A VOCATIONAL REHABILITATION TRANSITIONAL MANUAL FOR VETERANS WITH NEUROMUSCULAR DISORDERS

A Project

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by

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Date

Department of Special Education, Rehabilitation, School Psychology, and Deaf Studies
Abstract

of

A VOCATIONAL REHABILITATION TRANSITIONAL MANUAL FOR VETERANS WITH NEUROMUSCULAR DISORDERS

by

Renee Brewer

Purpose of the Project

The purpose of this project was to provide service connected (SC) Veterans a transitional manual to help them better understand the manifestation of their chronic and progressive neuromuscular disorders, Myasthenia Gravis, Multiple Sclerosis, and Parkinson’s disease. This manual will provide a valuable resource for Veterans in helping them continue meeting their independence in daily living or to help strengthen their ability to transition toward an individualized extended evaluation program (IEEP) aimed at possible employment.

Statement of the Problem

The current independent living program (ILP) services provided by Vocational Rehabilitation & Employment (VR&E) to SC Veterans diagnosed with progressive neuromuscular disorders of Myasthenia Gravis, Multiple Sclerosis, and Parkinson’s disease do not provide a clear, multidimensional analysis of what may be expected during the progressive stages in their disease. Knowledge in areas such as symptomology, functionality, medical needs, psychosocial impact, and needs in devices and
accommodations is necessary. Currently, there is no source that provides such a guide. Hence, there seems to be a considerable gap in the fundamental knowledge to help guide them in understanding their disabilities. Awareness in the progression of a Veteran’s own disease is crucial for him or her to achieve greater accomplishment toward meeting independent living needs, vocational training endeavors, potential abilities, and/or employment goals. Ahlstrom, Lindvall, Wenneberg, and Gunnarsson (2006) suggested one way of proffering support and reducing the feeling of uncertainty for people with progressive diseases is to provide information and education. A manual of this type is needed to provide the SC Veteran knowledge to promote a successful path toward their independent living needs or a path toward meeting their desired vocational rehabilitation training.

Sources of Data

The design of this transition manual is based on the author’s work-related experience and conversations with SC Veterans as well as phone conversations and interviews with DOR counseling staff Maria Hernandez, Veteran Affairs (VA) counseling staff Dr. Norman Corson and Jan Rollings-Rapoza, and Dorothy Devereux, owner of Vocational Resource Services. Reviews of literature were also utilized. Based upon conversations, interviews, and research, the author created a Vocational Rehabilitation Transitional Manual addressing specified needs of Veterans with neuromuscular disorders.
Conclusions Reached

The Vocational Rehabilitation Transition Manual for Veterans with Neuromuscular Disorders was developed specifically to provide SC Veterans knowledge and understanding about their neuromuscular disorders.

________________________, Committee Chair
Guy E. Deaner, Ph.D.

________________________
Date
DEDICATION

I would like to dedicate this project to my son Nicholas whose lending ear proved valuable. I would like to thank my Mom, Audrey Gonzales for being a constant source of encouragement throughout my academic career. Lastly, I would like to dedicate this project to all military Veterans for their dedication and achievements: for those who had the courage to sacrifice their life in defending honor, duty and country.
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Chapter 1

INTRODUCTION

Imagine experiencing unexplained and progressive symptoms of visual difficulties, fatigue, muscle weakness, muscle cramping, numbness, slowness of movement, stiffness, loss of coordination, or even paralysis. Next, imagine having been just informed by a doctor that the symptoms experienced for the past several months are due to a chronic and progressive neuromuscular disease. After hearing this, a person may find him or herself with an actual sense of relief in knowing the reason behind the different symptoms (Multiple Sclerosis Association of America [MSAA], 2012), while at the same time undoubtedly feeling as if one lost one’s compass and perspective, worried and frightened not knowing what might happen next. Even though a person is diagnosed with such a debilitating disease, he or she has the same thoughts and dreams of living a productive and fulfilling life (MSAA, 2012): to include activities in family and community involvement, as well as goals in continued employment and/or educational desires. Distinct populations within the U.S. that experience this type of diagnosis and trepidation are found among our military Veterans. This author’s experience in working with Veterans diagnosed with progressive neuromuscular diseases and insight gained about their plight and challenges to accommodate their needs is the basis for the development of this project.
Background of the Problem

The Department of Veterans Affairs (VA) Vocational Rehabilitation and Employment (VR&E) (also known as Chpt 31 program) is intended to help the service-disabled Veteran become independent in daily living and, to the extent possible, select, prepare for, and secure entry-level employment compatible with his or her interests, abilities, and physical capabilities (International Yacht Restoration Schools [IYRS], 2012). Such needs are addressed through VR&E’s “Five Tracks to Employment” and include re-employment, rapid access to employment, employment through long-term services, self-employment, and independent living. For Veterans with service connected (SC) disabilities so severe (such as accommodating the challenges of a neuromuscular disorder, i.e., medical, psychological, and social aspects) that they cannot immediately consider work, Chpt 31 program (also known as VetSuccess) offers services to improve their ability to live as independently as possible (U.S. Department of Veterans Affairs [USDVA], n.d.). This service is provided for Veterans under the independent living program (ILP) and is considered the “fifth track” to employment. For Veterans with capabilities congruent with vocational training, (meaning medical, psychological, and social aspects of the neuromuscular disorder have stabilized), VR&E provides “employment through long-term services,” considered the “third track to employment.”

