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## Occupational Therapy in Primary Care: Progressive Neurological Disorder

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Occupational Therapy in Primary Care: Progressive Neurological Disorder

by

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Submitted to the Occupational Therapy Department of the

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In partial fulfillment of the requirements

for the degree of

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This scholarly project, submitted by Amanda Callahan, MOTS and Danielle Chartier, MOTS 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.

Faculty Advisor Debra J. Hanson PhD, OTR/L, FAOTA

Date April 15, 2019

## PERMISSION

Title: Occupational Therapy in Primary Care: Progressive Neurological Disorder

Department: Occupational Therapy

Degree : Master of Occupational Therapy

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## ABSTRACT

The purpose of this scholarly project is to provide occupational therapists with a quick reference guide describing the unique role of occupational therapy to provide treatment for patients with multiple sclerosis within a primary care setting.

A substantial literature review was completed to gather knowledge on multiple sclerosis, occupational therapy, primary care, and the intertwining of these three concepts. The findings from the literature review assisted to guide the development of the product.

A collaborative client and therapist guide was developed to guide treatment for individuals with multiple sclerosis within a primary care setting. Occupational therapists bring a holistic perspective to the primary care setting. Therefore, quick and effective interventions are appropriate for primary care services. The project opens up a discussion for how occupational therapists can improve quality of life for individuals in a primary care setting.

## **CHAPTER 1**

### **Introduction**

Occupational therapy (OT) is an appropriate fit for primary care services. However, there is a lack of resources for OT's pertaining to primary care in the United States. The population of interest for this project are individuals with chronic neurological disorders, specifically to multiple sclerosis (MS). Multiple Sclerosis is a chronic progressive neurological disease impacting around 500,000 people in the United States with an age of onset commonly between 20 and 30 years old (Bautista & Grossman, 2014). It is unknown what the cause of MS is, however, it is known that there are a variety of factors that may lead to a diagnosis of MS (Ellis, Blackburn, & Bath-Hextall, 2013). MS is commonly known to have three separate types of the disease. These types are based on the symptoms, progression, and amount of relapses. Types of MS include relapsing-remitting, primary progressive, and secondary progressive. The most common type is relapsing-remitting, which there is severe deterioration with a slight recovery between relapses (Bautista & Grossman, 2014).

Multiple sclerosis is a complex disease which presents with a variety of symptoms. Significant symptoms of multiple sclerosis include fatigue (Bautista & Grossman, 2014) and balance (Litchfield & Thomas, 2010). These symptoms significantly impact occupational performance and quality of life. Jelinek (2009), states depression is a symptom that individuals with multiple sclerosis often experience due to the drastic changes in roles. Depression symptoms include but are not limited to lack of

interest, saddened mood for at least two weeks and irritability (Jelinek, 2009). The variety of symptoms that correlate with multiple sclerosis create a need for client-centered care.

Primary care enhances client-centered care by focusing on each individual's needs and referring clients to specialized treatment the client may need. Primary care is a unique niche focusing on the prevention of diseases (Metzler et al., 2012). The types of interventions that are being proposed consist of quick interventions that can be easily adapted to the primary care setting. These quick interventions are appropriate due to the high demand of a primary care setting and the nature of chronic neurological conditions, including multiple sclerosis (Dahl-Popolizio & Muir, 2017). Occupational therapists could assist in primary care by addressing the impact the client's diagnosis has on daily activities and providing educational material related to the diagnosis.

Occupational therapy plays a unique role within the primary care setting. The discipline can also specialize toward specific diagnoses within the setting, including multiple sclerosis. However, there are limited resources available regarding occupational therapy's role within a primary care setting when treating individuals with diagnoses such as multiple sclerosis. Therefore, a manual to guide treatment and intervention within the primary care setting for individuals diagnosed with multiple sclerosis was created. This manual is developed specific to occupational therapy. The manual includes five main areas including, assessments, areas of occupation, person components, relative mastery reflection, and occupational therapy intervention. The occupational adaptation model guided the development of this manual and the treatment approach occupational therapists will be encouraged to follow when treating clients. Along with any product developed for use, there is potential for disruption of the application of this manual.



The factors that will influence the application of occupational therapists in primary care and the product developed may include the buy-in from other professionals. Advocacy of the occupational therapy profession is important. This will assist other health professionals in understanding the value of occupational therapy within the primary care setting. Another factor that will influence the application of this product is its usability. It will be important for this product to be used with ease, due to the high demand in a primary care setting (Dahl-Popolizio & Muir, 2017). This manual was created using occupational therapy jargon, which could make it difficult for other disciplines to understand the treatment provided to clients. The manual describes a majority of the concepts used, however, there are some concepts that may not be properly explained.

Throughout the process, the use of several terms and concepts are used. However, there are a select few that are primarily used during the entirety. First, the diagnosis of multiple sclerosis is used. Multiple sclerosis is a chronic progressive neurological disease (Bautista & Grossman, 2014) with an unknown cause (Ellis, Blackburn, & Bath-Hextall, 2013). However, it is known that it is an immune-mediated disorder that creates lesions across various locations within the central nervous system (Bautista & Grossman, 2014). Due to the progressive and chronic nature of this disease, occupational therapists are appropriately fit to treat individuals with this diagnosis.

Occupational therapy is another key concept used throughout this process. Occupational therapy is a client-centered profession focused on the component of 'doing' (Boyt Schell et al., 2014). Occupational therapists treat individuals through the use of occupations. They can implement this treatment in a variety of settings, one including

within the primary care setting. Primary care is an emerging field of practice in relation to occupational therapy, and can allow occupational therapists to focus on prevention. When considering the population of individuals with multiple sclerosis, primary care can be used to prevent secondary impairments such as pain, depression and fatigue (Boyt Schell et al., 2014). Therefore, occupational therapists provide preventative treatment within the primary care setting for individuals with multiple sclerosis.

To guide the development of a product, the occupational adaptation model was utilized. This theory is driven by the assumption that if the patient becomes more adaptive, then they will become more functional (Schultz, 2014). This is relatable to the population encompassing progressive neurological disorders, as patients can experience several episodes of deterioration, which they need to learn how to adapt to. Helping the patient adapt to new lifestyle changes will then increase his or her function and quality of life. The occupational adaptation model focuses on an individual's relative mastery, encompassing the person's sense of satisfaction, efficacy, and effectiveness (Cole & Tufano, 2008). These components can impact the person's functional ability and assist him or her in adapting to changes. Adaptation can create a higher quality of life and can prevent the need for treatment in the future. This is also completed through a interactive and collaborative approach between the patient and occupational therapist.

The chapters incorporated within this scholarly project are arranged to allow the reader to build knowledge and resources for use of the therapist and client manuals. Chapter two provides a literature review of concepts including multiple sclerosis, occupational therapy, primary care, and the relation amongst these three concepts. Chapter three includes a methodology of how the literature was utilized to develop the

product. Chapter four consists of a therapist and client manual for occupational therapists to treat individuals with multiple sclerosis within a primary care setting. Chapter five is a conclusion of the purpose of this project, limitations, future use, and recommendations for use of this product. At the end of this project is a list of references used throughout the entire process.

## **Chapter II**

### **Literature Review**

The health profession is one that incorporates several disciplines to create a successful treatment plan for various patients. Occupational therapy is one amongst this profession, and is involved in a wide variety of settings working with numerous populations and diagnoses. One popular diagnosis which occupational therapists work with is multiple sclerosis (MS). This is a diagnosis that seeks assistance from several different services for treatment. Therefore, patients would benefit from receiving services in an environment which incorporates a variety of disciplines. An environment that matches this description is primary care. There are many considerations to take into account to discover the potential for occupational therapy involvement with patients with MS in the primary care setting. First, therapists must have detailed education on the diagnosis, including symptoms, current treatment approaches, and common issues faced by this population. Therapists must also understand the history, focus and cost of primary care, including the ability for primary care to enhance client-centered care. Therapists are able to provide thorough treatment to their patients if they are updated on current knowledge related to the diagnosis and the setting of practice.

## **Population**

### **Multiple Sclerosis**

Multiple Sclerosis is a chronic progressive neurological disease impacting around 500,000 people in the United States with an age of onset commonly between 20 and 30 years old (Bautista & Grossman, 2014). It is unknown what the cause of MS is, however, it is known that there are a variety of factors that may lead to a diagnosis of MS (Ellis, Blackburn, & Bath-Hextall, 2013). MS is diagnosed with an understanding of the person's history of remissions and exacerbations, the sighting of at least two separate neurological abnormalities by clinical tests, test results, lesions seen on MRI, or other criteria depending on symptoms of the individual (Reed, 2014). MS is an immune-mediated disorder that creates lesions primarily within the white matter of the central nervous system (CNS), which the lesions lead to a variety of symptoms, varying based on the location and size of the lesion (Bautista & Grossman, 2014). Lesions occur in any area within the CNS, which consists of the brain and spinal cord, leading to potential back pain. Symptoms occur within the motor, sensory, and cognitive areas of the central nervous system (Tyszka, & Farber, 2010). These are all large areas within the body, and therefore demonstrates why MS leads to a wide variety of symptoms. It is found that MS begins with relapsing and remitting symptoms, and patients later experience symptoms focused toward the type of MS they have (Litchfield & Thomas, 2010).

MS is commonly known to have three separate types of the disease. These types are based on the symptoms, progression, and amount of relapses. Types of MS include relapsing-remitting, primary progressive, and secondary progressive. The most common type is relapsing-remitting, which there is severe deterioration with a slight recovery

between relapses (Bautista & Grossman, 2014). Relapsing-remitting is responsible for around ninety percent of individuals with MS and contains separate attacks, which individuals typically progress over days or weeks (Cree & Hauser, 2018). This type of MS mainly affects females. Symptoms most often include sensory disturbances, Lhermitte sign, motor weakness, optic neuritis, impaired coordination, and fatigue (Saguil, Kane, & Farnell, 2014). Lhermitte sign is described as tingling in the neck and down the spine (Saguil et al., 2014). Although patients may experience other symptoms, the ones listed above are the most common symptoms experienced by individuals with relapsing-remitting MS. With this type of MS, it has been found that following initial attacks, patients typically have a significant or complete recovery, but when the attacks continue, recovery becomes less noticeable. (Cree & Hauser, 2018). It has also been found that between relapses, or attacks, patients are generally known to be neurologically stable (Cree & Hauser, 2018). Studies have shown that patients with relapsing-remitting MS have about a two percent risk each year of developing secondary progressive, leading to the conclusion that most patients with relapsing-remitting will develop secondary progressive MS (Cree & Hauser, 2018).

Secondary progressive is the next most common type of MS and always begins as relapsing-remitting MS (Cree & Hauser, 2018). Secondary progressive is more common in females than males. Patients are typically diagnosed with secondary progressive MS following a continual decrease in functional ability (Litchfield & Thomas, 2010). Within this type of MS, there is a steady deterioration that is not related to attacks, and a risk for possible severe relapses (Bautista & Grossman, 2014). Due to the continual decline in function, patients with secondary progressive MS will have more fixed neurological

disability than those with relapsing-remitting MS (Cree & Hauser, 2018). Therefore, this type is more severe than relapsing-remitting MS. Patients who experience a continual decline do not have as long of a break to regain function. Therefore, the focus for these patients should be on maintaining functional ability.

The next type, primary progressive has steady deterioration throughout the entire course of an individual's disease with no relapses (Bautista & Grossman, 2014). Primary progressive MS affects about ten percent of individuals with MS and is even in distribution between males and females (Cree & Hauser, 2018). This type of MS often begins later in life, but has a quicker development of disability (Cree & Hauser, 2018). The faster disability is likely due to individuals experiencing more lesions on their spine (Litchfield & Thomas, 2010). Lesions in this region lead to a greater amount of problems with lower limb movement, bladder and bowel control, and sexual function (Litchfield & Thomas, 2010). Due to the characteristics within this type, it is likely this could be the most severe type of MS.

### **Common Issues within Multiple Sclerosis**

MS often leads to a variety of symptoms that can vary on a daily basis. The most common symptom individuals with MS experience is a low-energy fatigue (Bautista & Grossman 2014). The fatigue associated with MS is often extreme and can lead to increased difficulty to complete daily tasks. Other symptoms impacting individuals with MS may include, but are not limited to paresthesias, abnormal gait, bladder and sexual dysfunction, vertigo, nystagmus, fatigue, muscle weakness, and speech disturbance (Bautista & Grossman 2014). According to Cree & Hauser (2018), they often initially undergo sensory loss, optic neuritis, diplopia, ataxia, vertigo, and paroxysmal attacks. MS

can also cause symptoms including Lhermitte sign, pain, dementia, visual loss, facial palsy, impotence, myokymia, epilepsy, and falling (Cree & Hauser, 2018). Although these symptoms can impact several aspects within an individual's daily life, they can all lead to impaired mobility, resulting in falls. Each patient experiences different symptoms at various impact levels.

Fatigue is a major symptom that patients with MS experience. According to Cree & Hauser (2018), fatigue impacts ninety percent of patients with MS and is the most common reason for work-related disability in the MS population. Because of this, it is important for patients to be aware of the way fatigue impacts their personal body and find ways to improve their levels of fatigue. Fatigue can also be heightened due to high temperatures, dementia, sleeping problems, and an increased effort in accomplishing basic activities of daily living (Cree & Hauser, 2018). Therefore, it is important for patients with MS to be aware of their environmental temperature and attempt to stay away from the heat to decrease levels of fatigue. Fatigue levels can also be addressed by encouraging patients to promote a positive sleeping environment to allow adequate rest. Experiencing appropriate rest will decrease the impact of other symptoms related to MS.

Balance is another common issue related to MS that can be impacted by fatigue. Balance can be influenced by a variety of factors, including vision and motor issues. Many patients with MS experience blurred or temporary loss of vision, leading to dizziness and balance issues (Litchfield & Thomas, 2010). Along with blurred vision, patients with MS often experience optic neuritis, which can lead to diminished visual acuity, dimness, or a decrease in color perception (Cree & Hauser, 2018). Vision and balance are directly related to one another, and are viewed as serious factors in MS, as



patients with balance concerns experience a higher fall risk. Over ninety percent of patients who have MS suffer from an impairment in mobility (Ellis et al., 2013). This impairment can lead to a decrease in the patient's ability to complete daily activities. It has been found that about half of patients with MS fall each year (Ellis et al., 2013). Falls can lead to even further dysfunction in an individual's daily life. Therefore, it is important to determine a way to prevent falls.

Patients with MS can also fall due to a motor impairment. Patients often experience a weakness in their limbs, both upper and lower. According to Cree & Hauser (2018), this can lead to a decrease in strength, speed, and manual dexterity, as well as exercise-induced weakness. Not only are the limbs affected by weakness, but sensation also causes issues within the limbs. Some of these concerns include tingling within the limbs, loss of sensation, muscle stiffness or spasms, tremors, and pain (Litchfield & Thomas, 2010). Due to these symptoms being most common within the limbs, patients often experience increased difficulty with their motor functioning skills. Other motor functioning impairments include speech and swallowing difficulties, bladder dysfunction, and constipation (Litchfield & Thomas, 2010). These symptoms all impact a patient's daily life.

### **Implications in Lifestyle for Multiple Sclerosis**

The majority of patients with MS experience a dramatic lifestyle change upon diagnosis of this disease. This is due to the variety of symptoms patients experience, and their need to attempt to manage these symptoms to prevent further damage to their body. Patients need to manage symptoms related to fatigue, balance, motor impairment, and

their psychological and emotional well-being. Management of patients' symptoms is dependent on each individual and the impact these symptoms have on him or her.

The needs of those with MS varies dramatically and is dependent on several factors. However, there are some needs that are common amongst every patient with MS. It is important for patients with MS to practice a healthy lifestyle, including maintaining appropriate body temperature, avoiding excessive environmental temperature, practicing adequate nutrition and exercise, maintaining proper mental and emotional health by receiving sufficient rest and relaxation (Bautista & Grossman, 2014). These factors all help prevent relapses and further deterioration in patients with MS. Therefore, patients with MS experience benefit from health-promoting activities and chronic disease management (Tyszka, & Farber, 2010). These factors will help the patient improve his or her health through participating in activities that lead to an increase in quality of life. Additionally, health-promoting activities help prevent deterioration and reduce mobility function. It has been found that around half of patients with MS need a walking aid within fifteen to twenty five years following diagnosis of the disease (Snook & Motl, 2009). Therefore, maintaining adequate health is a large priority for patients who have MS to prevent further damage.

Psychological health plays a major role in an individual's life with MS. Both depression and anxiety are common in patients with MS (Jelinek, 2009). These can lead to an even larger impact on the daily life of those with MS, as they have to manage these symptoms. It has been found that stress and psychological health directly correlate to MS exacerbations (Jelinek, 2009). Because of this, patients need to maintain awareness of their mental and emotional well-being to prevent further progress in the disease.

## **Current Treatments for Multiple Sclerosis**

Currently, there are several medications used as treatment techniques for people who have MS. Medications are categorized based on the symptom it treats.

Corticosteroids are often used for severe attacks to help decrease inflammation and increase nerve conduction (Bautista & Grossman, 2014). This medication is often used for a short period of time, whereas there are others used long-term. There are injectable medications which can help benefit patients with the relapsing-remitting form of MS prevent further relapses by decreasing the amount and size of lesions (Carrithers, 2014). It has been found that Interferon- $\beta$ , an immunization, has reduced the number of relapses by around twenty nine percent (Carrithers, 2014). Oral medications can also be effective in reducing relapse rates. However, there are more side effects related to oral medications, and they have been found to reduce relapses by eighteen percent to twenty three percent in patients with relapsing-remitting MS (Carrithers, 2014). There are multiple factors that help determine the most appropriate pharmacological treatment for patients. Therefore, it is uncommon for multiple patients to receive the same benefit from the same medication. Additionally, medications are not entirely effective for patients, therefore patients need to participate in other treatment strategies.

Many patients with MS receive treatment in a pharmacological form as well as in a physical form. Exercise training is a treatment strategy commonly used for patients with MS. Studies have proven that exercise training is beneficial as a behavioral strategy as MS progresses (Snook & Motl, 2009). However, it remains unclear as to how exercise training impacts walking mobility for individuals with MS (Snook & Motl, 2009). This is likely due to the varied effects resulting from the type of MS. Exercise training improves

the physical aspect of MS, including balance, as well as the mental and emotional aspect. This can lead to an improvement for each patient as it can improve the patient's quality of life. Another study found that exercise can lead to an increase in function and fitness for those with minimal MS (Tyska, & Farber, 2010). The same study found those with more severe MS, exercise could not have the same benefits (Tyska, & Farber, 2010). Therefore, exercise is appropriate for individuals with less severe MS.

