiveness, application, utilization, and caregiver responses. Another way to receive feedback would be to request it on the websites where information about the

product is provided. Through these resources, caregivers would also be able to provide feedback on use of the product and how it influenced their ability to care for themselves and the individual with MD.

This guide will serve as a resource for caregivers of individuals with MD to refer to throughout their journey as a caregiver. Through OTs providing the guide, caregivers will be able to better care for the individual with MD and themselves by maintaining their own physical, emotional and mental health. Being a caregiver for an individual with MD may be a challenging yet rewarding experience. It is the authors' hope that the caregivers find greater meaning, value and a sense of commitment from taking care of their loved one with MD. We have created this manual to help caregivers get the most out of their time with their loved one by learning how to best care for themselves.

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