Legislation developed to further define ILP needs was amended as of January 26, 1998 under 38 USC § 3109, Entitlement to Independent Living Services and Assistance (U.S. Government Printing Office [GPO], 2012a). This entitlement determined that [if]
achievement of a vocational goal by a Veteran currently is not reasonably feasible, such Veteran shall be entitled, in accordance with the provisions of section 3120 of this title, to a program of independent living services and assistance designed to enable such Veteran to achieve maximum independence in daily living. (38 USC § 3109, para. 2)

This amendment helped establish current Independent Living Program (ILP) services provided by the Vocational Rehabilitation and Employment program authorized by Congress under Title 38, Code of Federal Regulations, Chapter 31 (USDVA, 2010).

Programs found within the VA’s “five tracks to employment” can help Veterans prepare for and keep suitable jobs. However, when a Veteran is faced with a disability that has become so severe, such as a progressive neuromuscular disease, an ILP can help assist him or her, to the maximum extent possible, to live independently and participate in family and community life (USDVA, 2010). Although the severity of Veterans’ neuromuscular disabilities may displace them from employment, often education and insight about the progressive stages of their disease can help increase their medical, psychological, social, and vocational capabilities, leading to a successful vocational rehabilitation training program. This can accommodate individual strengths and challenges and allow greater success in completing their vocational goals.

An ILP (found within the five tracks to employment) can be the Veterans’ first step in pursuing their vocational rehabilitation goal for meeting their employment needs. Although the ILP is designed to provide Veterans (who cannot immediately consider
work) support in maximizing their independence in daily living, the current program is insufficient for providing the Veterans guidance in the manifestation process of their specified neuromuscular disease.

**Purpose**

The purpose of this project was to enhance the existing VR&E ILP by providing SC Veterans a guide to help them visualize the manifestation of their chronic and progressive neuromuscular disorders in order to help them continue meeting their independence in daily living or to help strengthen their ability to succeed in an individualized extended evaluation program (IEEP) aimed at feasible employment. The guide (see Appendix) will provide comprehensive knowledge of the diagnoses of Myasthenia Gravis (MG), Multiple Sclerosis (MS), and Parkinson’s disease (PD). It includes the chronological manifestation of these diseases such as symptomology, functionality, medical and emotional needs, psychosocial impact, and needs in technological accommodations. It also incorporates potential abilities and employment goals Veterans may achieve. The guide will help serve SC Veterans increase their awareness and understanding regarding the chronological nature of their neuromuscular disability, providing them a better visualization for a projected outcome.

**Statement of the Problem**

In working with the VA VR&E program for the past few years, this author identified a considerable need to help service connected (SC) Veterans better identify with the array of complexities found in meeting the needs of their neuromuscular
disorders. Veterans diagnosed with neuromuscular diseases have many questions, such as How will my neuromuscular disorder affect my independent living needs? and How can my needs be accommodated so I can be successful at my desired vocational goal?

The current ILP services provided by VR&E to Veterans diagnosed with progressive neuromuscular disorders do not provide a clear, multidimensional analysis of what may be expected during the progressive stages in the diseases. Currently, there is no source providing such a guide. As suggested by Jan Rollings-Rapoza, a VRC with 17 years experience in counseling for the VA and specializing in VA ILP for the past 12 years, “A guide to help Veterans with neuromuscular disorders specifically focus on their foreseeable challenges, to include needs and accommodations, would be a valuable resource in helping them to achieve their maximum potential” (personal communication, August 13, 2012).

Veterans receiving services through an ILP are presently provided primary aids and resources to help them with their independent living needs. However, there is a considerable gap in the fundamental knowledge the VA provides in helping them understand their disability. This lack of knowledge not only can create overwhelming anxiety for a Veteran diagnosed with a neuromuscular disorder and diminish his or her achievement goals in an ILP, but can also slow down the Veteran’s rehabilitation process by limiting their progress in an IEEP aimed at a vocational goal toward feasible employment. A Veteran’s goal at either improving their independent living needs or vocational needs through an Individualized Extended Evaluation Program (IEEP) aimed
at feasible employment can be limited without the veteran knowing the comprehensive nature of the disability.

Awareness and understanding of the progression of a Veteran’s own disease is crucial for better accomplishing the meeting of the independent living needs, vocational training endeavors, potential abilities, and/or achievement of employment goals. This entails a visualization of the projected rehabilitation needs around the specified disorder, such as MG, MS, and PD. This includes the progressive chronological manifestations of the diseases in such areas as symptomology, functionality, medical needs, psychosocial impact, and needs in devices and accommodations.

One way of proffering support and reducing the feeling of uncertainty for people with progressive diseases is to provide information and education (Ahlstrom, Lindvall, Wenneberg, & Gunnarsson, 2006). Therefore, the development of a guide to help Veterans better visualize the overwhelming challenges and accommodations of their progressive and chronic neuromuscular conditions will help promote better success in their paths toward meeting their independent living needs or a course toward their desired vocational rehabilitation training.

**Limitations**

Neuromuscular rehabilitation integrates several branches of knowledge (Lederman, 2010). However, due to the sheer volume of medical, psychosocial, functional, and vocational needs of Veterans with progressive neuromuscular diseases, this author is not providing an exhaustive guide on all specified, relevant, and
multidimensional aspects. This research focuses on Veterans enrolled in ILP services diagnosed with the “three most common” progressive neuromuscular diseases of a muscular symptomatic nature, more specifically, disorders of Myasthenia Gravis, Multiple Sclerosis, and Parkinson’s disease. The research of this project is limited to California and, specifically, Northern California. Additionally, this research was conducted during a limited time frame of August 1, 2012 through October 31, 2012.

Lastly, the most prevalent limitation to this study is the author bias. Due to the author’s own SC Veteran status along with experiences in working with many SC Veterans within a vocational rehabilitation environment, the author believes SC Veterans with neuromuscular disorders have greater potential to succeed in their vocational and employment goals when given the appropriate guidance, direction, and support.