Due to the portion of patients with MS who suffer from psychological conditions, it is beneficial for patients to receive psychological therapy. This does not only include pharmacological strategies, but can also include counseling or other therapies. Jelinek & Hassed (2009), state "undertaking psychosocial therapies as a routine part of their management plan may actually improve their clinical outcome" (p. 58). Therefore, this is a part of the multidisciplinary treatment that patients with MS need to receive. Additionally, it is important to ensure that this treatment, amongst all other treatments, is personalized to each patient to allow him or her to receive the greatest benefit.

Based on the given treatment strategies, patients with MS can receive the most benefit from participating in multidisciplinary treatment. Specifically including three main concepts; pharmacological strategies that reduce relapse rates, steroids to help with recovery as a result of relapses, and therapy to manage symptoms (Ellis et al., 2013). These treatments are all important to help patients with MS live a better quality of life. A large majority of the current treatments for MS incorporate a lifestyle change, as patients now have to include the treatments into their daily life.

## **What is Primary Care**

### **History**

American Occupational Therapy Association (2018), defines primary care as “the provision of integrated, accessible health care services by clinicians who are accountable addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community”.

Historically, in primary care, patients are scheduled for short visits with the physician in a small exam room. Nearly half of these visits are for acute medical needs; the remainder are for preventative care of chronic conditions management. (Dahl-Popolizio & Muir, 2017)

It is believed that primary care has existed since the 1920s in the United Kingdom (Starfield, Shi, & Macinko, 2005). Primary care has transitioned into several countries and has altered its services in many ways over the past one hundred years. Currently in the United States, there are more specialized physicians than primary care physicians, leading to a lesser quality health care systems (Starfield et al., 2005). This is something that can be fixed by refocusing the attention on primary care for incoming physicians. Primary care can lead to a lower health care cost, greater access to health services, and greater equality in health care amongst the entire population (Starfield et al., 2005). Therefore, primary care is beneficial for the population.

### **Client-Centered Care**

Primary care enhances client-centered care by focusing on each individual’s needs and creating referrals for further treatment as needed. Studies have proven that primary care allows physicians to gain awareness in the patient’s health and reduce the rate of

mortality and chronic health conditions (Starfield et al., 2005). This demonstrates that primary care can help to maintain and improve the health of individuals seeking services. Additionally, it has been found that the greater the ratio of primary care physicians to patients, the better the outcomes (Starfield et al., 2005). With this, primary care physicians and staff would have an increased amount of time to treat each patient, creating a more client-centered atmosphere.

There are many components that contribute to the overall satisfaction and efficiency of health care in a primary care setting. It is important for health care professionals to be aware of these components in order to increase satisfaction from their clients, and increase outcomes. According to Methley, Chew-Graham, Cheraghi-Sohi & Campbell (2017), there are three main factors that contribute to the overall satisfaction and well-being for individuals with multiple sclerosis and primary care services. These three concepts consist of access to primary care, positive interpersonal interactions, and continuity of care.

According to Methley et al. (2017), patients with MS have reported lengthy waits and frequent rearrangement of appointments resulting in frustration. Integration of occupational therapists would increase the access to primary care services for these individuals. Additionally, continuity of care is an important component in client-centered care due to the chronic nature of the disease. There are constant changes for an individual diagnosed with multiple sclerosis, some which may be embarrassing from a patient's perspective. Primary care professionals need to make close relations with patients in order to increase trust and honesty. Occupational therapy is a great profession that directly fits the needs of individuals with multiple sclerosis within primary care.

Occupational therapy can make a positive mark on primary care services by being a dependable and trustworthy trained profession that will enable hope and independence for individuals with multiple sclerosis.

Multiple sclerosis is a chronic condition that is constantly changing, requiring services to be a continuum. Throughout the different stages of multiple sclerosis, there will be different demands and changes within the individuals life. Therefore, goals and treatment will be changing throughout the therapeutic process. Occupational therapists use client-centeredness through this process in order to facilitate change, increase independence, and increase well being of the individual (Boyt Schell, Gillen, Scaffa, & Cohn, 2014).

### **Primary Care Focus**

Primary care is known amongst several populations across the United States. When people think of primary care, they often think of their primary care physician whom they visit for their health care needs. Primary care has four main features that it provides to patients. These include, first-contact access for each new need, extended person-focused care, comprehensive care for the majority of health needs, and coordinating care when it must be obtained elsewhere (Starfield et al., 2005). These features ensure patients will receive the services that will most benefit his or her needs.

### **Primary Care Cost**

Health care systems and costs are constantly changing in the medical world. Current reforms to the health care delivery systems emphasize paying for quality, high value care rather than volume and providing better care that leads to healthier populations (Centers for Medicare and Medicaid Services, 2015). It is estimated that the United States

spend three point two trillion dollars per year in healthcare dollars (The US Washington Post, 2016). The driver of these costs include chronic disease that are often preventable (The US Washington Post, 2016). The number of hospital visits are increasing due to the nature of chronic diseases. Continuous changes in chronic diseases, cause patients to return to their health professional for services. These factors are inflating healthcare costs and decreasing quality care for individuals.

Occupational therapy is a profession that can positively influence the healthcare system by providing cost-effective interventions that address many of the United States' needs and wants throughout various populations. Historically, primary care was assigned to physicians, physicians assistants, and nurse practitioners (Dahl-Popolizio & Muir, 2017). In the past, there was a sequence of steps an individual had to take when participating in primary care services. The patient actively visits a physician when symptoms start rapidly evolving and negatively influencing everyday activities (Dahl-Popolizio & Muir, 2017). This type of pattern leads to high costs in medical services and burnout from primary care practitioners. Occupational therapists can be the change in the primary health care system to reduce costs and intervene during the prevention period of an individual's lifespan. Occupational therapists will be the active face of health care prevention, which will change the way that health care is provided.

There are many factors that influence the demand and outcomes of the health care system in the United States. These factors include age-related decline, falls prevention and many others. The overall health of the United States population is based on demographics, lifestyle choices, access to health care services and quality.



## **Age-Related Decline**

As the population of the United States declines, overall physical health, mental well-being and functional ability decline, which negatively influences the cost of healthcare services. Thankfully, these factors are impacted by controllable lifestyle choices such as diet, exercise, lifestyle, social support, habits, and daily routine (The US Washington Post, 2016). Participating in these active choices has proven to result in a delay of age-related changes.

## **Falls Prevention**

Falls represent the leading cause of injury related death among older adults and had an estimated direct medical cost of 34 billion dollars in 2013 (Centers for Disease Control and Prevention, 2015). Research has shown that occupational therapy interventions save money by reducing the rate and risk of falls (Gillespie et al., 2012). These interventions also significantly reduce mortality rates in older adults (Jutkowitz, 2012). It has been found that about half of patients with MS fall each year (Ellis et al., 2013). Therefore, integrating occupational therapists into a primary care setting, will result in a beneficial cost to healthcare services.

## **Primary Care and Multiple Sclerosis**

### **Primary Care Benefits for Patients with MS**

Patients with MS would undergo great benefit from receiving primary care services due to the wide variety of symptoms and the lack of predictability within the disease. Primary care provided to patients using a multidisciplinary approach would allow each patient to receive services individualized to his or her specific needs. Additionally, primary care helps patients prevent the need for more intensive treatment in

the future as it addresses the key issues immediately. Primary care treats these issues as soon as they are identified. If the patient requires services outside of primary care, the primary care provider refers the patient to these services. This ensures the patient receives the correct service.

Patients with MS receive similar services from primary care as any other patient would. However, there have been studies that prove patients with MS often are unsure what to tell their primary care physician, due to a lack of education about their diagnosis (National Multiple Sclerosis Society, n.d.). With this, patients need to be educated on their diagnosis so they are familiar with their needs. According to the National Multiple Sclerosis Society (n.d.), a primary care physician focuses on co-morbidities and complications associated with the patient's diagnosis. Patients often partake in recommended screenings and receive immunizations at their primary care office (National Multiple Sclerosis Society, n.d.). If a patient is receiving these services from his or her primary care physician, it is likely the treatment can lead to a decreased severity of MS symptoms. Primary care physicians assist patients with MS with treatments related to their diagnosis rather than solely focusing on co-morbidity concerns.

Patients with MS can benefit from having a primary care physician as they are able to have a reliable resource to ask questions. Primary care providers who are not educated in MS are unable to correctly treat patients. Providers need education to treat symptoms, make referrals, and understand how medications are used for various symptoms (National Multiple Sclerosis Society, n.d.). Primary care providers treat several diagnoses, making it difficult to focus on one specific diagnosis. Allowing a

patient to receive services from a provider specialized in MS will help the patient receive effective treatment and education.

### **Current Treatment Approaches for Individuals with MS within Primary Care**

Treatment for patients with MS in primary care is often categorized based on the type of treatment provided. Common categories include treatment of acute attacks, treatment with disease-modifying agents, and symptomatic therapy. When treating acute attacks, patients frequently receive multidisciplinary treatment. This can include glucocorticoids, physical therapy, and occupational therapy. Glucocorticoids are typically used to treat both the patient's first attack and acute attacks (Cree & Hauser, 2018). Additionally, physical therapy and occupational therapy can work collaboratively with the patient to improve fine motor skills and mobility (Cree & Hauser, 2018). Therefore, acute attacks are most often treated using pharmacological strategies and therapeutic approaches.

Oftentimes, patients with relapsing MS and secondary progressive MS receive treatment through disease-modifying agents. Cree & Hauser (2018), have found there to currently be over one dozen agents approved to treat relapsing MS. Therefore, it is likely the patient's physician will determine the most appropriate agent based on multiple factors. Cree & Hauser (2018), listed the following medications to be beneficial in reducing the attack rate in relapsing MS and providing benefit related to the severity of the disease. These medications include, glatiramer, fingolimod, dimethyl fumarate (DMF), and natalizumab (Cree & Hauser, 2018). All the medications listed have been found to be effective for treating individuals with MS.

It is common for patients with MS to partake in therapy in addition to receiving pharmacological treatment. Patients typically receive therapy related to their own personal symptoms, known as symptomatic therapy. However, patients will also receive education on general strategies used amongst most individuals with MS to decrease the possibility of a relapse. These strategies can include, encouraging a healthy lifestyle through maintaining an optimistic outlook, having a healthy diet, and regularly exercising as tolerated (Cree & Hauser, 2018). Education on these strategies can be provided by several different disciplines, including nursing, physicians, occupational therapists, physical therapists, dietitians, and counselors.

Individualized therapy can be provided for patients dependent on their unique symptoms related to MS. Specifically, therapy can be provided for symptoms including ataxia, spasticity, weakness, pain, bladder dysfunction, depression, fatigue, and heat sensitivity (Cree & Hauser, 2018). Therapy for the symptoms listed varies based on each patient, however, there can be common treatment strategies for individualized symptoms. Although it has been found that ataxias are often intractable, studies have also shown that wrist weights, a thalamotomy, and deep-brain stimulation may be beneficial to the patient experiencing ataxia (Cree & Hauser, 2018). Spasticity is currently treated through receiving physical therapy and some medications, regular exercise, and stretching (Cree & Hauser, 2018). Only one treatment strategy was identified for weakness, bladder dysfunction, and depression. Weakness can be treated through potassium channel blockers, bladder dysfunction treated with urodynamic testing, and depression treated through the use of antidepressants (Cree & Hauser, 2018). Patients who experience pain can receive anticonvulsants, antidepressants, and antiarrhythmics (Cree & Hauser, 2018).

If none are beneficial, patients should be referred to a comprehensive pain management program (Cree & Hauser, 2018). Heat sensitivity is easily treated independently by the patient. This is done by heat avoidance, air-conditioning, or cooling garments (Cree & Hauser, 2018). Finally, fatigue can be treated through a variety of strategies. Some include assistive devices, assistance within the home when completing activities of daily living and instrumental activities of daily living, and management of spasticity (Cree & Hauser, 2018).

### **Current Treatment Team within Primary Care for Patients with MS**

Primary care services have been provided for several years. Historically, many patients receive their primary care services from a physician. In these services, patients have about half of their visits designated to acute care needs, whereas the rest is left for chronic conditions and preventative care (Dahl-Popolizio & Muir, 2017). Patients with MS typically receive their primary care services from their physician and nurse. Many patients with MS receive primary care services annually, unless an issue arises (Morrison & Geisser). This relates to the focus area in primary care of first-contact access for each new need. A large portion of the services provided within primary care include education and disease-modifying agents (Oliver, 2009). This often leaves the patient with little knowledge on interventions to attempt to improve his or her symptoms and quality of life. Patients with MS would benefit if they received further treatment. Additionally, those with MS would have an increased quality of life if they received primary care services in a multidisciplinary team format (Saguil et al., 2014).

Currently, the primary care provider could include a medical doctor, doctor of osteopathic medicine, nurse practitioners, and physician assistants (Dahl-Popolizio &

Muir, 2017). These providers coordinate the care of each patient, including making referrals to specialized disciplines, as well as monitor the patient's overall health. Within this aspect, primary care providers fulfill extended person-centered care and coordinating care when it must be obtained elsewhere. Primary care providers require an educational background in several diagnoses, and it is therefore beneficial for patients to have a primary care provider who is specialized in their specific diagnosis.

## **What is Occupational Therapy**

### **History of Occupational Therapists**

Occupational therapy is a client-centered profession that works with individuals across the lifespan. The profession of occupational therapy revolves around the importance of doing (Boyt Schell et al., 2014). Human beings have a natural instinct of doing, it is what makes each individual unique. The purpose of occupational therapy is to participate in occupations that are meaningful. There is a direct need of the profession of occupational therapy in primary care services.

The history of the occupational therapy profession is a unique transformation and highly influences the values of occupational therapy practitioners in current practice. The history of occupational therapy has been influenced by world events, personalities and social movements (Boyt Schell et al., 2014). Examples of these include, but are not limited to, industrialization, women's rights, wars, economic downturns, health care legislation, and the digital age.

The profession started around the 1800s when the moral treatment pre-paradigm was used in order to facilitate participation in daily activities contributing to the overall wellness of an individual's health. Themes that developed throughout this time led to

occupational therapy practice in mental health institutions. Individuals with mental health illnesses resulted in an increase in humane treatment and client-centered practice. The focus on the importance of participating in daily activities would last until the end of the nineteenth century (O'Brien & Hussey, 2018).

The beginning of the twentieth century brought the paradigm of occupation, which would facilitated the interrelatedness of mind, body and the environment to engagement in occupation. Reconstruction aids were introduced around the year 1917, who worked alongside nurses to implement handicrafts, vocational skills, and occupation based activities in order to engage the mind and hands of patients (O'Brien & Hussey, 2018).

A shift was implemented around the 1940s and 1950s, which focused on internal mechanisms of the body. Occupational therapy practitioners became involved in physical disabilities settings where neurological and intrapsychic components contributed to practice. Around this time, World War II highly influenced the need for occupational therapists in military hospitals. Occupational therapy provided services that consisted of recreation, leisure, and activities that engaged the mind. It is said that many formative concepts of the profession of occupational therapy had been “forgotten” during this time due to the switch in focus on the biomechanical model and physical dysfunction (O'Brien & Hussey, 2018).

Modern day themes resulted in a return to formative ideas and understanding the value of occupation is one's daily life. The twenty first century was a time of celebration, as the profession of occupational therapy continued to survive for 100 years. The Centennial Vision was soon created, “We envision that occupational therapy is powerful,

widely recognized, science driven, evidence-based, with a globally connected and diverse workforce meeting society's occupational needs" (The American Occupational Therapy Association, 2017).

Through the twenty first century, the profession of occupational therapy has continued to become more specialized. Areas such as prevention and wellness, vocational work programs, assistive technology and other new areas of practice soon emerged as the need for services increased with a wide variety of populations (O'Brien & Hussey, 2018).

### **Role of Occupational Therapy in Primary Care**

Occupational therapists work with individuals with chronic conditions to increase independence and quality of life through the participation of occupations. Occupational therapists play a unique role in this service by addressing the patient as a whole, considering factors such as contextual environments, habits, roles, routines, and other performance factors (Boyt Schell et al., 2014). Primary care is an emerging practice area for occupational therapists. However, despite occupational therapists unique skill sets, there are low numbers of occupational therapists in primary care in the United States. Occupational therapists are gradually being incorporated in primary care in other countries such as Canada, the United Kingdom and Australia (Dahl-Popolizio & Muir, 2017).

Primary care consists of prevention by catching the diagnosis early in the life continuum. When considering the population of individuals with multiple sclerosis, primary care can be used to prevent secondary impairments such as pain, depression and fatigue (Boyt Schell et al., 2014). Occupational therapists may use education groups, focus groups and other educational training to promote prevention of the disease through



healthy routine and habits. Health promotion in the areas of diet and exercise is implemented within this stage to increase prevention (Metzler, Hartmann, & Lowenthal, 2012). Management of medication and lifestyle choices are important aspects of prevention that occupational therapists can address. Occupational therapists can educate the at risk populations about the importance of how lifestyle choices impact their current and future occupational performance and overall well-being. Additional prevention strategies that occupational therapists can implement into the community can include safety and fall prevention, promotion of community integration, and assurance of access to community resources (Metzler et al., 2012).

The secondary approach of primary care focuses on direct intervention and treatment of the already existing diagnosis (Boyt Schell et al., 2014). If the disease is not caught early enough, the individual may have been diagnosed with multiple sclerosis, or developed symptoms that are parallel with the diagnosis. At this point, it is the occupational therapist's role is to address these individuals through a secondary approach. The secondary approach aims to reduce the impact of the disease that has already occurred. The function of this approach is to directly intervene the symptoms the individual is experiencing while simultaneously addressing how the diagnosis is influencing occupational performance and overall quality of life (Boyt Schell et al., 2014).

The tertiary approach comprises of management of the chronic disease. This approach focuses on providing patients with relief from symptoms, pain and stress of a serious illness regardless of the diagnosis (Boyt Schell et al., 2014). Multiple sclerosis, is a chronic disease which can bring many challenges through the individual's journey of

diagnosis. Typically, when an individual is diagnosed with multiple sclerosis, neurological deficits are vast, with remissions and exacerbations gradually producing disability (Reed, 2014). Therefore, management of a chronic disease is necessary due to the changing nature.

A magnetic resonance imaging (MRI) of the central nervous system lesions and other additional testing may occur to inform the patient and any healthcare professional involved of the prognosis and management of the disease (Reed, 2014). The most common symptom individuals with MS experience is low-energy fatigue (Bautista & Grossman 2014). It is common at this stage that occupational therapists promote fatigue management for individuals with multiple sclerosis to promote occupational performance. For example, a therapist may provide an energy conservation management schedule to promote healthy habits in the individuals routine.