**Definition of Terms**

*Assistive Technology*

Assistive technology is technology used by individuals with disabilities in order to perform functions that might otherwise be difficult or impossible. Assistive technology can include mobility devices such as walkers and wheelchairs, as well as hardware, software, and peripherals that assist people with disabilities in accessing computers or other information technologies (Access It, 2012).

*Co-morbidity*

Two or more coexisting medical conditions or disease processes additional to an initial diagnosis (Anderson, Darer, Ferrucci, Fried, & Williamson, 2004)
Disability

Disability is defined as difficulty or dependency in carrying out activities essential to independent living, including essential roles, tasks needed for self-care and living independently in a home, and desired activities important to one’s quality of life (Anderson et al., 2004).

Independent Living Program (ILP)

For Veterans whose service connected disabilities are so severe they cannot immediately consider work (USDVA, 2010). The Independent Living program is to make sure that each eligible Veteran is able, to the maximum extent possible, to live independently and participate in family and community life, increasing their potential to return to work. Services may include the following:

- Assistive technology
- Specialized medical, health, and/or rehabilitation services
- Services to address any personal and/or family adjustment issues
- Independent living skills training
- Connection with community-based support services. (USDVA, 2010).

Individualize Extended Evaluation Program (IEEP)

The purpose of an extended evaluation for a Veteran is to determine the current feasibility of the Veteran achieving a vocational goal, when this decision reasonably cannot be made on the basis of information developed during the initial evaluation. During the extended evaluation, a Veteran may be provided:
- Diagnostic and evaluative services
- Services to improve his or her ability to attain a vocational goal
- Services to improve his or her ability to live and function independently in the community

The determination of the reasonable feasibility of a Veteran achieving a vocational goal will be made at the earliest time possible during an extended evaluation, but not later than the end of the period of evaluation, or an extension of that period. Any reasonable doubt as to feasibility will be resolved in the Veteran's favor. (National Archives and Records Administration, 2012, 38 U.S.C. 3106(c), Pub. L. 99-576)

Multiple Sclerosis

A slowly progressive central nervous system disease characterized by disseminated patches of demyelination in the brain and spinal cord, resulting in multiple and varied neurologic symptoms and signs, usually with remissions and exacerbations (Kaplan & Porter, 2011b).

Myasthenia Gravis

A disease characterized by episodic muscle weakness, chiefly in muscles innervated by cranial nerves, and characteristically improved by cholinesterase-inhibiting drug (Kaplan & Porter, 2011a). It is a chronic autoimmune neuromuscular disorder that is characterized by fluctuating weakness of the voluntary muscle groups (Job Accommodation Network [JAN], 2011b).
**Neuromuscular Disease**

A disease affecting one or more constituent components of the neuromuscular unit, which comprise motor neurons, neuromuscular synapses, and skeletal muscle (Muntoni & Wood, 2011).

**Palliative Care**

Palliative care is defined as “relieving or soothing the symptoms of a disease or disorder” (American Academy of Hospice and Palliative Medicine, 2012, para. 1). Palliative care is for people of any age, and at any stage in an illness, whether that illness is curable, chronic, or life threatening. Palliative care may actually help one recover from illness by relieving symptoms such as pain, anxiety, or loss of appetite, as one undergoes sometimes difficult medical treatments or procedures, such as surgery or chemotherapy (American Academy of Hospice and Palliative Medicine, 2012).

**Parkinson’s Disease**

An idiopathic, slowly progressive, degenerative central nervous system disorder with four characteristic features: slowness and poverty of movement, muscular rigidity, resting tremor, and postural instability (Kaplan & Porter, 2011b). It belongs to a group of conditions called motor system disorders (JAN, 2011c).

**Presumptive Service Connected Disability**

In the context of VA claims adjudication, a presumption relieves Veterans of the burden to prove that a disability or illness was caused by a specific exposure
during service in the Armed Forces. When a disease is designated as presumptively service connected, the individual Veteran does not need to prove the disease was incurred during service (Congressional Research Service, 2010). The conditions of Myasthenia Gravis, Multiple Sclerosis, and Parkinson’s disease are considered to be presumptive service connected diseases by the VA.

*Quality of Life (QoL)*

Refers to the capacity to engage in and derive satisfaction from socially and psychologically meaningful thought and behavior. Physical, psychological, and social function all contribute to QoL (Piccininni, Falsini, & Pizzi, 2004).

*Serious Employment Handicap (SEH)*

Represents a significant impairment of a Veteran’s ability to prepare for, obtain, or retain employment consistent with his or her abilities, aptitudes, and interests, and results in substantial part from a service connected disability (Veterans Benefits Administration [VBA], 2011).

*Service Connected Disability*

Service connected disabilities are current chronic disabilities diagnosed by a medical professional and determined by the United States Department of Veterans Affairs (USDVA) to have been caused or aggravated by military service or secondary to an existing service connected disability (Minnesota State Colleges and Universities, 2011).
Veteran

A person who served in the active military, naval or air service, and who was discharged or released under conditions other than dishonorable (Social Security Online, 2011)

Vocational Rehabilitation and Employment (VR&E)

The Vocational Rehabilitation and Employment (VR&E), also known as Vet Success and sometimes referred to as the Chpt 31 program, assists Veterans with service connected disabilities to prepare for, find, and keep suitable jobs. For Veterans with service connected disabilities so severe they cannot immediately consider work, VR&E offers services to improve their ability to live as independently as possible. Depending on their circumstances, Veterans will work with their VRC to select one of the following five tracks of services:

- Reemployment (with a former employer)
- Rapid access to employment
- Employment through long term services including OJT, college, and other training
- Self-employment
- Independent living services