Considering the population of multiple sclerosis, occupational therapists are specially trained to intervene and hold a role in primary health services for individuals with chronic medical conditions. Multiple sclerosis is a complex diagnosis that consists of many variables that impact one's occupational performance and quality of life (Reed, 2014). The complexity of the diagnosis can lead to physical, cognitive, and psychosocial components. A diagnosis of multiple sclerosis commonly leads to symptoms of decreased muscle strength, urinary frequency or urgency, fatigue, psychosocial issues such as depression, anxiety, and cognitive impairments such as difficulty with memory (Reed, 2014). Primary care will help treat these symptoms before they worsen, increasing the patient's quality of life (Clifford & O'Brien, 2018).

## **Value of Occupational Therapists**

The Occupational Therapy Practice Framework (OTPF) is a document that guides the delivery of the occupational therapy profession through a domain and process. The OTPF describes the dynamic relationship of domains in the occupational therapy profession such as occupation, patient factors, performance skills, performance patterns, and context or environment (American Occupational Therapy Association, 2014). All of these factors are treated as equal and influence how therapy services are delivered (American Occupational Therapy Association, 2014). The process of the OTPF describes the components of services delivered to the patient such as the evaluation, intervention, and targeting of the outcomes (American Occupational Therapy Association, 2014). All of these components in the occupational therapy process makes the profession unique, client-centered and evidence based.

Occupational therapy is a unique, holistic (integration of mind, body, spirit), and client-centered profession that enables independence through treatment of occupations (American Occupational Therapy Association, n.d.). “Where science, creativity, and passion collide” (The American Occupational Therapy Association, 2017). Occupations in the profession of occupational therapy refers to the daily tasks one participates in everyday (Boyt Schell et al., 2014). According to the American Occupational Therapy Association (2017), there are eight occupations that occupational therapists treat in practice. These occupations consist of: ADLs (activities of daily living), IADLs (instrumental activities of daily living), education, work, sleep, leisure, social participation and play. The patient receiving therapy is the agent of change, and actively

participates and influences therapy outcomes with the facilitation of the therapist (Grajo, 2017).

Occupational therapists serve a wide variety of populations, from neonatal care to hospice care near the end of life (Boyt Schell et al., 2014). To be qualified to provide services for these populations, occupational therapists must acquire hard and soft skills to provide the best care. These skills include but are not limited to communication, adaptation, observation, written and technology skills. Additionally, there are a wide variety of settings that occupational therapists can work in such as mental health, physical dysfunction, community, prevention and wellness, productive aging, work industry and other areas of practice (Boyt Schell et al., 2014).

### **Occupational Adaptation as a Guide**

Occupational therapy is a profession that is strongly driven through theory. According to Cole & Tufano (2008), “theory helps describe, explain, and predict behavior and/or the relationship between concepts or events” (p. 55). Therefore, theory helps guide the practice of occupational therapy by allowing therapists to utilize what they already know when treating a patient. A variety of theories have been developed to help form the role of occupational therapy within a number of practice settings. Theory includes models and frames of references, which both work as a basis to practice. The Occupational Adaptation (OA) model developed by Schkade and Schultz in 1992, has some unique aspects that are applicable to practice within the primary care setting.

Occupational adaptation describes the dynamic relationship and integration of two global components that have been presented in the profession of occupational therapy for decades (Schultz, 2014). The theory is driven by the assumption that if the patient

becomes more adaptive, then they will become more functional (Schultz, 2014).

Adaptation is a particularly important aspect to consider for individuals with MS due to the progressive nature of the disease. MS can occur across the lifespan, and roles are constantly changing throughout the lifespan. Therefore, adaptation is necessary for individuals to maintain independence. Additionally, patients with MS are able to have more independence when following the OA model, as the patient is responsible for making adaptations. This occurs through a trial and error process, which the patient is constantly evaluating what worked, what did not work, and what he or she could do different in the future (Schkade and Schultz, 1992). Trial and error is also a component of internal adaptation, another aspect of the occupational adaptation model (Schkade and Schultz, 1992).

Occupational adaptation is defined as the extent to which a person's perceived identity corresponds to his or her competence performing occupations of personal importance in a relevant environment; it is an ongoing process (Lexell, Iwarsson & Lund, 2011). This can correlate with the mental health components related to MS. Many patients with MS frequently experience anxiety and depression. OA is a model that addresses these components through intervention, allowing the individual to rate his or her level of efficiency, effectiveness, and satisfaction. These three components make up an individual's relative mastery (Cole & Tufano, 2008). Relative mastery can influence the individual's functional ability and adapt to changes. Therefore, it is important to address these components to ensure the patient is successful and does not allow mental health concerns to lead to a relapse. Patients would receive benefit from tracking the components of their relative mastery and reflecting on ways to improve their mastery

levels. Due to the nature of this model, OA is appropriate for the primary care setting, as patients are learning ways to improve their quality of life through adaptation. Patients are provided with tools necessary to assist them in preventing more issues. Adaptation can prevent further disability, which can decrease the need for additional specialized treatment.

There are six main principles of the OA model that influence how it is used functionally in practice (Grajo, 2017). The principles are described and related to an individual with MS below.

1. “The person is an occupational being who has a desire to master his/her environment. A person manifests this through participation in occupations” (Grajo, 2017, p. 291).

The first principle by Dr. Mary Reilly (1962), asserts that individuals have a desire to master his/her environment. People innately want to participate in occupations by doing which influences the individuals habits, roles, and routines. Individuals participate in mastery of environments through occupational engagement in various contexts throughout the lifespan. The desire to master occupations is an internal process which the individual uses their cognitive, sensorimotor and psychosocial skills to adapt to occupations that are meaningful to him or her (Grajo, 2017).

Individuals diagnosed with multiple sclerosis are occupational beings and have the desire to master the environment around them. Commonly, individuals with multiple sclerosis experience a process of trial and error to determine what strategies are most effective regarding participation in meaningful occupations (Lexell et al., 2011).

Adaptation is a constant and dynamic factor that these individuals use on a daily basis, which is parallel with the component of the desire for mastery.

2. “The occupational environment demands mastery from the person. These demands enable or restrict successful participation in occupations” (Grajo, 2017, p. 291).

Contexts of occupation are interrelated conditions and variables within and surrounding the person that influence occupational participation (American Occupational Therapy Association, 2014). There is a constant demand for mastery from the environment that influences how an individual performs in context. The occupational environment asserts its demand for mastery from people through role demands and expectations (Grajo, 2017). The person contains the press for mastery of the environment. The demands and the ability of the individual to adapt these demands influences the person and enables or restricts the participation in occupations.

Individuals with multiple sclerosis experience occupational adaptation second principle by encountering the internal press for mastery and demand from the environment. When an individual is diagnosed with multiple sclerosis their habits, routines, roles, and expectations do not change from their previous demands without a diagnosis. Therefore, individuals adapt to master the environment to preserve the formerly capable sense of self (Lexell et al., 2011).

3. “The person’s level of mastery and the environment’s level of demand for mastery create occupational roles and role demands or expectations, occupational challenges, and responses from the person. Collectively, these roles, role demands, challenges, and responses are called the “press for mastery”” (Grajo, 2017, p. 291).

Fulfillment in roles are meaningful to individuals with and without a disability. When people perceive that they are able to fulfill important occupational roles, they feel a sense of mastery and competence (Grajo, 2017). Therefore, the person's level of mastery of the environment creates a response from the individual regarding their satisfaction of these factors.

When using occupational adaptation, patients balance personal identity and competence throughout various phases of life to create a press for mastery (Lexell et al., 2011). This enables individuals to be independent through adaptation in occupations.

4. "To navigate the press for mastery, the person goes through the normative and developmental process of occupational adaptation" (Grajo, 2017, p. 291).

Occupational challenges are typical within any individual's daily life. Through occupational adaptation, it is necessary for people to identify these occupational challenges and ways to create change (Grajo, 2017). The person must be aware of his or her capabilities to have an effective way to overcome challenges. Through occupational adaptation and occupational challenges, individuals determine their personal relative mastery, including efficiency, effectiveness, and satisfaction (Grajo, 2017). Therefore, occupational adaptation incorporates a psychological component into its model.

Adaptation is said to be ongoing and dynamic for individuals with chronic diseases (Lexell et al., 2011). MS is included in this, and it is important for individuals to create an adaptation plan to assist with determining an occupational fit. This will enable individuals to determine a typical adaptation process throughout their course of MS. Patients with MS will benefit in this area if they maintain a positive attitude, as it will assist them toward relative mastery.



5. “During participation in occupations within an occupational environment, a person may experience an occupational performance breakdown. The person may respond adaptively or dysadaptively to a performance breakdown” (Grajo, 2017, p. 292).

The test of a person’s occupational adaptiveness is when he or she experience a performance breakdown during occupational performance and participation (Grajo, 2017). A method that individuals with multiple sclerosis may use includes avoiding occupations that may result in failure (Lexell et al., 2011). Many individuals allow others in their environment to impact the way they adapt to their environment, which can lead to either a positive or negative impact (Lexell et al., 2011). This can include individuals with MS, especially if the individual is living with others. Because of this, when using the occupational adaptation model, it is important to be aware of the patient’s motivation level to indicate his or her ability to assert personal needs and respond appropriately to any performance concern.

Teaching alternative methods during an occupational performance breakdown is essential for the individual to learn from the therapist. These may include assistive devices to increase adaptation and occupational performance (Lexell et al., 2011). Some individuals have reported experiencing a decrease in motivation and interest to use assistive devices due to the stigma associated with one’s disability. It is important for the therapist to help the patient overcome the feeling of stigma.

6. “The most important role of the OT is to elicit an adaptive response from the client. The OT also must enable the client to participate in occupations, facilitate the environment, and use occupations to empower the occupational adaptation process” (Grajo, 2017, p. 292).

When occupational therapists use the OA model it is important to enable the patient to be the agent of change throughout the treatment process, facilitate the environment to make the patient as successful as possible, and increase the patient's adaptive capacity, relative mastery and developing readiness skills for occupations the patient finds meaningful. Occupational therapists must work in a client-centered manner, which they identify where in the occupational adaptation process their patients are and make recommendations as appropriate (Lexell et al., 2011). Client-centeredness can also assist occupational therapists in supporting the patient's sense of self in the present and future to enhance occupational adaptation (Lexell et al., 2011).

### **Relation amongst Multiple Sclerosis, Primary Care, and Occupational Therapy**

Primary care providers could lack the fulfillment of the focus areas of comprehensive care for the majority of health needs due to their broad focus area. Occupational therapists could fill the gap and fulfill a specialized role. Research has proven that primary care providers have displayed interest in allowing occupational therapists to join the primary care team, and occupational therapists are in turn confident in becoming members of the team (Dahl-Popolizio & Muir, 2017). It has however been found that the main reason occupational therapy is not common in the primary care setting is due to the lack of knowledge from the referring primary care provider (Dahl-Popolizio & Muir, 2017). Occupational therapists could assist in this setting by addressing the impact the diagnosis has on daily activities and providing educational material related to the diagnosis.

Occupational therapists have the skills in providing assessment and treatment for physical dysfunction, behavioral and mental health, and the clinical thinking skills to

work with individuals across the lifespan (American Occupational Therapy Association, 2014). These attributes contribute significant value to the overall healthcare team and would positively contribute to the value of primary care for individuals with multiple sclerosis. Occupational therapy services are client-centered, meaning the patient is the number one priority throughout the entire occupational therapy process. The occupational therapy profession gives individuals hope and independence through the use of meaningful occupation during treatment. Addressing daily occupations and patient motivation has been the basis of occupational therapy for over one hundred years. (Dahl-Popolizio, Manson, Muir & Rogers, 2016).

Occupational therapists are equipped to address the whole person in a primary care setting for individuals, groups, and populations (Roberts, Farmer, Lamb, Muir & Siebert, 2014). Occupational therapy practitioners are well prepared to serve individuals in a primary care setting by addressing needs of the individual across the lifespan, particularly those with or at risk for, one or more chronic conditions (Roberts et al., 2014). Occupational therapy practitioners have distinct knowledge of the significant impact that habits and routines have on individual's health and wellness will make the profession's own unique contribution to primary care settings. The improvement of one's overall wellness in a multitude of populations and delivery of appropriate treatment requires a mindful and strategic profession. Occupational therapist's role in primary care services addresses how the impact of occupation influences overall well-being and independence. The role of how occupational therapists function in primary health care services can be explained by breaking up three distinct types of health care service approaches, including primary, secondary, and tertiary care.

Throughout each stage, it is important that occupational therapists consider how family, friends and community relationships are either hindering or supporting the individual's overall health and well-being. Multiple sclerosis tends to bring on psychological symptoms such as depression, low self-esteem, anxiety and loss of self which impacts overall wellness (Reed, 2014). It is important that occupational therapy practitioners view the individual holistically and address a multitude of factors to treat the patient as a whole (O'Brien, & Hussey, 2018).

In conclusion, occupational therapy practitioners need to be integrated into the primary healthcare setting. There is a direct need for a development of a primary care program that will include occupational therapists into the multidisciplinary team within this setting. Occupational therapists have the skills, attributes, and core values to make a difference in primary healthcare and in individual lives that this profession comes across. There is a need for a product which demonstrates the unique role of occupational therapy in working with patients with multiple sclerosis.

**CHAPTER III**  
**METHODOLOGY**  
**Research Gathering**

The literature review influences the product by setting the ground knowledge that indicates the symptoms, needs, and occupational performance issues that are often experienced from an individual diagnosed with multiple sclerosis (MS). It describes the types of MS and current treatments used for this disease. Primary care was also described, including the history and traditional treatment within this setting. The literature review supports the hypothesis that occupational therapy is a relevant discipline within the primary care setting. Occupational therapy will implement interventions focusing on prevention, including the prevention of pain, fatigue, and depression (Boyt Schell et al., 2014). Occupational therapists can also implement safety and fall prevention, the promotion of community integration, and assurance of access to community resources (Metzler et al., 2012). Therefore, a product including the role of occupational therapy within primary care and treating individuals with MS was created.

The need for the development of the product was based on a lack of clinical guides for occupational therapists treating individuals with multiple sclerosis in a primary care setting. Research was completed to determine appropriate background information on the topics of primary care, multiple sclerosis, and occupational therapy. This information was used to educate the client and therapist, and to develop an intervention

guide. Research was completed through the University of North Dakota's Harley E. French library, and the American Journal of Occupational Therapy (AJOT). Databases within the library that were used include CINAHL and PubMed. Common search terms used within these databases included, 'primary care', 'occupational therapy', 'multiple sclerosis', 'treatments in primary care', 'occupational adaptation model', 'multiple sclerosis treatments' and a variety of combinations using 'AND' with two search terms. Articles were selected based on the inclusion of the above search terms, the inclusion of the multiple sclerosis population, date of publication (within the past fifteen years), occupational therapy relevancy, primary care relevancy, and any other relevant treatment for this population.

Initially, twenty articles were reviewed related to this topic to serve as a foundation for further investigation on topics relevant to this project. These articles lead to common findings of background information on each topic including, MS, primary care, and occupational therapy. Literature review findings substantiate a lack of occupational therapy treatment resources for individuals with MS within primary care. Along with the use of scholarly articles, a variety of occupational therapy textbooks also contributed to the findings.

A client guide was created that includes educational components and reflective journaling. The Occupational Adaptation (OA) model was used to guide the treatment process. The impact of balance issues and fatigue are highlighted along with methods the therapist can use to treat these symptoms.

The results of the literature review showed the two most common symptoms of MS to be fatigue and balance concerns (Cree & Hauser, 2018). It was also found that

many individuals with MS are not fully educated on their disability, and are unsure what to share with their healthcare provider (National Multiple Sclerosis Society, n.d.). Additionally, many individuals with MS experience ongoing progressive symptoms, requiring occupational therapy services throughout the duration of their disease (Bautista & Grossman, 2014). These ongoing symptoms also support the need for primary or preventative care services for patients with MS.

### **Model Guiding Product Development**

The Occupational Adaptation (OA) model was chosen to influence the development of this product. This model addresses ongoing adaptation throughout the entire occupational therapy process (Schultz, 2014). The occupational adaptation model focuses on relative mastery directed toward the three person components of sensorimotor, psychosocial, and cognitive systems (Cole & Tufano, 2008). Therefore, these person components, including examples of problem areas and interventions, are included within the product. The product also consists problem areas and interventions related to areas of occupation. The OA model was incorporated into the therapist handout to educate the occupational therapist on how to facilitate components of the OA model into treatment such as relative mastery and internal adaptation from the client. The concepts of internal adaptation are seen in both the client and therapist manual through a trial and error process of efficiency through occupations. Reflective activities are incorporated in both manuals to allow clients to become aware of their own internal adaptation process.

The OA model is an essential component of this product due to the ongoing struggle experienced by individuals with chronic progressive diseases. The therapist

facilitates change by addressing physical, cognitive and psychosocial needs while the client is the agent of change during the therapy process (Schultz, 2014).

### **Overview and Purpose of Product**

The purpose of this scholarly project was to develop a clinical guide for occupational therapy practitioners to utilize for individuals with multiple sclerosis (MS) in a primary care setting. Ultimately, this product is separated by two different guides, one guide for the therapist and one for the client. It was decided to separate these two products due to the differences in language, purpose and usability. A guide was created for the client that was personal and gave the client an opportunity to reflect on how multiple sclerosis influences occupational performance and quality of life. A guide was created for the therapist to follow and respond to reflective journaling, questions regarding occupational performance, symptomatology and other factors regarding the well-being of individuals with multiple sclerosis.

A primary care setting calls for quick, effective interventions. Therefore, the product created had heavy emphasis on treatments derived from occupations that could be used in a timely manner, with a high emphasis on re-assessment through reflective journaling pieces. The therapist guide categorizes all eight occupations and symptomatology. Therefore, the therapist can quickly look up information based on the types of problems the client is showing. By using this guide, occupational therapists can provide evidence-based practice which may increase well-being, satisfaction and distill hope for the future from the client.

A multidisciplinary approach is encouraged as the client is provided with education and resources that address how other professions can facilitate well-being for



individuals with multiple sclerosis (Reed, 2008). The client is educated on the roles of allied-health professionals, and referral information if needed. It is important for a team of healthcare professions such as physical therapists, occupational therapists, speech therapists, case management professions, and others to collaborate together, due to the vast complexity of multiple sclerosis. Teamwork will increase well-being of the client, efficiency in therapy services and outcomes.

This product can be the start of the bridge to meaningful conversation between individuals with multiple sclerosis and health care professionals in a primary care setting. The product consists of five main areas, including assessments, areas of occupation, person components, a relative mastery reflection, and occupational therapy intervention. Assessments were guided by the occupational adaptation model, including the steps this model uses to guide the assessment process. Areas of occupation and person components both incorporated common problems individuals with MS experience and treatments to be used with each problem. Reflective pieces were incorporated within this product to facilitate discussion between the client and the therapist regarding satisfaction of performance in occupations. The reflective component will improve communication between the client and therapist, and are beneficial to assist clients in increasing their self-awareness, strengths, and weaknesses. Additionally, reflective pieces are beneficial from the client's perspective to assist them in tracking their habits, routines, and how multiple sclerosis influences their quality of life. Finally, the occupational therapy intervention included therapist weekly recommendations, referral sources for other professionals that may treat individuals with MS, and an educational component for the patient to understand occupational therapy.