This program is administratively found within the Department of Veterans Affairs, Veterans Benefits Administration. The Code of Federal Regulations that governs VR&E ILP is Title 38 Part III USC Chapter 31 (USDVA, 2010).
Vocational Rehabilitation Transitional Manual

The Merriam-Webster dictionary (vocational, n.d.) describes vocational as “Of, relating to, or undergoing training in a skill or trade to be pursued as a career,” while Brodwin, Siu, Howard, and Brodwin (2009) define rehabilitation as “counseling a person with a disability to assist that individual to acquire skills necessary for maximum functioning and greater independence” (p. ix). The terminology of transition is also defined by Webster (transition, n.d.) as “The process or a period of changing from one state or condition to another.” Together, these terminologies describe the definition of a vocational rehabilitation transitional manual as a guide that allows a Veteran with a diagnosed condition as defined under one of the three most common disabilities to assist [them] to acquire skills necessary for maximum functioning and greater independence.

Organization of the Project

The remaining segments of this project include a review of literature in Chapter 2. The review is organized by explaining the origin and significance of ILP, origin and significance of IEEP, the significant barriers and successes experienced by those diagnosed with a neuromuscular disorder, as well as accommodations in assistive technology. Chapter 3 presents the project methodology. Chapter 4 provides a summary and recommendations. The project, to be utilized by the Veteran as a comprehensive guide to address potential challenges, entitled A Vocational Rehabilitation Transitional
Manual for Veterans with Neuromuscular Disorders, is included as the Appendix followed by a list of references.
Chapter 2

REVIEW OF THE LITERATURE

Introduction

This literature review is organized in the order of statistics, presumptive service connection, and the origin and significance of both Independent Living and Individualized Extended Evaluations. The review continues with symptoms and limitations of those with neuromuscular disorders, management of neuromuscular disorders, as well as accommodations in assistive technology.

Neuromuscular disorder is a broad term encompassing many different syndromes and diseases that either directly or indirectly impair the function of the skeletal muscles, the muscles that move the limbs and trunk (The Cooperative International Neuromuscular Research Group [CINRG], 2012). Hence, the remainder of this project uses the term “three most common neuromuscular disorders” as interchangeable with “neuromuscular disorder(s)” along with their commonalities in areas of symptomology/functionality, psychosocial impacts, emotional/spiritual needs and needs in assistive devices in identifying Myasthenia Gravis, Multiple Sclerosis, and Parkinson’s disease.

Statistics

United States Veterans are in a distinctive class of Americans that has served and defended our country. As of 2010, the Veteran population stood at approximately 21.6 million (National Center for Veterans Analysis and Statistics (NCVAS), n.d.) out of a U.S. population of nearly 314.7 million (U.S. Census Bureau, 2012). Approximately

In reference to Chpt 31 VR&E services, approximately 9,470 California SC Veterans have been found entitled and are now currently enrolled, with an estimated 3,200 of those SC Veterans residing in Northern California (Norman Corson, personal communication, August 27, 2012). Currently, 122 of these Veterans utilize independent living program (ILP) services (Corporate Waco Indianapolis New York Roanoke Seattle [CWINRS], 2012). Among these SC Veterans utilizing ILP services are those who have been diagnosed with a progressive and debilitating neuromuscular disorder of Myasthenia Gravis, Multiple Sclerosis, or Parkinson’s disease (CWINRS, 2012). Of those Veterans receiving ILP services, three have been diagnosed with Myasthenia Gravis, two with Multiple Sclerosis, and two with Parkinson’s disease (CWINRS, 2012).

Currently, nationwide, at least one in 3,500 individuals develops a neuromuscular disease at some time during their life (Cup et al., 2011). For example, the prevalence rate for MG in the United States is estimated at 14 to 20 per 100,000 population with approximately 36,000 to 60,000 cases in the United States (Myasthenia Gravis foundation of America, Inc. [MGFA], 2010). However, myasthenia gravis is probably
under diagnosed making the prevalence most likely higher (Abbott, 2010). Additionally, as suggested by the author, this estimate includes that for females, the average age of onset is 20-30 years and 60-80 years for males. As stated by Howard (as cited in Abbott, 2010), most patients with MG are over 50 years of age. At present, patients receiving MG treatment usually lead full productive lives, although the mortality rate is about 5-9% (Maggi & Mantegazza, 2011).

Next, the occurrence rate of MS in America is approximately 400,000 persons (National Multiple Sclerosis Society [NMSS], 2012). The age at onset of MS ranges from 15 to 60 years, typically 20-40 year (Kaplan & Porter, 2011b). Of the aforementioned total, the VA Health Care System cares for more than 16,000 Veterans with MS and more than 6,000 of those have service connected MS (Paralyzed Veterans of America, 2011). Currently, the VA estimates that about 40,000 Veterans have the disease (Paralyzed Veterans of America, 2011). Only 5-10% of people with MS develop problems severe enough to interfere significantly with daily life (Broadwin et al., 2009). Forty percent to 60% have disturbances in mood and suicide risk may be as high as 15% (Beaumont, 2008; Freedman, 2005; Goldman & Ausiello, 2004) (as cited in Broadwin et al., 2009). Fatigue is the most common and difficult symptom of MS and occurs, in varying degrees, in about 80% of cases (Broadwin, 2009). Only 10% affected will need wheelchair support (Broadwin et al., 2009) and the most widely held hypothesis is that MS occurs in patients with a genetic susceptibility and is triggered by certain environmental factors (Centers for Disease Control and Prevention [CDC], 2010).
Lastly, America’s rate of Parkinson’s disease is estimated at approximately 1.5 million, and approximately 15% of those diagnosed are under 50 (JAN, 2011c). Today, the VA provides care to more than 80,000 Veterans living with Parkinson’s disease. This disease occurs most commonly after the age of 40 (Falvo, 1999). Collins et al., (as cited in Haar, Kirkevold, Hall, & Ostergaard, 2010) state, “It is the second most common neurodegenerative disease worldwide” (p. 408). In the United States, it is estimated that 60,000 new cases of Parkinson’s disease are diagnosed each year (JAN, 2011c) with the mean age of onset at 57 years (Kaplan & Porter, 2011b). This disease affects both men and women in almost equal numbers (JAN, 2011c).