In summary, primary care is an emerging setting, which is fitting for the occupational therapy role. However, there are a lack of resources for occupational therapists within the primary care setting. The clinical guide emphasizes the importance of occupation and how occupational therapists can facilitate treatment by using direct occupation based treatments. This product can be expanded to other chronic conditions to improve quality of life and occupational performance. Due to the product focus on MS, it would require further development to meet the needs of the clients with other chronic conditions.

# Occupational Therapy in Primary Care: Progressive Neurological Disorder

*A Guide for Occupational Therapists*

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## INTRODUCTION

### **Primary Care**

As an occupational therapist in a primary care setting, you treat patients using a different approach. With the dynamic nature of the diagnosis of multiple sclerosis you may use primary, secondary, and tertiary approaches to address the needs of your clients. These approaches are implemented in this handout and will facilitate the efficiency of your work in a primary care setting while working with an individual with multiple sclerosis.

You have time demand challenges requiring you to work efficiently in a timely manner. You may only have 8-10 minutes per patient to provide the best care possible and send them on their way after your time is up. This handout has been created for your unique circumstance to help individuals with MS. The multidisciplinary nature of primary care services requires you to implement a communicative and holistic approach to the team. These components will be facilitated by the reflective demand of the product below. To address this unique role of treatment within primary care, this therapist guide has been created. The therapist user guide provided is unique in nature due to the fact that therapists can use it as a quick treatment guide to facilitate function for individuals with multiple sclerosis in a primary care setting. Additionally, there are a dynamic multitude of diagnoses that this user guide will be able to cover, ultimately becoming appropriate for the high demand and dynamic approach primary care consists of.

### **Occupational Adaptation**

Occupational adaptation is driven by the assumption that if the client becomes more adaptive, he or she will become more functional (Schultz, 2014). Adaptation is a particularly important aspect to consider for individuals with MS due to the progressive nature of the disease. MS can occur across the lifespan, therefore roles are constantly changing. Because of this, adaptation is necessary for individuals to maintain independence. Additionally, patients with MS are able to have greater independence when following the OA model, as the patient is responsible for making adaptations. This occurs through a trial and error process, which the patient is constantly evaluating what worked, what did not work, and what he or she could do different in the future. This manual allows the therapist to practice a trial and error process by providing the client with reflective forms to identify what treatments are effective.

Occupational adaptation is defined as the extent to which a person's perceived identity corresponds to his or her competence performing occupations of personal importance in a relevant environment; it is an ongoing process. This can be related to the

mental health components related to MS. Many patients frequently experience anxiety and depression. OA is a model that can address these components through intervention, as it allows the individual to rate his or her level of efficiency, effectiveness, and satisfaction. These three components make up an individual's relative mastery (Cole & Tufano, 2008). Relative mastery can influence the individual's ability to function and adapt to changes. Therefore, it is important to address these components to ensure the patient is successful and does not allow mental health concerns to lead to a relapse. Patients would receive benefit from tracking the components of their relative mastery and reflecting on ways to improve their mastery levels. Due to the nature of this model, OA is appropriate for the primary care setting, as patients are learning ways to improve their quality of life through adaptation. Patients are provided with tools necessary to assist them in preventing more issues. Adaptation can prevent further disability, which can decrease the chance for additional specialized treatment.

### **Pertinent Background Information about Multiple Sclerosis**

Multiple Sclerosis (MS) is a chronic progressive neurological disease impacting around 500,000 people in the United States with an age of onset commonly between 20 and 30 years old (Bautista & Grossman 2014). It is unknown what the cause of MS is, however, it is known that there are a variety of factors that may lead to a diagnosis of MS (Ellis, Blackburn, & Bath-Hextall, 2013). MS is an immune-mediated disorder that creates lesions primarily within the white matter of the central nervous system (CNS), which the lesions lead to a variety of symptoms, varying based on the location and size of the lesion (Bautista & Grossman 2014). Lesions occur in any area within the CNS, which consists of the brain and spinal cord, leading to potential back pain. Symptoms occur within the motor, sensory, and cognitive areas of the central nervous system (Tyszka, & Farber, 2010).

MS has three different types of disease, each varying based on symptoms, progression, and amount of relapses. Types of MS include relapsing-remitting, primary progressive, and secondary progressive. The most common type is relapsing-remitting, which there is severe deterioration with a slight recovery between relapses (Bautista & Grossman, 2014). Symptoms most often include sensory disturbances, Lhermitte sign (tingling in the neck and down the spine), motor weakness, optic neuritis, impaired coordination, and fatigue (Saguil, Kane, & Farnell, 2014). Secondary progressive is the next most common type of MS and always begins as relapsing-remitting MS (Cree & Hauser, 2018). Within this type of MS, there is a steady deterioration that is not related to attacks, and individuals are at risk for possible severe relapses (Bautista & Grossman, 2014). Primary progressive has steady deterioration throughout the entire course of an

individual's disease with no relapses (Bautista & Grossman, 2014). There is a greater amount of problems with lower limb movement, bladder and bowel control, and sexual function (Litchfield & Thomas, 2010).

Individuals with MS experience a variety of symptoms. According to Cree & Hauser (2018), fatigue impacts ninety percent of patients with MS and is the most common reason for work-related disability in the MS population (p. 5). Along with fatigue, balance issues and motor impairments are also major symptoms experienced by individuals with MS. Cree & Hauser (2018) also stated individuals with MS often initially experience sensory loss, optic neuritis, weakness, paresthesias, diplopia, ataxia, vertigo, paroxysmal attacks, and bladder concerns (p. 2). MS can also cause symptoms including lhermitte sign, pain, dementia, visual loss, facial palsy, impotence, myokymia, epilepsy, and falling (Cree & Hauser, 2018). This therapist guide provides pertinent information related to each area of occupation allowing you as the therapist to tailor your interventions according to the needs of your clients.

### **Occupations**

According to the Occupational Therapy Practice Framework (American Occupational Therapy Association, 2014), there are eight different occupations categorized as: ADL's (Activities of Daily Living), IADL's (instrumental activities of daily living), rest and sleep, education, play, leisure and social participation. Below is information outlining all eight of these occupations, symptomatology of multiple sclerosis, and how these symptoms influence everyday performance.

All subcategories of occupations are influenced by multiple sclerosis and occupational performance. Two common symptoms of multiple sclerosis include fatigue and balance issues (Reed, 2014). These two symptoms can negatively impact an individual's daily routine and habits.

There are a number of occupations one participates in throughout their daily routine. The occupations one chooses to participate in influences habits, roles, routines, interests, and values. According to (National Multiple Sclerosis Society, n.d.), individuals diagnosed with multiple sclerosis may be unaware of symptoms and how these influence everyday performance. Individuals need to be aware of the symptoms that are experienced to increase self-management, advocacy for oneself and become grounded in becoming an active agent of change throughout treatment. Therefore, it is important to have awareness of background information to help prevent further disability and increase awareness of typical progression of the disease.



### **Guidelines for use of Therapist Guide**

The following is a user guide for therapists to facilitate treatment among the eight different occupations for individuals with MS. The therapist will use this guide when treating individuals with MS within the primary care setting. There is a client handout that goes along with this therapist guide. The therapist is instructed to provide each client with materials from the client handout that would be of benefit to him or her. The client handout provides individuals with information relating to each occupation and how MS impacts these occupations. There are examples of typical issues related to fatigue and balance within each occupation. The client is provided with a reflective component within this to keep track of challenges and areas of strength throughout time. Within each area of occupation, there are also examples related to other functional deficits that the client may experience. Additionally, there is a section which the client is educated on what to expect from occupational therapy services. These include examples of interventions the therapist will provide related to various symptoms individuals with MS experience. The approaches used for guiding occupational therapy interventions are also explained for the clients. Occupational therapy interventions have been demonstrated to be effective in increasing well-being, independence, functional capacity, and activity performance (Baker & Tickle-Degnen, 2001).

### Assessments related to the Occupational Adaptation Model

According to Schultz (2014), the occupational adaptation model comprises of five steps which guides the process of evaluation through occupational therapy. The following is a descriptive list of what types of assessments fit into these five steps. The purpose of this section is to give occupational therapists a quick guide on how to evaluate individuals diagnosed with multiple sclerosis in a primary care setting through assessments that are congruent with the occupational adaptation model. These five steps consist of:

#### Step 1: Occupational environment and role participation and performance

Assessment	Relation with OA, product & occupation
<p><b>Role Checklist</b></p> <p><b>Purpose:</b> Assess a client's perception of participation in past, present and future roles</p> <p><b>Format:</b> Questionnaire and rating form, usually self-administered</p> <p><b>Time Required:</b> 15 minutes (Reed, 2007).</p>	<p>Relation with OA:</p> <ol style="list-style-type: none"> <li>1. Assesses relative mastery (what is the person's perception of their performance?)</li> </ol> <p>Relation with product:</p> <ol style="list-style-type: none"> <li>1. A quick assessment that can be completed within one treatment session (10 minutes)</li> </ol> <p>Relation with occupation:</p> <ol style="list-style-type: none"> <li>1. Assesses what roles the person is participating in therefore, OT's can apply this knowledge</li> </ol>

Assessment	Relation with OA, product & occupation
<p><b>OPHI-II (Occupational Performance History Interview - II)</b></p> <p><b>Purpose:</b> Rates occupational identity, occupational competence</p> <p><b>Format:</b> Three part assessment includes semi-structured interview, rating scales and life narrative</p> <p><b>Time requirement:</b> 1 hour to complete interview; can be administered in 2 sessions if necessary (Schultz-Krohn, 2007).</p>	<p>Relation with OA:</p> <ol style="list-style-type: none"> <li>1. Has the client identify their occupational role and needs</li> </ol> <p>Relation with product:</p> <ol style="list-style-type: none"> <li>1. Consists of reflection pieces regarding past occupational performance. Gives the client an opportunity to reflect on treatment.</li> </ol> <p>Relation with occupation:</p> <ol style="list-style-type: none"> <li>1. Extensive interview collection information regarding the person's past and current participation in occupations.</li> </ol>

**Step 2: Physical, social, cultural features of primary occupational environment or role**

Assessment	Relation with OA, product & occupation
<p align="center"><b>Craig Hospital Inventory of Environmental Factors (CHIEF)</b></p> <p><b>Purpose:</b> Quantifies the degree to which aspects of the environment (physical, social, political) facilitate or inhibit full participation in the lives of people with disabilities</p> <p><b>Format:</b> Paper and pencil questionnaire</p> <p><b>Time Required:</b> 10 minutes (Gitlow, 2007)</p>	<p>Relation with OA:</p> <ol style="list-style-type: none"> <li>1. Assesses the person's outlook on the environment: what facilitates and inhibits occupational performance</li> <li>2. The person is the agent of change</li> <li>3. Demand of mastery from the environment</li> </ol> <p>Relation with product:</p> <ol style="list-style-type: none"> <li>1. A quick assessment that can be completed within one treatment session (10 minutes)</li> </ol> <p>Relation with occupation:</p> <ol style="list-style-type: none"> <li>1. Environment of the person leads to occupation, which this assessment evaluates</li> <li>2. Person identifies barriers to occupation</li> </ol>

Assessment	Relation with OA, product & occupation
<p align="center"><b>Volitional Questionnaire</b></p> <p><b>Purpose:</b> Provides a format for communicating volition through interactions with the environment and for identifying the optimal conditions and supports needed for this expression.</p> <p><b>Format:</b> Observation-based behavior rating scale</p> <p><b>Time Requirement:</b> 30-40 minutes (Schultz-Krohn, 2007)</p>	<p>Relation with OA: An individual's motivation is an important component of their ability to internally adapt to the contextual environment around them and how they react to the problems presented.</p> <p>Relation with product: The product gives the individual an opportunity to reflect on volitional/motivational components throughout their daily routine.</p> <p>Relation with occupation: Directly measures how volition (motivation) is influential of what occupations a person performs and how they successful they are within occupational performance.</p>

### Step 3: Sensorimotor, cognitive, and psychosocial status

Assessment	Relation with OA, product & occupation
<p><b>Nine-hole peg test</b></p> <p><b>Purpose:</b> Measure unilateral finger dexterity to determine the extent of fine motor impairment</p> <p><b>Format:</b> Performance-based timed task</p> <p><b>Time Requirement:</b> 10 minutes for both hands (Amini, 2007)</p>	<p>Relation with OA:</p> <ol style="list-style-type: none"> <li>1. Directly evaluated performance</li> </ol> <p>Relation with product:</p> <ol style="list-style-type: none"> <li>1. A quick assessment that can be completed with one treatment session (10 minutes for both hands)</li> </ol> <p>Relation with occupation:</p> <ol style="list-style-type: none"> <li>1. Directly measures performance skills which collects information for the therapist regarding occupational capacity and performance</li> </ol>

Assessment	Relation with OA, product & occupation
<p><b>Allen's Cognitive Level Test</b></p> <p><b>Purpose:</b> Brief screening test to estimate the client's cognitive function and capacity to learn and to guide treatment goal setting.</p> <p><b>Format:</b> Tasks analysis of a standardized visual-motor task</p> <p><b>Time Requirement:</b> Approximately 20 minutes (Cooke, D., &amp; Finkelstein Kline, N., 2007)</p>	<p>Relation with OA:</p> <ol style="list-style-type: none"> <li>1. Cognitive function is evaluated through adaptive gestalt, which is a major component when looking at the overarching theme of the occupational adaptation model.</li> </ol> <p>Relation with product:</p> <ol style="list-style-type: none"> <li>1. Product facilitates the process of creating goals through reflection and collaboration with the therapist.</li> </ol> <p>Relation with occupation:</p> <ol style="list-style-type: none"> <li>1. Assesses cognitive function through observation of performance of occupation.</li> </ol>

**Step 4: Client's level of relative mastery in the primary occupational environment or role**

Assessment	Relation with OA, product & occupation
<p><b>COPM (Canadian Occupational Performance Measure)</b>  <b>Purpose:</b> Detect change in a client's self-perception of occupational performance over time  <b>Format:</b> Semi-structured, interview-based rating scale, administered individually  <b>Time Required:</b> Typically administered in 30-40 minutes (Schultz-Krohn, 2007)</p>	<p>Relation with OA:</p> <ol style="list-style-type: none"> <li>1. Internal process of adaptation of the person</li> <li>2. Self-perception of the individuals occupational performance</li> </ol> <p>Relation with product:</p> <ol style="list-style-type: none"> <li>1. A quick assessment and can be completed within one treatment session (30-40 minutes)</li> <li>2. Does not require materials other than the assessment itself which is conducive to a primary care setting</li> </ol> <p>Relation with occupation:</p> <ol style="list-style-type: none"> <li>1. The measurement of self-care, productivity and leisure</li> <li>2. Measures occupations that can be intervened within a primary care setting</li> </ol> <p>(Schultz-Krohn, 2007)</p>

Assessment	Relation with OA, product & occupation
<p><b>Relative Mastery Scale</b>  <b>Purpose:</b> Assess individual's perception on their effectiveness, efficacy and satisfaction regarding their responses to occupational changes  <b>Format:</b> Pencil and Paper  <b>Time Requirement:</b> 20 minutes (George, Schkade &amp; Ishee, 2004)</p>	<p>Relation with OA:</p> <ol style="list-style-type: none"> <li>1. The individuals that are assessed through the relative mastery scale and measures efficacy and satisfaction over time</li> </ol> <p>Relation with product:</p> <ol style="list-style-type: none"> <li>1. Individuals are able to determine their perceived efficacy of performing occupations based on their symptoms of MS. This is reflected in the journaling portion of the client handout</li> </ol> <p>Relation with occupation:</p> <ol style="list-style-type: none"> <li>1. Individuals are assessing their performance related to occupations</li> </ol>

**Step 5: Facilitating or limiting relative mastery in the primary occupational environment or role**

Assessment	Relation with OA, product & occupation
<p><b>Functional Independence Measure (FIM)</b></p> <p><b>Purpose:</b> Evaluates 18 items related to 6 areas relevant to independence in activities of daily living. Completed through observation.</p> <p><b>Format:</b> Performance-based timed task</p> <p><b>Time Required:</b> About 45 minutes (Fasoli, 2014)</p>	<p>Relation with OA:</p> <ol style="list-style-type: none"> <li>1. Measures relative mastery</li> </ol> <p>Relation with product:</p> <ol style="list-style-type: none"> <li>1. Paints a picture for the primary care provider what the person and capable of and influences treatment interventions</li> </ol> <p>Relation with occupation:</p> <ol style="list-style-type: none"> <li>1. Directly measures performance skills that facilitate occupations</li> </ol>

Assessment	Relation with OA, product & occupation
<p><b>Assessment of Motor and Process Skills</b></p> <p><b>Purpose:</b> Measurement the quality of performance in basic and instrumental ADL's, assistance in planning intervention</p> <p><b>Format:</b> Observation- based rating scale; computerized scoring available</p> <p><b>Time Requirement:</b> 30-40 minutes (Furphy, 2007)</p>	<p>Relation with OA:</p> <ol style="list-style-type: none"> <li>1. Measures person components, which is parallel to the OA model.</li> </ol> <p>Relation with product:</p> <ol style="list-style-type: none"> <li>1. The AMPS assesses ADL's, which can be used a guide when using this product.</li> </ol> <p>Relation with occupation:</p> <ol style="list-style-type: none"> <li>1. ADL's is an important occupation that is highly emphasized in this product. ADL's was</li> </ol>

## Patient Intake Form

Patient's Name: \_\_\_\_\_ Date of Birth: \_\_\_\_/\_\_\_\_/\_\_\_\_

Today's Date: \_\_\_\_/\_\_\_\_/\_\_\_\_ Who Referred You: \_\_\_\_\_

Primary Physician: \_\_\_\_\_ Physician's Number: \_\_\_\_\_

Leisure Activities: \_\_\_\_\_

\_\_\_\_\_

Current level of function:

- ☐ Independent
- ☐ Cueing
- ☐ Minimal Assistance
- ☐ Moderate Assistance
- ☐ Maximal Assistance
- ☐ Dependent

Motivations for therapy: \_\_\_\_\_

\_\_\_\_\_

Client goals/priorities: \_\_\_\_\_

\_\_\_\_\_

Current methods used to relieve symptoms: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Check any of the following that you are experiencing difficulty completing:

- |   |   |
|---|---|
| <input type="checkbox"/> Bathing/Showering  | <input type="checkbox"/> Sexual Concerns                  |
| <input type="checkbox"/> Dressing   | <input type="checkbox"/> Shopping                         |
| <input type="checkbox"/> Grooming   | <input type="checkbox"/> Driving                          |
| <input type="checkbox"/> Cooking/Preparing meals/Washing dishes                       | <input type="checkbox"/> Falling                          |
| <input type="checkbox"/> Increased/excessive fatigue levels                           | <input type="checkbox"/> Increased depression or anxiety  |
| <input type="checkbox"/> Difficulty taking care of others                             | <input type="checkbox"/> Difficulty completing work tasks |
| <input type="checkbox"/> Difficulty transferring from one area to another             |   |
| <input type="checkbox"/> Difficulty participating in hobbies and social participation |   |
| <input type="checkbox"/> Difficulty sleeping or sleeping too much (specify) _____     |   |

### **Pain Assessment**

On a scale of 0-10, 0 being no pain, 10 being the worst pain you've experienced, how would you rate your pain right now?

0	1	2	3	4	5	6	7	8	9	10
No pain									Worst Pain	

Using the same scale, how would you rate your pain when you are feeling at your best?

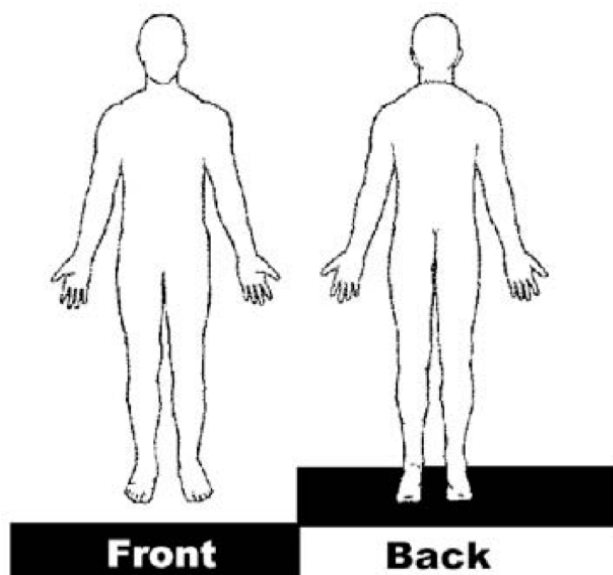
0	1	2	3	4	5	6	7	8	9	10
No pain									Worst Pain	

Using the same scale, how would you rate your pain when you are feeling at your worst?

0	1	2	3	4	5	6	7	8	9	10
No pain									Worst Pain	



**Shade in any areas of the images below in which you experience pain.**



**Additional Questions/Concerns I have in General:**

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**Guidelines for use of occupation chart.** A chart was created to provide therapists with general information regarding common problems individuals with multiple sclerosis experience related to each area of occupation. The chart provides examples of treatment for each problem that the therapist can use within the primary care setting. Therapists should use this chart by first determining the client's problem areas, then establishing the specific area of occupation that is impacted. The therapist will find a similar problem related to what his or her client is experiencing and look at the treatment for this problem. Therapists are directed to alter each treatment to match the client's needs.

## Areas of Occupation

### Activities of Daily Living

Problem	Treatment/Intervention
Decreased functional performance regarding dressing	Introduce assistive devices (button hooks, shoe horn, replacing zippers/small buttons, dressing stick, reacher, etc.)
Decreased functional performance regarding showering	Shower equipment (shower chair, larger handrails, grab bars, handheld shower head, modified shampoo/conditioner containers for increased grasp, etc.)
The need to practice a proper nutritional diet	Educate the patient on a healthy balanced diet to assist in promoting positive mental and physical health. Patient's diet should consist of a low animal fat, no dairy products, omega-3 fatty acids, and vitamin D (Jelinek & Hassed, 2009).
Functional mobility (walking) concerns, due to balance issues	Walking aids, such as a cane or walker can help assist the individual with safe mobility. Exercise training can benefit walking.
Sexual dysfunction complications	Assistive devices (such as intimate rider, body bouncer, liberatory shapes, love bumper, etc.)
Increased urgency to urinate	Implement a bladder program
Transfers (shower, bed, toilet)	Transfer assistive device (hoyer lift, grab bars)

Swallowing difficulties, impacting eating and drinking	Assistive device regarding eating (Liftware, universal eating tool, scooper bowl & plates, gravity assistive cup, etc.)
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#### Instrumental Activities of Daily Living

Problem	Treatment/Intervention
Taking care of children	Refer the patient to outside services they may be able to receive to assist with child care
Decreased functional ability to drive	Provide adaptive equipment options for driving. If not possible, educate patient on public transportation options such as the bus, taxi, or train
Difficulty with home management due to balance and/or fatigue levels	Encourage individuals to take frequent breaks while completing home management tasks. If this is not effective, provide individuals with information to receive assistance with home management, such as a friend, family member, or cleaning company
Difficulty with shopping due to balance and/or fatigue levels	Encourage the individual to walk as much as possible throughout the store. If needed, educate the individual on the use of a scooter while shopping. Educate on or implement other forms of transportation the individual can use.

#### Rest and Sleep

Problem	Treatment/Intervention
Patients may experience decreased amount of sleep	Educate patients on the importance of maintaining a consistent sleep schedule
Patients may experience difficulty sleeping due to their level of pain	Provide patients with pain management strategies, such as yoga, meditation, or other relaxation techniques

## Education

Problem	Treatment/Intervention
Decreased energy impacting ability to learn	Encourage patients to take frequent breaks during learning to promote the best quality performance
Decreased mental and emotional well-being, impacting their motivation and concentration level	Ensure the patient is experiencing positive mental and emotional thoughts. Provide the patient with coping skills and ways to improve motivation

## Work

Problem	Treatment/Intervention
Decrease in fine motor skills	Type-aide computer, fine motor strengthening program, larger writing utensils, modify work demands
Susceptibility to fatigue	Encourage patients to take frequent breaks throughout the work day as needed. Educate on self-advocacy so the individual can assert his/her needs to a manager.
Decreased ability to carry objects to complete job demands	If the individual is able to walk, encourage use of a cart to push heavier objects. Upper extremity strengthening. Modify job demands and implement reasonable accommodations.
Difficulty finding a job willing to accommodate the individual's needs	Educate the individual on workers rights and the Americans with Disabilities Act

## Play

Problem	Treatment/Intervention
Decreased energy or motivation to explore different play options	Encourage the patient to take advantage of new opportunities. Assist the patient with identifying new play options related to his or her interests

Visual deficits	If certified, provide patient with vision therapy. Refer patient to an optometrist if necessary
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#### Leisure

Problem	Treatment/Intervention
Increased fatigue	Regular aerobic exercise and participation in activities can help improve patient's level of fatigue
Decrease in muscle strength, flexibility, and increase in muscle spasms	Provide the patient with muscle relaxation strategies and aerobic exercise
Depressive symptoms	Determine what is causing the patient's depression. Educate the patient on coping strategies, community support systems, counseling services, and refer to a psychiatrist if necessary.

#### Social Participation

Problem	Treatment/Intervention
Impaired speech	Educate patient on assistive devices related to speech. Refer to speech language pathologist
Fatigue	The patient should take breaks as needed to engage fully in social participation.

Information from the tables above was gathered from Reed (2014).

## Person Components

Multiple sclerosis is a unique diagnosis being the nature of the disease has a diverse amount of symptoms. Among these symptoms comprise of problems regarding sensorimotor, cognitive and psychosocial, all a part of the adaptive gestalt within the Occupational Adaptation model. It is important for individuals to balance these three aspects within their daily routine to maintain a high quality of life.

**Guidelines for use of person components chart.** A chart has been provided to the therapist to inform them of the sensorimotor, cognitive and psychosocial issues that are pertinent to individuals with multiple sclerosis. The problem is provided on the left hand side, while the treatment/interventions that are congruent with these specific problems are to the right. The therapist should use this to guide the treatment and intervention process for individuals with multiple sclerosis. Therapists are encouraged to modify the treatment to fit the wants and needs of the client.

### Sensorimotor

Problem	Treatment/Intervention
Spasticity and Contractures	Provide program of strength exercises to decrease spasticity and contractures
Fatigue	Keeping a diary/journal of reported fatigue
Sensory loss	Provide sensory based treatment
Increase in falls	Provide patient with a strengthening program that addresses both balance and strength, yet does not cause fatigue (i.e. aerobic exercise)
Visual deficits	Modify the environment to promote natural lighting, eyewear, other assistive devices, etc.

### Cognitive

Problem	Treatment/Intervention
Memory	Introduce memory aids (journal, note cards, calendar, reminders, color system)
Problem Solving	Educate client on energy conservation techniques, modifying the environment

Decreased awareness of symptoms related to the disease	Educate patients on the symptoms related to the disease so they know what to be aware of and what to notify their practitioner about
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#### Psychosocial

Problem	Treatment/Intervention
Increased depressive symptoms	Promote positive coping strategies, stress reduction and relaxation techniques. If symptoms continue without improvement, refer to a psychologist or psychiatrist
Decreased sense of self-efficacy	Journaling positive self qualities, use of positive reinforcement
High stress levels	Determine the cause of the stress and provide stress management strategies. Educate the patient on relaxation and the importance of maintaining low stress levels (high stress can lead to further exacerbations and relapses)

Information from the tables above was gathered from Reed (2014).

If you have questions regarding information related to assistive devices or the Americans with Disabilities Act, feel free to reference information on the American Occupational Therapy Association's website ([www.aota.org](http://www.aota.org)).

## Reflection

### INTRODUCTION

Take some time and think back to this previous week. There is a possibility that you have been juggling many activities such as taking care of yourself, running errands, working a job, and resting. What were you feeling in the past week and how do you think these symptoms have influenced the way you have performed throughout the week? As you did your best to juggle all of the things you need to do in one day, you probably noticed that some activities are harder than others.

At times, we can ignore these challenges and expect them to go away on their own. Multiple sclerosis impacts activities that we do everyday, and may impact our self-esteem, confidence and quality of life. This handout will directly help you explore how to conquer these challenges and will give you the segway to brainstorm with your occupational therapist or other healthcare professionals that will help you along your journey.

A guide has been created for you to work along with your occupational therapist. The following is information that you will need to assist with your treatment. The focus of treatment will be on areas of occupation and they include activities of daily living (ADL's), instrumental activities of daily living (IADL's), rest and sleep, education, work, play, leisure, and social participation. We know you struggle carrying out various tasks and some symptoms interfere with your daily tasks more than others.

When you attend occupational therapy, you can expect your therapist to begin with what will feel like an interview. The therapist will ask you questions related to your symptoms and the impact they have on your daily life. The therapist will then consider treatment options that match your needs and wants and will improve your quality of life. You can then expect the therapist to work with you to determine your opinion on the treatment options. Then, the therapist will complete the treatment with you, and will educate you on treatments you can complete at home. Your occupational therapist will work with you to create your own modifications and adaptations. Sometimes you will be expected to journal about your concerns and look at your life and routines. You are the one in charge of your therapy and the occupational therapist will look at the changes you want and include these into your sessions. The occupational therapist will also move from one area of occupational challenge to another to meet your concerns and treat every area. Throughout your treatment, the occupational therapist will ensure you are the center of treatment and you are able to recognize what works and what does not work.

We know there is a large amount of information here. Your therapist will assign you parts to complete between each treatment session. He or she will have specific



instructions related to your unique case. In general, to use this product, start with the area which you feel you may need assistance in. Then, look at the examples of what can happen and what you can do to help with these concerns. Finally, complete the reflective component to allow yourself to think of what you are feeling and keep track of your symptoms. Tell your therapist if you have any questions or concerns either regarding your symptoms or this handout.

## ACTIVITIES OF DAILY LIVING (ADL'S)

Activities of daily living are things that you do everyday. Some examples of activities consist of taking a shower, brushing your teeth, getting dressed, and going to the bathroom. Below is a scale that will help you understand your symptoms and how they influence your everyday routine.

### What are Examples of Activities of Daily Living?

<b>Bathing/Showering</b> Obtaining and using supplies - Soaping - Rinsing - Drying - Maintaining body position	<b>Dressing</b> Selecting and obtaining appropriate clothing - Dressing - Undressing - Fastening/adjusting clothes and shoes	<b>Functional Mobility</b> Moving from one position to another - Bed mobility - Wheelchair ability - Transfers
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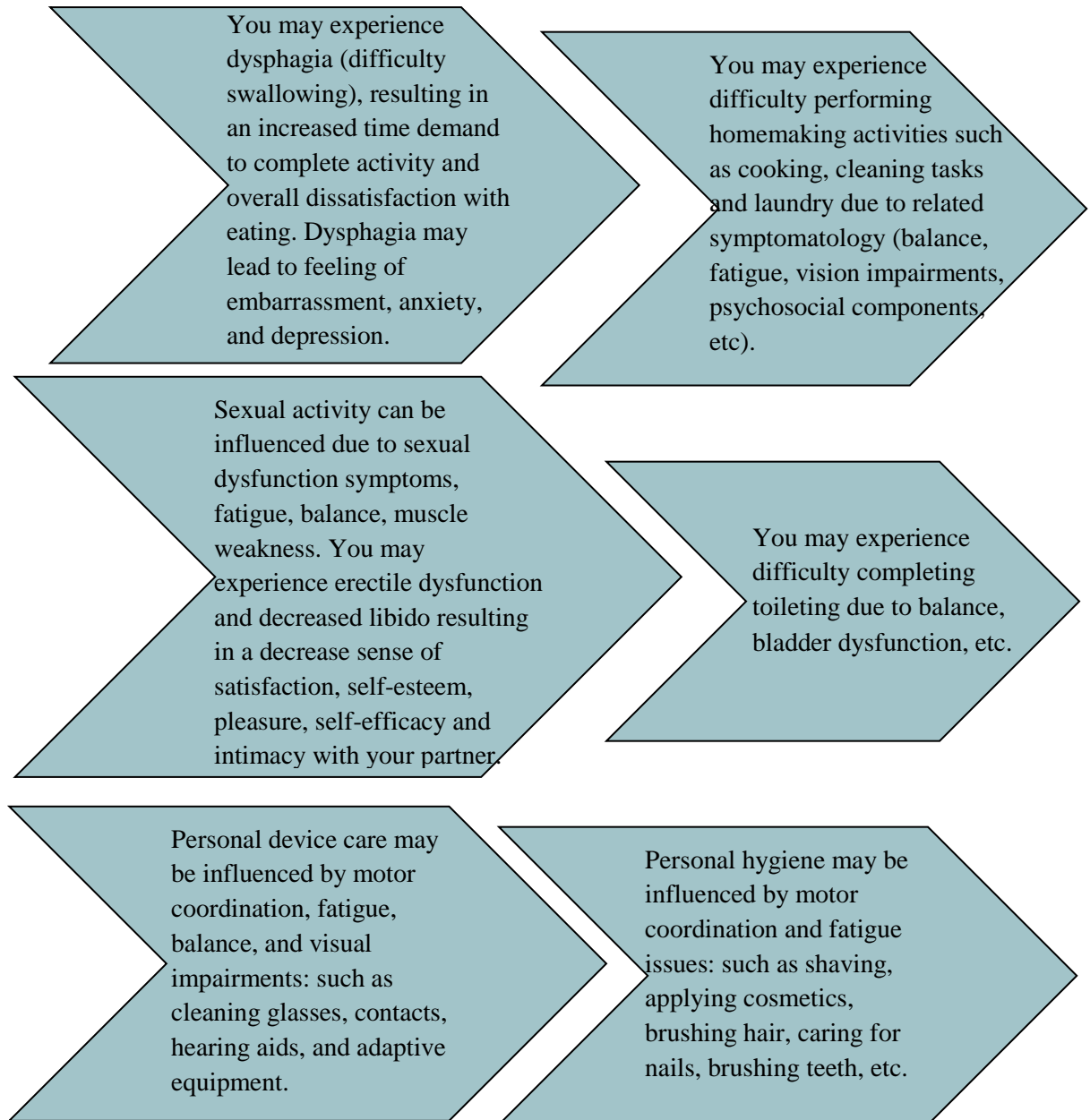
(American Occupational Therapy Association, 2014)

Occupation	Fatigue	Balance
Bathing, showering	You may need to take breaks to manage fatigue, resulting in an increased time to complete this task. Taking a cooler shower would decrease fatigue, but would also decrease satisfaction with the bathing/showering	You may have difficulty maintaining position throughout the task, influencing the time needed to complete this activity. You may not participate in bathing/showering when appropriate due to a fear of

	routine.	falling.
Dressing	You may need to take breaks to manage fatigue, resulting in an increased time to complete this task. You may have to use adaptive equipment to complete this task to lessen fatigue.	You may not participate in dressing activities when appropriate due to a fear of falling. An increase in likelihood for falls may lead to other injuries depending on your fall history. The fear of falling cycle may lead to other psychosocial symptoms, such as depression and anxiety. There is an overall decreased ability to complete dressing, which could decrease your independence and self-efficiency level.
Functional mobility	You may begin to require the use of an assistive device when walking or completing other functional mobility tasks. These may include but are not limited to, a cane, walker, wheelchair, grab bars placed around the house, and bed assist handle. You need to be cautious when participating in functional mobility to avoid falls, which can lead to further concerns. Weakness in the muscles leads to balance concerns, which impacts functional mobility. If you are not participating in functional mobility as frequently, your body will weaken, including joints. Therefore, for if you are having difficulty supporting the ankle joint when walking, an ankle-foot-orthosis (AFO) may be beneficial.	You may need to move slower when performing functional mobility. You may need assistance in completing some functional mobility tasks to reduce the level of energy needed. If you know in advance that you may be required to walk a long distance, it may be beneficial to provide a back-up plan. With this, you may find yourself avoiding some activities involving walking due to the fear of becoming fatigued. It is also important to plan for the environmental temperature and dress accordingly. Taking breaks and staying hydrated is also important.

Information from the table above was received from: American Occupational Therapy Association (2014); Bautista & Grossman (2014); Cree & Hauser (2018); Ellis, Blackburn, & Bath-Hextall (2013); Litchfield & Thomas (2010); Reed (2014); Saguil, Kane, & Farnell (2014).