**Presumptive Service Connection**

The United States has provided benefits in varying degrees to those who have worn the uniform and suffered disabilities in service to the nation (Congressional Research Service, 2010). Veterans who have shown their disability was incurred or aggravated, or that the death resulted from a disability incurred or aggravated, in the line of duty in the active military are granted a service connected disability (Congressional Research Service, 2010). However, if the relationship between disability and military service is not readily apparent, the burden of proving service connection can be a challenge to the Veteran (Congressional Research Service, 2010).

Because of these circumstances, Congress, along with the Department of Veterans Affairs, has relied on presumptions to help ease the burden placed on the Veteran (Congressional Research Service, 2010). To further define such “status,” Congressional
Research Service (2010) states, “When a disease is designated as presumptively service-connected, the individual Veteran does not need to prove that the disease was incurred during service” (p. 4). The VA presumes specific disabilities diagnosed in certain Veterans were caused by active duty due to the unique circumstances of their military service. As USDVA (as cited in Arapahoe County, 2011) stipulates, “If one of these conditions is diagnosed in a veteran in one of these groups, VA presumes that the circumstances of his/her service caused the condition, and disability compensation can be awarded” (para. 2).

The legislative history of Veterans’ disease presumptions dates back to 1921 when Congress established a presumption of service connection with an amendment to the War Risk Insurance Act of 1914 (P.L. 63-193) (Congressional Research Service, 2010). This established presumptions of service connection for tuberculosis and neuropsychiatric disease occurring within two years of separation from active duty military service (Congressional Research Service, 2010). The next piece of Legislation that established presumptions of service connection was the World War Veterans Act of 1924 (P.L. 68-242), which was enacted on June 7, and included specific diseases as presumptively service connected, such as mental illness, tuberculosis, and paralysis agitans (also known as Parkinson’s disease) (Congressional Research Service, 2010). With the enactment of P.L. 80-748 on June 24, 1948, the VA significantly expanded chronic disease and tropical disease categories that were previously established. This enactment also authorized the VA to add additional chronic diseases to the list.
(Congressional Research Service, 2010). By the time P.L. 85-56 was enacted on June 17, 1957, there were 40 chronic diseases or disease categories and 17 tropical diseases that were presumptively service connected (Congressional Research Service, 2010).

After taking into consideration the anxiety of Vietnam Veterans, the Veterans’ Dioxin and Radiation Exposure Compensation Standards Act of 1984 (P.L. 98-542) was passed, which allowed the VA to develop regulations for disability compensation for Vietnam Veterans exposed to Agent Orange (Congressional Research Service, 2010). Resulting from the Act of 1984, the Agent Orange Act of 1991 (P.L. 102-4) established for the first time a presumption of service connection for diseases associated with herbicide exposure. This Act stipulated that Veterans were no longer required to provide proof of exposure they thought to be associated with herbicides (Congressional Research Service, 2010).

The Act of 1991 also codified presumption of service connection for chloracne, non-Hodgkin’s lymphoma, and soft tissue sarcoma and established an entirely new process for evaluating the health effects of exposure to herbicides containing dioxin as well as for establishing presumptions of service connection for diseases associated with such exposure (Congressional Research Service, 2010). Within previous legislations, Congress has, on three separate occasions, created presumptive programs for three distinct groups of Veterans: Atomic Veterans, Vietnam Veterans, and Gulf War Veterans, as well as adding on presumptions for specific groups of Veterans such as former prisoners of war (POWs) (Congressional Research Service, 2010). Some diseases are
presumed service connected if they appear within a certain period of time after service. This allowed period of time to be called the presumptive period, ranging from one year to appearing any time after service (Abrams, Bartley, & Jones, 2008).

Among the service connected diseases Congress has found to be “presumptive service connected” are the diseases Myasthenia Gravis, Multiple Sclerosis, and Parkinson’s disease (VBA, 2010). Myasthenia Gravis and Multiple Sclerosis are defined as presumptive conditions under 38 CFR §3.309(e), Disease subject to presumptive service connection (a) chronic diseases.

The following diseases shall be granted service connection although not otherwise established as incurred in or aggravated by service if manifested to a compensable degree within the applicable time limits under §3.307 following service in a period of war or following peacetime service on or after January 1, 1947, provided the rebuttable presumption provisions of §3.307 are also satisfied. (MVC Workforce Development, 2012, p. 2)

Parkinson’s disease is defined as a presumptive condition under 38 CFR §3.309 Disease subject to presumptive service connection (e) Disease associated with exposure to certain herbicide agents.

If a Veteran was exposed to an herbicide agent during active military, naval, or air service, the following diseases shall be service-connected if the requirements of §3.307(a)(6) are met even though there is no record of such disease during
service, provided further that the rebuttable presumption provisions of §3.307(d) are also satisfied. (VBA, 2010 p. 7)

In general, no other presumption of service connection has had so many congressional hearings, or has been so extensively studied and debated, as has the establishment of presumption of service connection for diseases associated with exposure to Agent Orange (Congressional Research Service, 2010).