### Other Functional Issues Related to ADL's:



### Reflective Journal for Activities of Daily Living

1. On a scale of 0 to 10, with 0 no influence and 10 being highly influenced, how have your individual symptoms related to multiple sclerosis influenced your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly influenced

2. On the same scale, how would you rate your USUAL influence of symptoms on your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly influenced

3. On the same scale, how would you rate your BEST level of influence of symptoms on your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly influenced

4. On the same scale, how would you rate your WORST level of influence of your symptoms on your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly Influenced

### **Additional Reflective Information**

What has helped me carry out my daily routine tasks? (i.e. I have turned down the temperature of the water while taking a shower)

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What has been still a challenge regarding carrying out my daily routine? (i.e. I am having difficulty taking a shower without feeling extreme fatigue after)

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Are there any updates with my daily routine that I should share with my primary care provider? (i.e. I have been experiencing difficulty swallowing while eating and/or drinking)

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How have I been feeling related to emotional well-being? (i.e. I feel disappointed when I feel fatigued after taking a shower)

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How have I been feeling related to my physical well-being? (i.e. I experience muscle pain when I am exposed to the heat)

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Additional Questions/Concerns I have in General:

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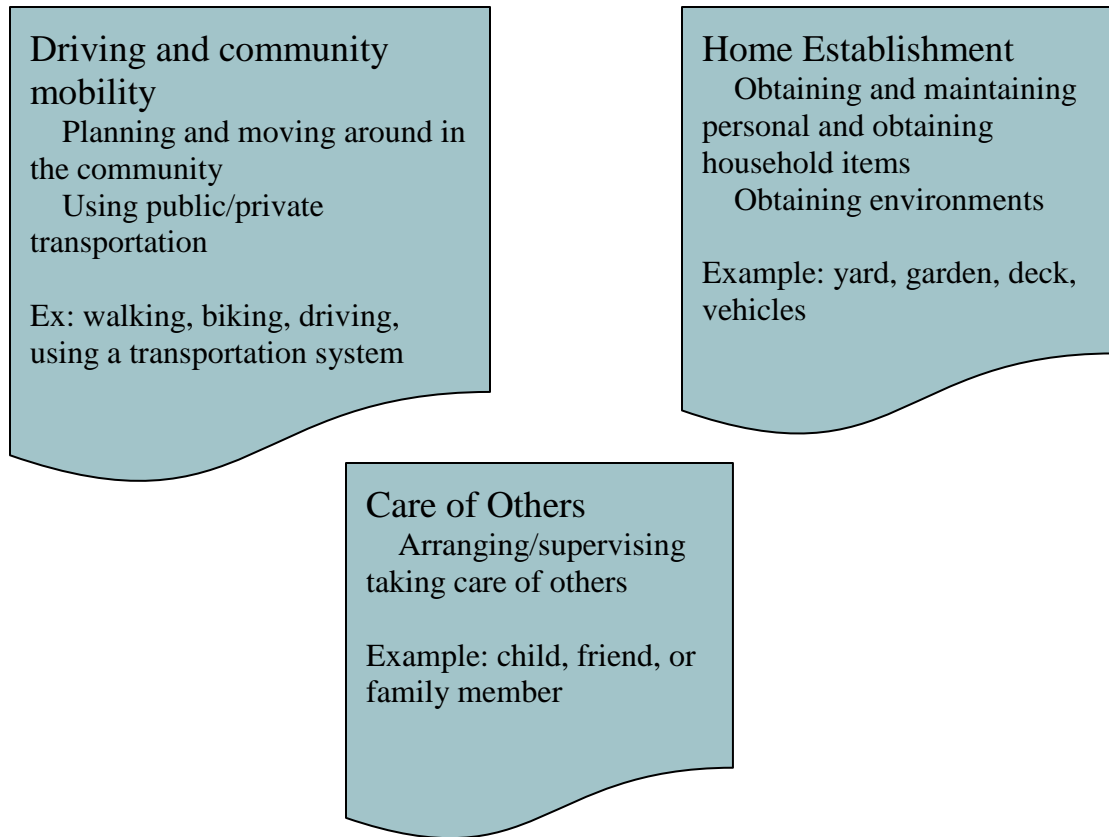
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## INSTRUMENTAL ACTIVITIES OF DAILY LIVING (IADL'S)

Instrumental activities of daily living (IADL) are activities that support daily life within your home and community (American Occupational Therapy Association, 2014). Some examples of IADL's may include taking care of your child or spouse, organization medication and driving around the community.

### What are Examples of Instrumental Activities of Daily Living?



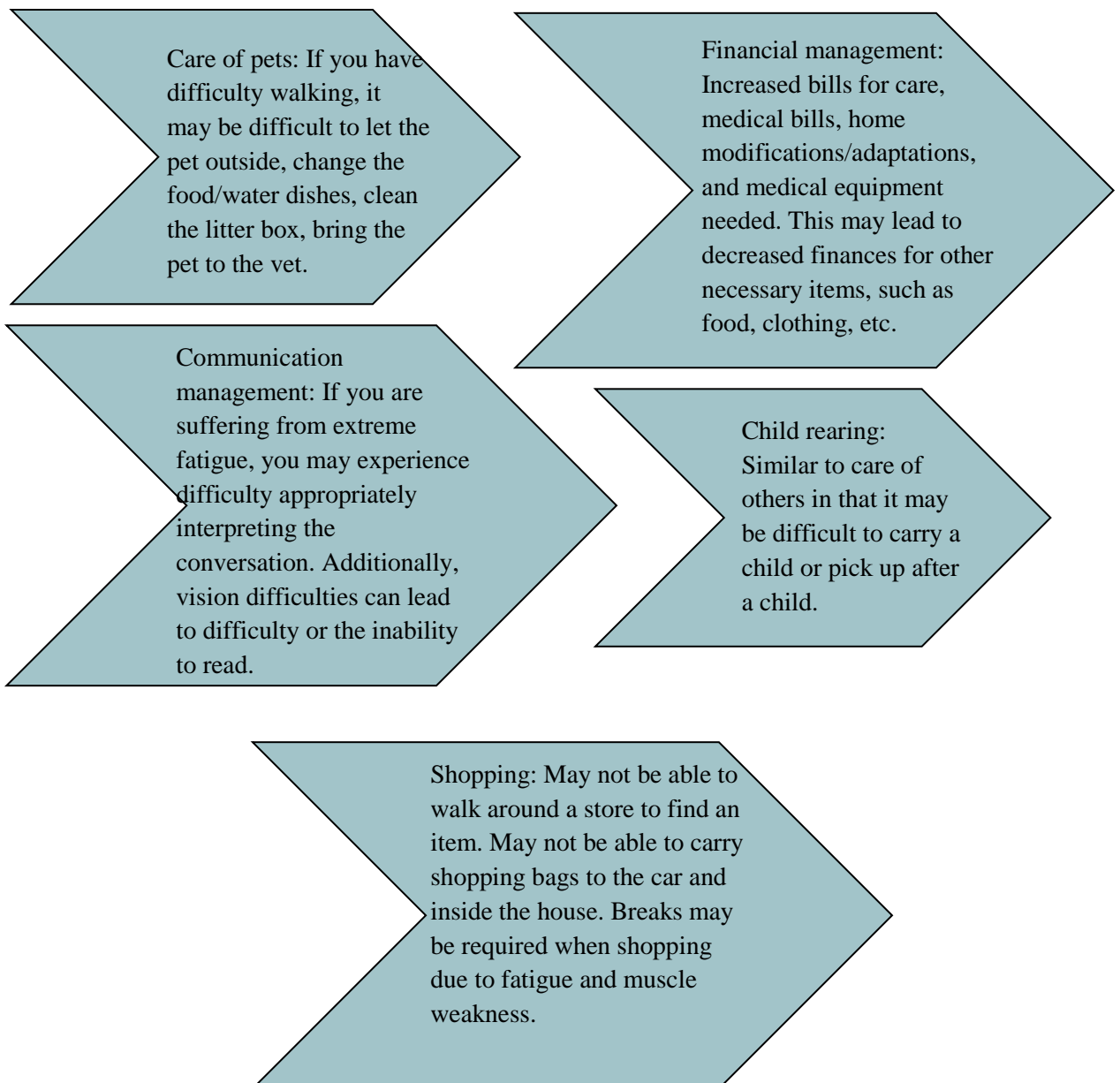
(American Occupational Therapy Association, 2014)

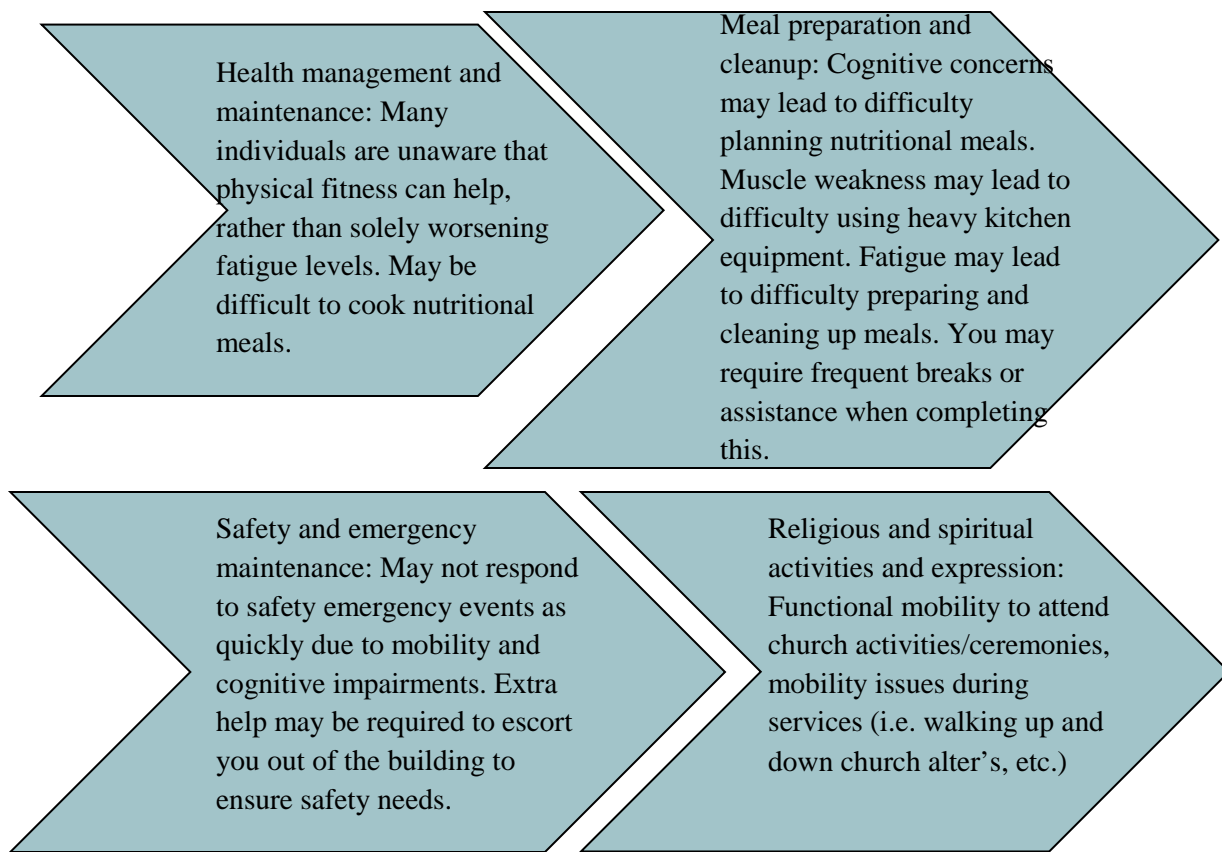
Occupation	Fatigue	Balance
Care of others	You may experience difficulty caring for others when experiencing the low-energy fatigue. You may have difficulty with waking up in the middle of the night for a child and increased difficulty picking up after others.	You may have weakness of limbs, decreased coordination, and difficulty or the inability to carry a child or push a wheelchair.
Home establishment and management	If you have balance difficulties you need to be careful to avoid falling. It can be difficult to complete cleaning activities, such as vacuuming or sweeping the floors. It may be difficult for you to garden if you have difficulty with balance, as you may not be able to kneel down on the ground.	You need to be cautious when participating in home management due to the extreme heat sensitivity related to fatigue. Therefore, if you are participating in cleaning activities, you need to take frequent breaks to stay hydrated and maintain an appropriate body temperature. Garden work may enhance fatigue levels due to the intensity of this and the heat outside.
Driving and community mobility	You may experience decreased or completely stop driving in the community due to fatigue. You may have difficulty with walking. Cognitive symptoms such as decreased attention and distractibility may negatively influence your ability to drive safely and independently.	You may experience decreased ability to get your full body into the car, decreased trunk control when driving, and decreased ability to walk, influencing your ability to access public transportation (i.e. bus or taxi) or other modes of transportation.

Information from the table above was received from: American Occupational Therapy Association (2014); Bautista & Grossman (2014); Cree & Hauser (2018); Ellis, Blackburn, & Bath-Hextall (2013); Litchfield & Thomas (2010); Reed (2014); Saguil, Kane, & Farnell (2014)



### Other Functional Issues Related to IADL's:





### Reflective Journal for Instrumental Activities of Daily Living

1. On a scale of 0 to 10, with 0 no influence and 10 being highly influenced, how have your individual symptoms related to multiple sclerosis influenced your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly influenced

2. On the same scale, how would you rate your USUAL influence of symptoms on your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly influenced

3. On the same scale, how would you rate your BEST level of influence of symptoms on your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly influenced

4. On the same scale, how would you rate your WORST level of influence of your symptoms on your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly Influenced

### **Additional Reflective Information**

What has helped me carry out my daily routines? (i.e. Allowing my significant other to help with laundry)

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What has made it more challenging to carry out my daily routine? (i.e. I have not been taking breaks while completing tasks)

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Are there any updates with my daily routine that I should share with my primary care provider? (i.e. I have been experiencing blurred vision while driving)

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How have I been feeling related to emotional well-being? (i.e. I feel happy when I can care for my child without assistance)

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How have I been feeling related to my physical well-being? (i.e. I am experiencing shoulder pain when picking up my child)

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Additional Questions/Concerns I have in General:

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## REST AND SLEEP

Rest and sleep is a key player in health and wellness. Imagine having a full “to-do” list and only getting four hours of sleep the night before. Now imagine having that same “to-do” list with eight hour of sleep the night before. How do you think you would function differently between these two? Below is a scale and reflective piece that will help you make more sense of your sleep/rest routines and how they impact your ability to function in everyday activities. Rest and sleep is defined as “activities related to obtaining restorative rest and sleep to support healthy, active engagement in other occupations” (American Occupational Therapy Association, 2014).

### What are Examples of Rest and Sleep?

<b>Rest</b> Engaging in quiet and effortless actions that interrupt physical and mental activity= relaxed state	<b>Sleep Preparation</b> Engaging in routines that prepare the self for a comfortable rest Preparing the physical environment for periods of unconsciousness	<b>Sleep Participation</b> Taking care of personal needs for sleep Performing care of toileting needs and hydration
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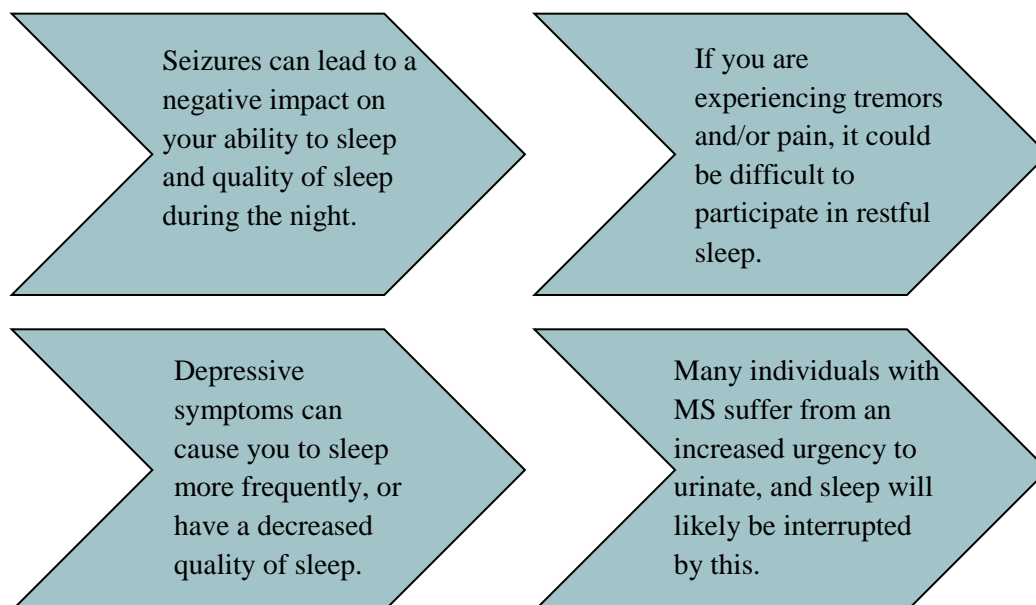
(American Occupational Therapy Association, 2014)

Occupation	Fatigue	Balance
Rest	You may feel the urge to rest more frequently. You may also have difficulty waking up to complete daily activities.	Rest is not directly related to balance as you are likely laying down.
Sleep preparation	Grooming, dressing, and making the bed may be difficult to complete if you are experiencing a large amount of fatigue. Frequent breaks are encouraged as needed. Determining the temperature to set the room at could be a challenge if you are very	Dressing and making the bed could be difficult if you have poor balance. You may require assistance with these activities, as it could enhance the risk of falling.

	sensitive to the heat. With this, you need to make sure that you wear appropriate clothing to bed based on the temperature.	
Sleep participation	You may sleep more restful if you are very fatigued. Fatigue could be enhanced if you are unable to sleep through the night due to bladder concerns.	If you need to use the bathroom in the middle of the night, your balance could be worsened due to fatigue and lighting. You would benefit from having night lights placed in appropriate areas between the bedroom and bathroom.

Information from the table above was received from: American Occupational Therapy Association (2014); Bautista & Grossman (2014); Cree & Hauser (2018); Ellis, Blackburn, & Bath-Hextall (2013); Litchfield & Thomas (2010); Reed (2014); Saguil, Kane, & Farnell (2014)

### Other Functional Issues Related to Rest and Sleep



### Reflective Journal for Rest and Sleep

1. On a scale of 0 to 10, with 0 no influence and 10 being highly influenced, how have your individual symptoms related to multiple sclerosis influenced your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly influenced

2. On the same scale, how would you rate your USUAL influence of symptoms on your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly influenced

3. On the same scale, how would you rate your BEST level of influence of symptoms on your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly influenced

4. On the same scale, how would you rate your WORST level of influence of your symptoms on your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly Influenced



### **Additional Reflective Information**

What has helped me carry out my daily routines? (i.e. I have been taking naps in the middle of the day and I am still able to sleep through the night)

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What has made it more challenging to carry out my daily routine? (i.e. I have been waking up seven times in the middle of the night to use the restroom)

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Are there any updates with my daily routine that I should share with my primary care provider? (i.e. I am now sleeping 12 hours a night instead of 8)

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How have I been feeling related to emotional well-being? (i.e. I have been feeling depressed, causing me to sleep more frequently)

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How have I been feeling related to my physical well-being? (i.e. I have been in too much pain to sleep well at night)

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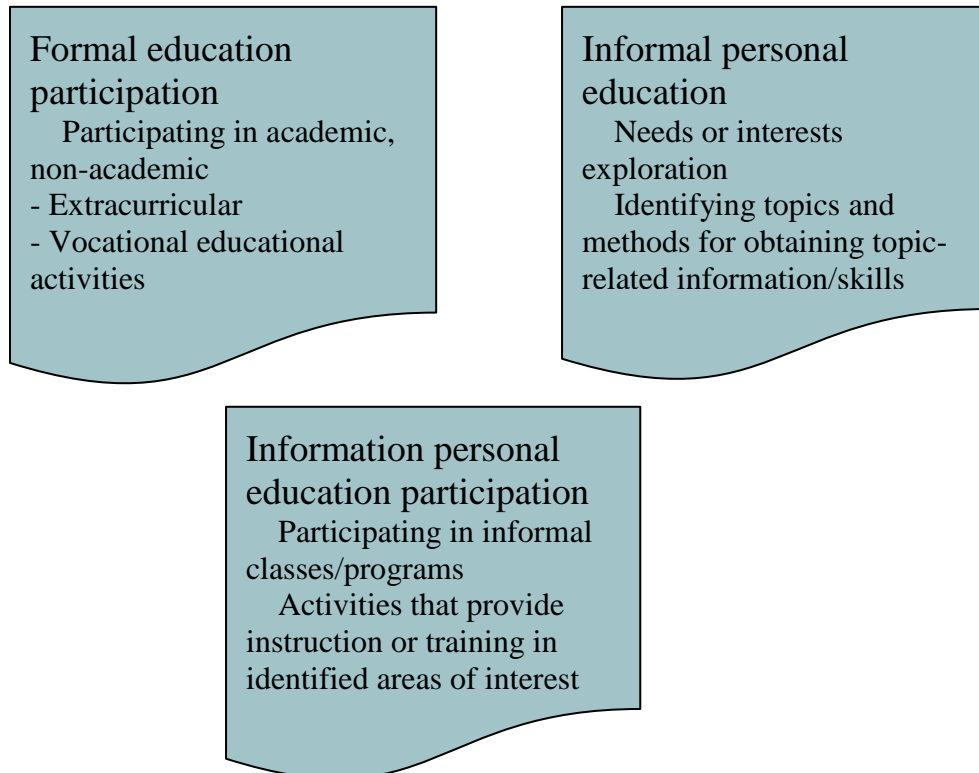
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## EDUCATION

Education in this sense, does not only apply to students in a school or college setting. Education include activities that support learning and participation in an educational environment (Christiansen & Townsend, 2010, p. 423)” (American Occupational Therapy Association, 2014).

### What are Examples of Education?

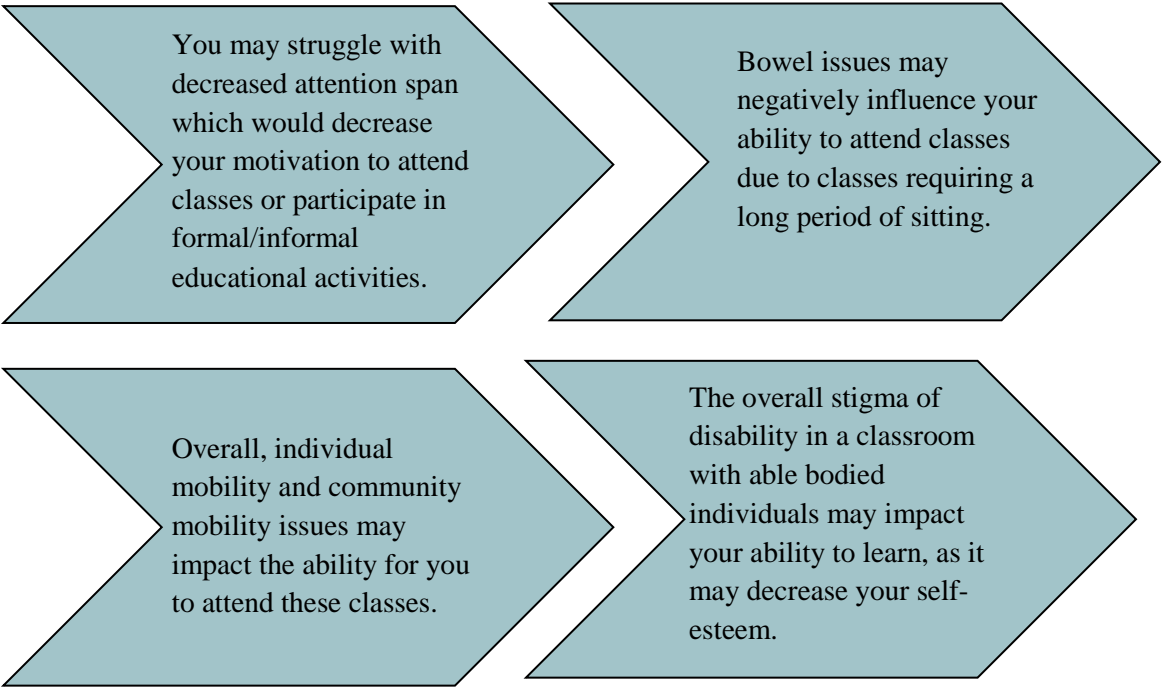


(American Occupational Therapy Association, 2014)

Occupation	Fatigue	Balance
Formal education participation	You may not be able to attend activities during formal education participation due to fatigue. The energy level required in order to complete assignments and attend class may be too high for you if you are suffering from fatigue.	Balance is needed to attend class. You may have difficulty sitting up straight in class.
Informal personal education needs or interests	You may feel a lack of energy in order to obtain information regarding skills. You could experience decreased energy to attend tasks.	Balance is influenced when sitting at a table/ desk.
Informal personal education participation	Decreased energy conservation when attending classes of interests. Energy influences transportation.	Your balance could be influenced when participating in educational activities or training.

Information from the table above was received from: American Occupational Therapy Association (2014); Bautista & Grossman (2014); Cree & Hauser (2018); Ellis, Blackburn, & Bath-Hextall (2013); Litchfield & Thomas (2010); Reed (2014); Saguil, Kane, & Farnell (2014)

### Other Functional Issues Related to Education:



You may struggle with decreased attention span which would decrease your motivation to attend classes or participate in formal/informal educational activities.

Bowel issues may negatively influence your ability to attend classes due to classes requiring a long period of sitting.

Overall, individual mobility and community mobility issues may impact the ability for you to attend these classes.

The overall stigma of disability in a classroom with able bodied individuals may impact your ability to learn, as it may decrease your self-esteem.

## Reflective Journal for Education

1. On a scale of 0 to 10, with 0 no influence and 10 being highly influenced, how have your individual symptoms related to multiple sclerosis influenced your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly influenced

2. On the same scale, how would you rate your USUAL influence of symptoms on your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly influenced

3. On the same scale, how would you rate your BEST level of influence of symptoms on your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly influenced

4. On the same scale, how would you rate your WORST level of influence of your symptoms on your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly Influenced

### **Additional Reflective Information**

What has helped me carry out my daily routines? (i.e. I am taking frequent breaks in my studying to lay down and rest)

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What has made it more challenging to carry out my daily routine? (i.e. I am having difficulty concentrating on my schoolwork due to my symptoms)

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Are there any updates with my daily routine that I should share with my primary care provider? (i.e. I simply do not have any energy to complete my schoolwork)

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How have I been feeling related to emotional well-being? (i.e. I have been too stressed to focus on my schoolwork)

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How have I been feeling related to my physical well-being? (i.e. I am unable to sit in a chair for the length of time needed to complete my studying)

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Additional Questions/Concerns I have in General:

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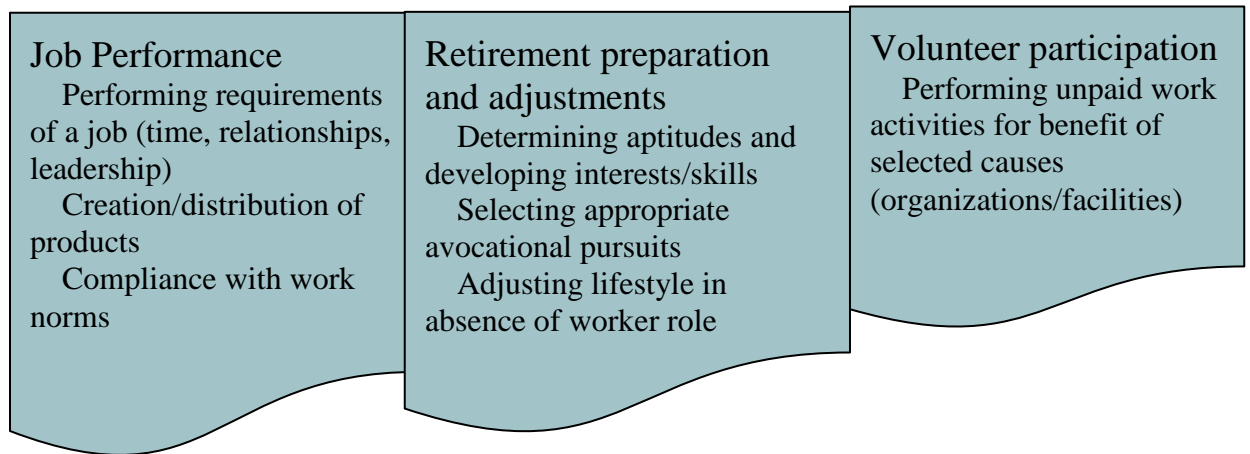


## WORK

Work in this case, does not only include a profession, career or job that you may participate in exchange for money or other forms of satisfaction, but it also includes volunteerism and other forms of work that an individual can participate in (Christiansen & Townsend, 2010, p. 423)” (American Occupational Therapy Association, 2014).

Below is a reflective journal that will help you and your therapist better understand how multiple sclerosis impacts the occupation of work.

### What are Examples of Work?



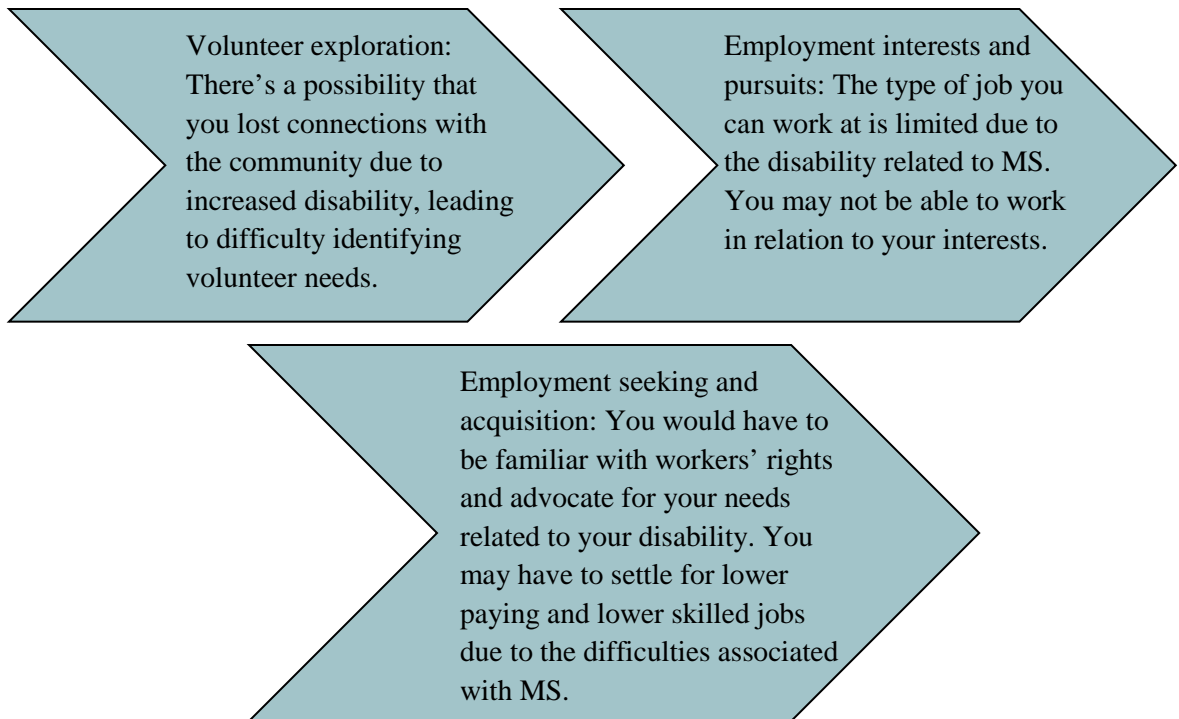
(American Occupational Therapy Association, 2014)

Occupation	Fatigue	Balance
Job performance	You may require more time to complete tasks and increased need for breaks throughout a shift. You may have to cut back on tasks performed during the day if your fatigue levels are getting too high. You should not be participating in physical work tasks that can lead to fatigue in the typical person. Fatigue is the most common reason for a work-related disability in those with MS.	If tasks include walking, or other physical activity other than sitting at a desk, you may have difficulty completing these tasks. They may not be able to carry objects needed to complete work.

Retirement preparation and adjustment	If you are experiencing fatigue, you may not be able to be involved in as many activities as once hoped to be upon retirement. You may not have the ability to complete leisure tasks along with daily activities due to fatigue levels.	Activities associated with retirement will be limited if you experience balance issues. Activities may be adjusted more toward therapy rather than “typical” retirement activities involving interests.
Volunteer participation	You may not be able to perform as much volunteer work as you hoped due to increased levels of fatigue. Volunteer work would have to be limited to low-energy demanding work. Frequent breaks may be necessary to have enough energy to complete a shift.	Volunteer work is limited to work that does not consist of carrying heavy items, and possibly work that is wheelchair accessible. The opportunity for you to sit during the volunteer shift would be necessary. Outdoor volunteer work would be limited if it was associated with landscaping, garbage pickup, recycling, or any other physically demanding tasks.

Information from the table above was received from: American Occupational Therapy Association (2014); Bautista & Grossman (2014); Cree & Hauser (2018); Ellis, Blackburn, & Bath-Hextall (2013); Litchfield & Thomas (2010); Reed (2014); Saguil, Kane, & Farnell (2014)

### Other Functional Issues Related to Work:



### Reflective Journal for Work

1. On a scale of 0 to 10, with 0 no influence and 10 being highly influenced, how have your individual symptoms related to multiple sclerosis influenced your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly influenced

2. On the same scale, how would you rate your USUAL influence of symptoms on your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly influenced

3. On the same scale, how would you rate your BEST level of influence of symptoms on your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly influenced

4. On the same scale, how would you rate your WORST level of influence of your symptoms on your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly Influenced

### **Additional Reflective Information**

What has helped me carry out my daily routines? (i.e. My manager allows me to take a break whenever I feel I need it)

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What has made it more challenging to carry out my daily routine? (i.e. My job has too many physical demands incorporated within it)

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Are there any updates with my daily routine that I should share with my primary care provider? (i.e. I can no longer complete the tasks at my job and I don't know what to do about this)

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How have I been feeling related to emotional well-being? (i.e. I have been really motivated and able to complete my work)

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How have I been feeling related to my physical well-being? (i.e. I cannot complete my tasks at work because of my muscle soreness)

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## PLAY

Play is defined as “any spontaneous or organized activity that provides enjoyment, entertainment, amusement or diversion (Parham & Fazio, 1997, p. 252)” (American Occupational Therapy Association, 2014). Some of these play activities can consist of playing a sport, card game, leisure activity, or playing with you grandchild.

### What are Examples of Play?

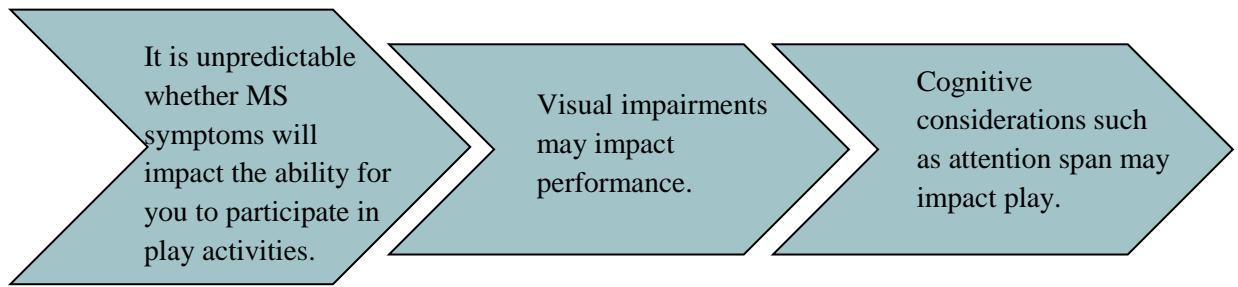
<b>Play exploration</b> Identifying appropriate play activities  Including: exploration play, practice play, pretend play, games with rules, constructive play, symbolic play	<b>Play participation</b> Participating in play Maintain a balance of play with other occupations Obtaining/using and maintaining toys, equipment and supplies
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(American Occupational Therapy Association, 2014)

Occupation	Fatigue	Balance
Play exploration	Fatigue may negatively influence your ability to explore which type of play or activities you are interested in.	Balance may be challenged when sitting up in a chair while participating in play exploration.
Play participation	You may have to take frequent breaks during play activities, decreasing enjoyment and meaning of the activity.	Many play activities require balance, which may decrease performance and satisfaction during this time.

Information from the table above was received from: American Occupational Therapy Association (2014); Bautista & Grossman (2014); Cree & Hauser (2018); Ellis, Blackburn, & Bath-Hextall (2013); Litchfield & Thomas (2010); Reed (2014); Saguil, Kane, & Farnell (2014)

### Other Functional Issues Related to Play:





## LEISURE

Leisure is defined as “non-obligatory activity that is intrinsically motivated and engaged in during discretionary time, that is, time not committed to obligatory occupations such as work, self-care, or sleep (Parham & Fazio, 1997, p. 250)” (American Occupational Therapy Association, 2014). Below is a scale that is combined with play and leisure, due to the similarity and redundancy to both occupations.