**Origin and Significance of Independent Living**

The Rehabilitation Act of 1973 (P.L. 93-112) and the Rehabilitation Act Amendments of 1992 (P.L. 102-569) are the current authorizing legislation for independent living services (Wilson, 1998). In 1976, the Vocational Education Act Amendments of 1967 (P.L. 90-99) and 1968 (P.L. 90-391) helped improve services for those with disabilities (Wilson, 1998). This 1976 Vocational Act resulted in increased funding for vocational education services to facilitate appropriate consumer input and, to some extent, control the score of services offered by both federally funded and privately owned disability service organizations and programs (Wilson, 1998). The author also indicates, that collectively, these pieces of landmark legislation serve as a framework for ILP services (Wilson, 1998).

Legislation initially shaped to address the vocational rehabilitation of Veterans due to severe service connected disabilities was first established as an amendment to the War Risk Insurance Act of 1917. This authority established courses for rehabilitation and vocational training for Veterans with dismemberment, sight, hearing, and other
permanent disabilities (USDVA, n.d.). The Vocational Rehabilitation Act of 1918, Public Law 65-178, expanded eligibility for vocational rehabilitation training to any honorably discharged disabled Veteran of World War I whose disabilities were considered vocationally “handicapping” (VBA, 2011). This Act was significant in that it was the first public policy in the U.S. that legislated comprehensive funding for assistive technology (AT). However, it was limited by its Veterans-only restriction and its required link to employment potential (Paralyzed Veterans of America, 2011). The Smith-Fess Act was passed in 1920 and set the stage for future rehabilitative legislation by broadening funded vocational rehabilitation services to all disabled citizens, not just Veterans. It provided funding for prosthesis, for example, if it was considered necessary for completion of work-related training (Paralyzed Veterans of America, 2011).

The Rehabilitation Act of 1973 became landmark legislation requiring “equality of opportunity through its provisions relating to consumer involvement, emphasis on persons with severe disabilities, creation of the National Institute on Handicapped Research, emphasis on program evaluation and the advancement of civil rights of persons with disabilities” (Martin and Gandy as cited in Paralyzed Veterans of America, 2011, p. 296). Additionally, the Rehabilitation Services Administration (RSA) was established by Congress as the principal federal agency authorized to carry out Titles I, III, VI, and VII, as well as specified portions of Title V of the Rehabilitation Act of 1973 to include independent living for individuals with disabilities (U.S. Department of Education, 2010).
In 1978, the Rehabilitation Act of 1973 was amended. This provided an array of independent living services (Moffat, Usiak, & Wehmeyer, 2004).

VA’s IL Program was first established in 1980 by Public Law 96-466, the Veterans Rehabilitation and Education Amendments of 1980. Initially, that law provided for the establishment of a four-year pilot program designed to provide independent living services for severely disabled Veterans for whom the achievement of a vocational goal was not reasonably feasible. The number of Veterans who could be accepted annually into the pilot program was capped at 500. In 1986, the program was extended through 1989 and then, in 1989, it was made in Public Law 101-237, the Veterans’ Benefits Amendments of 1989. In 2001, the 500 annual cap on enrollees was increased to 2,500 (U.S. Senate Committee on Veterans Affairs, 2009).

An ILP within Chpt 31 can be provided to Veterans who have SC disabilities so severe they cannot immediately consider work and can offer services to improve their ability to live as independently as possible (USDVA, n.d.). This program is authorized under Title 38, Code of Federal Regulations, Chapter 31, Training and Rehabilitation for Veterans with service connected disabilities (USDVA, n.d.). The primary goal of the VR&E program is to make sure each participant is able, to the maximum extent possible, to live independently or to obtain and maintain suitable entry-level employment (USDVA, 2005). To further clarify the first stage objective of the VR&E program, Norman Corson, Assistant VR&E Officer, Oakland regional office (personal communication, August 27, 2012), said, “Meeting the Veterans’ independent living needs
is the primary objective in providing VR&E services.” Also, the VBA’s Longitudinal Study (2010) states, “More than half of the Veterans participating in VR&E have a serious employment handicap, which means there is significant impairment of a Veteran’s ability to prepare for, pursue, or retain employment consistent with the Veteran’s abilities, aptitudes, and interests” (p. 11). This study continues in saying, “These Veterans receive additional supportive services which may include extensions of entitlement, adaptive equipment, job coaching and independent living services” (p. 7).

Means and Bolton (1992) indicate the importance in an ILP program by specifying, “Rehabilitation authorities recognize ILPs are in a unique position to offer employability services to persons with severe handicaps because employment success can often be achieved most efficiently within the context of an in-depth rehabilitation program” (p. 22). According to the research study, the two authors also suggest, “It may be assumed that ILPs are able to make unique contributions to the employment goals of some consumers” (p. 26). They go on to add, “This is due to the ILP focus on independent living needs supportive of vocational rehabilitation” (Means & Bolton, 1998, p. 26). All Veterans who apply for VR&E services are offered an individualized assessment of their interests, skills, and disability needs. Upon completion of the individualized evaluation process, Veterans enter a rehabilitation program to become job ready in their selected vocational choice or to achieve the maximum ability to live independently in the community (VBA, 2010). Services for ILP promote a philosophy of independent living including consumer control, peer support, self-help, self-
determination, equal access, and individual and system advocacy. This can allow greater integration and full inclusion of individuals with disabilities in community leadership, empowerment, independence and productivity (University of South Florida, Colleges of Arts and Sciences, n.d.).

**Origin and Significance of Individualized Extended Evaluation**

Extended evaluation involves the provision of one or more vocational rehabilitation services designed to assess whether the applicant or customer is capable of benefiting from or capable of continuing to benefit from vocational rehabilitation services in terms of an employment outcome (Washington State Legislature, 2005). In other words, the purpose of the extended evaluation is to obtain information necessary to make an eligibility decision or to determine if trial work experience can be utilized (Washington State Legislature, 2005).