### What are Examples of Leisure?

#### Leisure exploration

Identifying interests, skills, opportunities, and appropriate leisure activities

#### Leisure participation

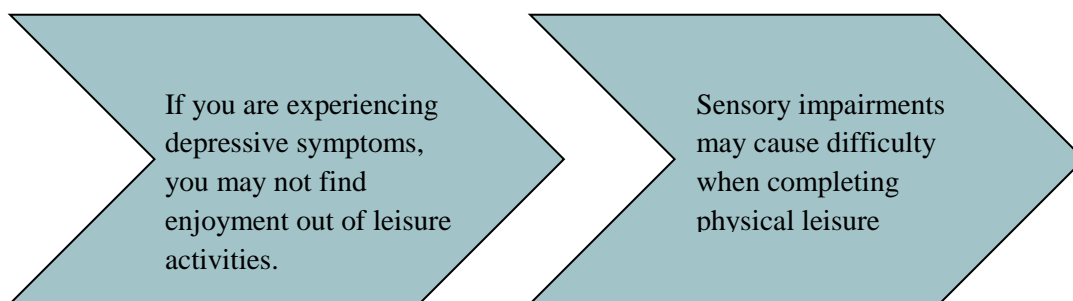
Planning and participating in appropriate leisure activities  
Maintaining a balance of leisure activities with other occupations  
Obtaining, using, and maintaining equipment and supplies as appropriate

(American Occupational Therapy Association, 2014)

Occupation	Fatigue	Balance
Leisure exploration	You may experience increased difficulty identifying leisure activities of interest due to the limitation of participating in low-demand activities.	You may experience difficulty identifying leisure activities of interest that allow you to either sit or have limited movement during participation.
Leisure participation	You may require frequent breaks when participating in leisure activities, which can decrease your level of satisfaction in participation. You may also need to participate in fewer activities to prevent fatigue.	Activities may need to be altered or limited to allow you to sit while completing the activity.

Information from the table above was received from: American Occupational Therapy Association (2014); Bautista & Grossman (2014); Cree & Hauser (2018); Ellis, Blackburn, & Bath-Hextall (2013); Litchfield & Thomas (2010); Reed (2014); Saguil, Kane, & Farnell (2014)

### Other Functional Issues Related to Leisure



(American Occupational Therapy Association, 2014)

### Reflective Journal for Play and Leisure

1. On a scale of 0 to 10, with 0 no influence and 10 being highly influenced, how have your individual symptoms related to multiple sclerosis influenced your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly influenced

2. On the same scale, how would you rate your USUAL influence of symptoms on your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly influenced

3. On the same scale, how would you rate your BEST level of influence of symptoms on your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly influenced

4. On the same scale, how would you rate your WORST level of influence of your symptoms on your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly Influenced

### **Additional Reflective Information**

What has helped me carry out my daily routines? (i.e. I have found new leisure activities that are friendly with my symptoms)

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What has made it more challenging to carry out my daily routine? (i.e. I can no longer do what I enjoy doing)

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Are there any updates with my daily routine that I should share with my primary care provider? (i.e. I have difficulty accessing resources to allow me to participate in activities)

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How have I been feeling related to emotional well-being? (i.e. I have no interest in doing any activities)

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How have I been feeling related to my physical well-being? (i.e. I am experiencing pain when I go for walks)

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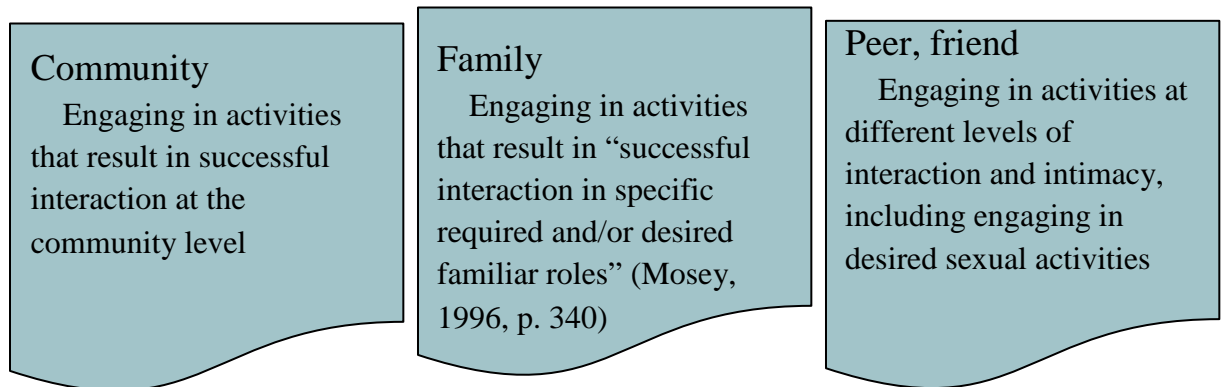
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## SOCIAL PARTICIPATION

Social participation is defined as the “interweaving of occupations to support desired engagement in community and family activities as well as those involving peers and friends” (Gillen & Boyt Schell, 2014, p.607). Involvement in a subset of activities that involve social situations with others (Bedell, 2012) and that support social interdependence (Magasi & Hammel, 2004). Social participation can occur in person or through remote technologies such as telephone calls, computer interaction and video conferencing.” (American Occupational Therapy Association, 2014).

### Examples of Social Participation

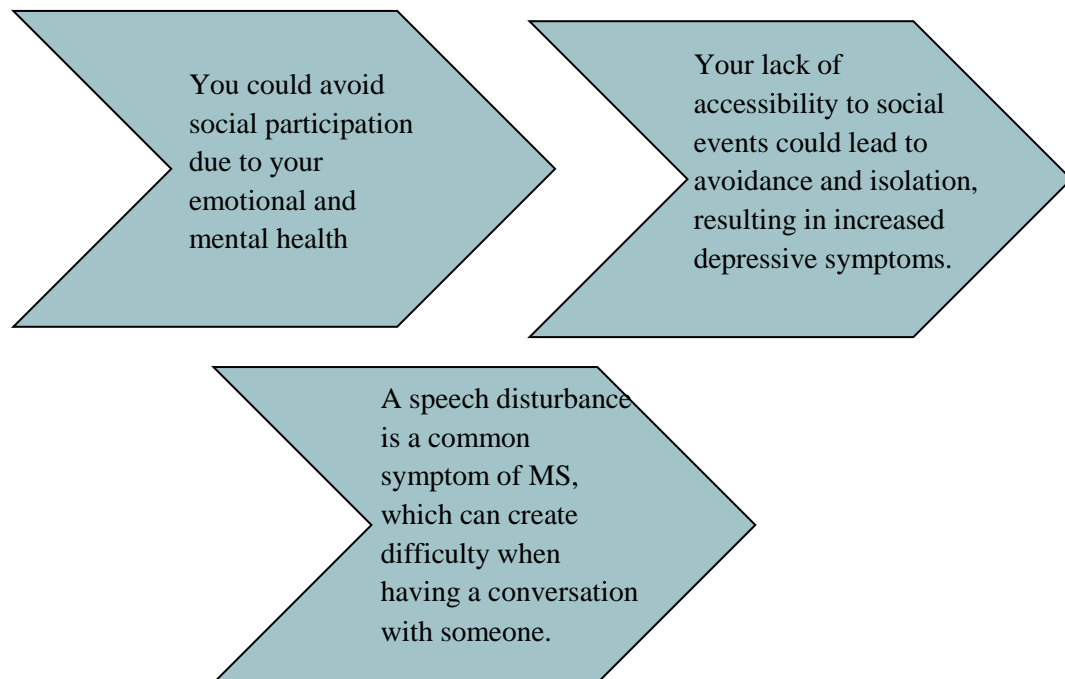


(American Occupational Therapy Association, 2014)

Occupation	Fatigue	Balance
Community	Frequent breaks may be required during social activities. Avoid prolonged standing during a conversation.	Repositioning of body during social interaction. Sit down as needed.
Family	Frequent breaks may be required during social activities. Avoid prolonged standing during a conversation.	Repositioning of body during social interaction. Sit down as needed.
Peer, friend	Frequent breaks may be required during social activities. Avoid prolonged standing during a conversation.	Repositioning of body during social interaction. Sit down as needed.

Information from the table above was received from: American Occupational Therapy Association (2014); Bautista & Grossman (2014); Cree & Hauser (2018); Ellis, Blackburn, & Bath-Hextall (2013); Litchfield & Thomas (2010); Reed (2014); Saguil, Kane, & Farnell (2014)

### Other Functional Issues Related to Social Participation



### Reflective Journal for Social Participation

1. On a scale of 0 to 10, with 0 no influence and 10 being highly influenced, how have your individual symptoms related to multiple sclerosis influenced your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly influenced

2. On the same scale, how would you rate your USUAL influence of symptoms on your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly influenced

3. On the same scale, how would you rate your BEST level of influence of symptoms on your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly influenced

4. On the same scale, how would you rate your WORST level of influence of your symptoms on your ability to participate in your ADL routine?

0   1   2   3   4   5   6   7   8   9   10

No influence

Highly Influenced



### **Additional Reflective Information**

What has helped me carry out my daily routines? (i.e. My friends have been coming to me so I do not have to waste energy going to them)

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What has made it more challenging to carry out my daily routine? (i.e. My speech impairment is making it difficult to socialize with others)

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Are there any updates with my daily routine that I should share with my primary care provider? (i.e. My speech is worsening)

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How have I been feeling related to emotional well-being? (i.e. I have been isolating from others)

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How have I been feeling related to my physical well-being? (i.e. I have to make sure I switch between sitting and standing while socializing)

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# **Occupational Therapy Intervention**

## **Instructions on Use of Therapist Recommendations**

The therapist recommendation form is provided for you as a therapist to create a weekly treatment plan for your client. You will use this to provide your client with instructions on what he or she should complete before the next treatment session. You will give this sheet to your client at the conclusion of each session and explain your recommendations to your client. After you explain, ask your client to re-teach you to ensure he or she understands what is recommended. Provide your client with materials from the client manual necessary to complete each recommendation. Instruct the client to record within the reflective journaling sections to allow the two of you to discuss this at the next appointment.

### **Therapist Weekly Recommendations**

The following list is what you have identified as an issue within your daily life:

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To help with these issues, I would like you to complete:

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Please complete this and document on your reflective journal how you feel before, during, and after. If you have any questions before your next appointment, please call the office.

### **Examples of weekly recommendations:**

**Case Study #1:** Anne is a 52 year old client who comes into your office experiencing extreme fatigue impacting several daily activities. She is unable to take a shower every day due to the level of fatigue resulting from this. She cannot cook a full meal from start to finish. She can no longer work because she cannot make it through her entire shift without needing to rest. Her level of fatigue has lead to increased depressive symptoms.

**The following list is what you have identified as an issue within your daily life:**

Extreme fatigue impacting several areas of your life. Increased depression as a result.

**To help with these issues, I would like you to complete (activity adaptations, readiness skills):**

For showering: take cooler showers, use a shower chair, shower first thing in the morning.

For cooking: take frequent breaks to sit, prepare the meal while sitting down, gather all items needed a couple of hours before actually cooking the meals, ask for help from others.

For working: ask for breaks throughout the day, work short shifts, complete limited physically-demanding tasks, sit while completing work tasks.

For depression: journal thoughts and feelings, journal positive quotes, stress reduction techniques, use positive coping strategies, relaxation and meditation.

**Case Study #2:** Judy is a 35 year old client who comes into your office stating she is beginning to experience balance issues. Her balance is affecting her ability to carry her one year old son around and care for him. She is also having difficulty getting on the floor to play with her son. This is causing high stress levels, leading to a decrease in overall mental health. She is also taking college courses part-time, in which these stress levels are causing a negative impact. Her balance also impacts her ability to complete household tasks such as cooking and cleaning. Her husband works 55 hours each week, and has little time to help her out with their son and household tasks.

**The following list is what you have identified as an issue within your daily life:**

You are experiencing difficulty with your balance leading to a decreased ability to care for your son and complete household tasks. Your stress from this is impacting your schooling. Your husband is very busy and has little time to assist.

**To help with these issues, I would like you to complete (activity adaptations, readiness skills):**

For overall balance: complete aerobic exercise five times per week for 30 minutes each time, participate in muscle relaxation, use of a walking cane

Childcare: use parenting resources, hire a babysitting, register for respite services to provide you with breaks

Household tasks: hire a cleaning company/person, purchase a rolling chair to be able to sit while cleaning, complete meal preparation while seated

Stress levels: positive coping skills, relaxation, yoga, meditation, journaling, make priority lists

## **Referrals**

The dynamic nature of multiple sclerosis requires a multidisciplinary approach to address the many challenges one may face related to this diagnosis. Other professionals that may take part in this process include, but are not limited to: physical therapists, speech therapists, respite care, and case managers.

### **Physical therapists:**

According to the American Physical Therapy Association (2018) physical therapists help patients reduce pain and improve or restore mobility. Physical therapists work to educate their clients on how to prevent or manage their symptoms in order to achieve long-term benefits.

### **Speech therapists:**

According to the American Speech-Language and Hearing Association (n.d.), speech therapists work to prevent, assess, diagnose, and treat speech, language, social communication, cognitive communication, and swallowing disorders in adults and children.

### **Respite care:**

According to the National Institute of Aging (2017), respite care provides short-term relief for primary caregivers. Care can be provided at home, in a healthcare facility, or at an adult day center. Respite care is essential to this population due to the high needs that are required for care.

### **Case manager:**

According to the Case Management Society of America (2017), case management is a collaborative process of assessment, planning, facilitation, care coordination, evaluation, and advocacy for options and services. These help meet an individual's and family's comprehensive health needs through communication and available resources to promote cost-effective outcomes.

### **Parenting resources:**

According to the American Psychological Association (n.d), parenting resources can range from ensuring children's health and safety, preparing children for life as productive adults and transmitting cultural values. Multiple sclerosis is often diagnosed pre-retirement age (before the age of 65), which promotes the need for parental resources for individuals with multiple sclerosis.

**Tips for you as an occupational therapist**

As a healthcare provider, you need to ensure you are treating the patient's family as a whole, as MS impacts the entire family's dynamics.

Recommend your clients to maintain a healthy, balanced diet, engage in an exercise program focused on the client's abilities, encourage the client to not smoke (National Multiple Sclerosis Society, n.d.)

Alter every treatment to match each individual client's wants and needs.

Reach out to others to ask for assistance as needed.

**Precautions**

Precautions are defined as taking care in advance to prevent harm (Definition of precaution, 2018). The following is a list of precautions that are relevant for individuals diagnosed with multiple sclerosis that therapists need to be aware of when providing care.

1. Individuals should avoid heat when appropriate (bathing, showering).
2. Individuals should avoid fatigue when possible by taking intermediate breaks while participating in an activity.
3. Individuals are at risk for falls. Functional mobility should be considered as well as contextual environments when providing treatment.
4. Cigarette smoking may accelerate the course of illness (Reed, 2014).



## What other treatments/benefits should the client expect when attending occupational therapy services?

Here are some treatments that you can expect from your occupational therapist for other symptoms related to MS. Although these are not comprehensive, they are some examples for you to have an idea of what to expect. Your occupational therapist will also instruct you on how often and how long to complete these activities when you are at home. Your therapist will focus on what is best for you. Your occupational therapist will follow five approaches during your therapy sessions. These include, create/promote; establish/restore; maintain; modify; prevent (American Occupational Therapy Association, 2014). Below you will see examples of how your occupational therapist will use these approaches during your therapy sessions:

<b>Create/Promote</b>	The therapist will help you practice skills in your home and in the community that will increase your ability to perform in various occupations.
<b>Establish/Restore</b>	The therapist will help you develop new skills to assist with your daily tasks.
<b>Maintain</b>	The therapist will help you save the skills you have regained to increase your ability to participate in activities and improve your quality of life.
<b>Modify</b>	The therapist will help you find new ways of completing activities to improve your performance and independence.
<b>Prevent</b>	The therapist will help you find strategies to stop further disability from occurring.

**The following are some strategies which your occupational therapist can help you if you are experiencing symptoms related to MS.**

<b>If I am experiencing...</b>	<b>My OT can help me by...</b>
Fatigue	Energy conservation techniques
Balance Issues	Walking aid
Sensory Disturbances	Sensory based treatment
Motor Weakness	Exercise programs
Impaired Coordination	Implementing big motor movements in an exercise program
Bladder/Bowel Control	Bladder/bowel programs
Abnormal Gait	Gait program or practicing walking
Dementia	Reminder strategies
Visual loss	Environmental changes and scanning techniques
Epilepsy	Referral to additional professionals
Vertigo	Balance program
Speech Disturbances	Referral to speech-language pathologist

## **CHAPTER V**

### **Summary**

Occupational therapy is a good fit for work within primary care, but resources for treatment of progressive neurological disorders are lacking in this setting. With this, a scholarly project was created to provide occupational therapists with a quick reference guide describing the unique role of occupational therapy to administer treatment to individuals with multiple sclerosis (MS). This guide includes a therapist and a client version to equip both users with educational information to implement best treatment strategies.

The development of the guide was completed using the Occupational Adaptation model as a reference. The guide includes five categories: 1) assessments, 2) areas of occupation, 3) person components, 4) relative mastery scale, and 5) occupational therapy intervention. The five categories allow for holistic and client-centered treatment of each individual. Interventions are developed to provide the therapist with tools to adapt to the client's needs based on specific symptoms. The reflective component allows for the client to document how he or she feels between therapy sessions at separate times of the day and after completing various activities. This increases the reliability of communication between the client and therapist during therapy appointments.

While there are many benefits of this project, there are limitations that could potentially influence the implementation of this product. The population focused upon was narrow, which influences the number of individuals that can benefit. Additionally,

the project focused on multiple sclerosis in general, and did not separate the three distinct types of this disease. This limitation would influence how occupational therapists use this product in a primary care setting. Therapists may need to generalize their current knowledge of the population, while adapting the product to the specific needs of the client. Further, the authors of this project have limited experience in a primary care setting and working with individuals with neurological disorders. Therefore, it is possible that the product could have potential bias due to the decreased clinical experience of the students. Lastly, the project has not been piloted, therefore there is not research evidence to support product use.

This project could be implemented in an existing primary care setting where occupational therapists are currently working. At this time, this guide is best suited for use with individuals diagnosed with multiple sclerosis. However, the guide has potential to address issues common to other neurodegenerative disorders including Parkinson's Disease, and Amyotrophic Lateral Sclerosis. Although developed for use in a primary care setting, the guide could be further developed for use in inpatient acute, inpatient rehabilitation and outpatient rehabilitation settings.

To further refine this guide, it is recommended that an outline of the project be presented to a focus group with occupational therapists to ascertain their opinions of the guide's feasibility for use in a primary care setting. Through the focus group, unique perspectives might be collected to further refine and revise the guide's development.

Once the guide is further refined, a research study might take place to collect information on the perspectives of occupational therapists who are actually using the guide in practice. Participation action research, a methodology involving active

participation of research subjects in the research design would be appropriate for product refinement.

The development of this quick reference guide was completed with the intention to prevent the need for an increase in services for the patient. Through use of the guide there will be an increase in communication between the client and therapist, allowing for more effective treatment for the client. Additionally, the guide provides clients with an educational component regarding the expectations for occupational therapy services. Overall, this guide will positively impact the client's quality of life and independence through occupational therapy treatment within primary care.

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