The Smith-Fess Act of 1920, also known as the Civilian Vocational Rehabilitation Act, is considered the starting point of public rehabilitation for people with disabilities. Funding was provided to the states on a 50/50 match (Moraru & Neilson, 2012). The Vocational Rehabilitation Act Amendments of 1965 further expanded the federal-state funding ratio to 75:25 and provided 6- and 18-month extended evaluations to determine if more severely handicapped individuals might benefit from vocational rehabilitation services, thereby making it possible to provide many services prior to formal acceptance into a program (University of South Florida, Colleges of Arts and Sciences, n.d.).
As defined under Federal Legislation, Title 38, CFR 21.57 (a), the purpose of an extended evaluation for a Veteran with a serious employment handicap is to determine the current feasibility of the Veteran’s achievement of a vocational goal, when this decision cannot reasonably be made on the basis of information developed during the initial evaluation (GPO, 2011). Title 38, CFR 21.74 (a) states that in general terms, an extended evaluation may be authorized for the period necessary to determine whether the attainment of a vocational goal is reasonably feasible for the Veteran. The services that may be provided during the period of extended evaluation are listed in §21.57(b) (136), which reads: (b) Scope of services. During the extended evaluation, a Veteran may be provided:

(1) Diagnostic and evaluative services;

(2) Services to improve his or her ability to attain a vocational goal

(3) Services to improve his or her ability to live and function independently in the Community

(4) An allowance as provided in §21.260. (GPO, 2012b, para. 1)

The National Archives and Records Administration (2012) defines this timeframe by, The determination of the reasonable feasibility of a Veteran achieving a vocational goal will be made at the earliest time possible during an extended evaluation, but not later than the end of the period of evaluation, or an extension of that period. Any reasonable doubt as to feasibility will be resolved in the Veteran's favor. (para. 1)
Symptoms and Limitations of Neuromuscular Disorders

Most neuromuscular diseases (NMD) have a progressive clinical course characterized by increase in muscular weakness (Piccininni et al., 2004). Sooner or later, patients are confronted with impairments in function, activity limitations, and participation restrictions (Cup et al., 2011). Leigh (as cited in King, Duke, & O’Connor, 2009) suggests, “Many decisions and choices are required by people as they journey with their disease and they experience progressive physical, psychological and social losses” (p. 746). Haar et al. (2010) indicate that getting a diagnosis for some individuals can create anxiety about what may happen next. For example, after conclusion of their research, Haar et al. (2010) found that one such participant indicated a specific response after being diagnosed with PD, stating, “The diagnosis caused speculation about what the future would bring” (p. 412). For example, neuromuscular conditions are complex and varied and most cause generalized muscle weakness (Haar et al., 2010).

Skeletal muscle is the most abundant tissue in the body, and many neuromuscular disorders are multisystemic conditions (Muntoni & Wood, 2011). For example, Muntoni and Wood also indicate that in addition to affecting skeletal muscle, these disorders affect other forms of muscle (such as cardiac and smooth muscle), the central nervous system and other tissues. The authors go on to suggest, “Depending on the precise cause of the disease and the neuromuscular components that are primarily affected, these diseases result in a range of clinical manifestations” (Muntoni & Wood, 2011, p. 621). As
Brodwin et al. (2009) specify, these movement disorders can consist of extreme slowness of movement or complete or partial absence of movement.

For example, indicators of Myasthenia Gravis have many different signs and symptoms, which may be quite noticeable or vague and can include fatigue and weakness especially with increased exercise (Armstrong & Schumann, 2003). The primary muscles most frequently involved with MG include those that control eye movement, eyelids, chewing, swallowing, coughing, and facial expression. Muscles that control breathing and movements of the arms and legs may also be affected (JAN, 2011b). Symptoms of MG can cause fatigue/weakness, vision impairment, speech impairment, and fine and gross motor impairment (JAN, 2011b). Drachman (2007) also suggests Myasthenia Gravis can manifest as an unstable or waddling gait, weakness in arms, hands, fingers, or legs, and can cause drooping of the head and neck. Armstrong and Schumann (2003) conclude, “Individuals [with MG] may complain of abnormal smile and difficulty pronouncing words” (p. 73). The authors also add, “Patients may also have respiratory problems related to muscle weakness” (p. 73). Additionally, Kulkantrakorn, Sawanyawisuth, and Tiamkao (2010) add that patient research findings suggest, “From the patient’s perspective, myasthenia gravis symptoms largely affect physical and emotional functionality in large part due to culture and socioeconomic status” (p. 571).

Indicators of Multiple Sclerosis are often characterized by a pattern of exacerbation and remission and can be mild or severe (JAN, 2011a). For example, Symptoms can include numbness in limbs to severe paralysis or loss of vision (JAN,
2011a). Brodwin et al. (2009) suggest additional symptoms of Multiple Sclerosis include fatigue, muscle weakness, numbness, spasticity, slurred speech, muscle cramps, bladder or bowel problems, sexual dysfunction, and possible paralysis. The authors also indicate, “In addition to fatigue, approximately half the people with MS develop some degree of progressive cognitive dysfunction, which affects ability to think, reason, concentrate, and remember” (p. 324). For example, as suggested by Leigh (as cited in King et al., 2009), patients who experienced numerous changes in response to progressive decline in functioning meant they continuously lived with uncertainty, not knowing what aspect of life would be “lost” next. Gordon, Lewis, and Wong (as cited in Roessler, Rumrill, and Fitzgerald (2004) indicate, “Many people with MS who are capable of retaining employment leave the workforce prematurely due to their fears about the uncertainties of their condition” (p. 100).

Symptoms of Parkinson’s disease, which often appear gradually yet with increasing severity, may include slowness of movement, tremor, muscle rigidity, and abnormalities of postural reflexes (JAN, 2011c). Kaplan and Porter (2011c) add, “A resting tremor of one hand is often the first symptom” (p. 1765). The authors also indicate, “In most patients, the disease begins insidiously” (p. 1765). Although some patients have relatively few troublesome symptoms for many years, others will have especially severe cases that leave them with little or no mobility in just a few years (JAN, 2011c). Poewe (as cited in Haahr et al., 2010) suggests, “They often develop neuropsychiatric and other non-motor symptoms, such as depression, anxiety, reduced
cognitive function, sleep disturbances, fatigue and autonomic disruptions” (p. 409). Limitations with daily tasks include getting in and out of bed, rising from a chair, walking, maintaining balance, and turning to look behind while driving (Baron et al., 2011). Also, Brodwin et al. (2009) indicates, “The effects of PD can interfere with activities such as shaving, buttoning clothes, or cutting food” (p. 57).

Lastly, another challenging aspect for those with a NMD can be due to employment and or vocational limitations from the disease (Roessler et al., 2004). For example, distress is associated with work experienced by those with neuromuscular disorders and is related to several activities including prolonged duration of low-level activity; no facilities on the job; and the exertion, frustration, and discomfort experienced in travel to and from work (Brodwin et al., 2009). These authors also suggest, “Depending on the nature and extent of paralysis, respiratory and global muscle involvement results in a wide spectrum of vocational limitations” (p. 105). Also, physical impairments, activities such as ambulation, and employment present major challenges due in large part to fatigue from overuse of muscles, a noticeable limp, slowness of gait or inability to walk, and shortness of breath (Brodwin et al., 2009). As Roessler et al. (2004) also suggest, “increased fatigue, pain, physical limitations, and cognitive disturbances negatively affect the person’s ability to perform job functions, which ultimately requires job modification or restructuring efforts to restore job-person compatibility” (p. 100).
Management of Neuromuscular Disorders

Despite differences in etiology and pathogenesis, patients with NMD share the clinical feature of increasing muscle weakness over time. As there is currently no curative therapy for most NMD, disease management addresses mainly the treatment of the functional limitations (Pieterse et al., 2008a). As Pieterse et al. (2008b) suggest in Part Two, “In the early stages of the disease, patients with slowly progressive, chronic neuromuscular disorders (NMD) usually have mild functional limitations” (p. 863). However, as Deluca and Nocentini (2011) explain, “It is important in determining a diagnosis in the early stages the disorder” (p. 213). Schenkman et al. (2011) also suggest, “Based on accumulated evidence, it is clear that early physical intervention can have positive benefits for these individuals” (p. 1340). Additionally, “To benefit from current mechanistic understanding of muscle disorders, it is important that the diagnosis of a muscle disorder be made early” (Spuler, Stroux, Kuschel, Kuhlme, & Kendel, 2011, p. 1).

“There are two major reasons why establishing a prognosis for a chronic disease that can span most one’s life is important: 1) to provide guidance for making decisions about the future, and 2) to determine the level of aggressiveness and timing of therapeutic interventions” (Deluca & Nocentini, 2011, p. 199). As Strange (as cited in Alstrom et al., 2004) indicates, “By providing information and education, this may help the patient to mobilize his or her own resources and develop new ways of coping with illness-related problems in order to achieve goals in life in spite of the disease” (p. 133). Hence, people
who have a better understanding of their condition can be empowered to self-care more effectively and are more likely to initiate behavioral actions that challenge their fears (Lederman, 2010). Also, Rae-Grant et al. (2011) indicate, “Self-management programs may foster awareness and skills to help prevent negative outcomes, such as falls, and encourage positive health behavior, such as exercise” (p. 1096).

Living with a neuromuscular disease has its challenges, though. Performance of basic functional activities is critical to maintaining independence and staving off disability (Schenkman et al., 2011). The course of the disease often varies across individuals as well as within the same individual at different times during the course of the disease (Deluca & Nocentini, 2011). As well, Lederman (2010) suggests “treatment should be goal-oriented, with clear input regarding the patient’s expectations and personal goals. Maintenance of physical independence in those with neuromuscular disorders is important, but is not determined by this alone” (Lederman, 2010, p. 90). For example, McCluskey (2007) said, “as physical capacity waned, psychological, religious and existential factors appeared to maintain and even improve the patient’s quality of life” (p. 408).

Halbertsma et al. (as cited in Piccininni et al., 2004) also suggests, “The increase in disability is reflected in the individual’s social participation and greatly conditions the perception of the quality of life (QoL)” (p. 113). King et al.’s (2009) research in regard to “ongoing change and adaptation” suggests that positive change to stress resulted in sustained self-esteem and positive self-perception and well-being (p. 745). Similar levels
of disability are also conditioned by many other factors, such as the patient’s personality, his/her lifestyle before the onset of disease, humor, initiative, and economic and environmental factors. “Therefore, each individual perceives the disease in a different way” (Piccininni et al., 2004, p. 113). For example, Corey (2009) has suggested, “For many clients in crisis, the spiritual domain offers solace, comfort, and is a major sustaining power that keeps them going when all else seems to fail” (p. 454).

Although there are concerns regarding disabilities in neuromuscular disease, symptoms can be managed (Jamero & Dundore, 1982). For example, the most common symptoms of MG (50% of cases) are drooping of the eye with fluctuations in weakness and fatigue, which improve with rest (Armstrong & Schumann, 2003). Although severity ranges from mild to severe, complete remission can occur (Abbot, 2010). Those diagnosed with MS have a relatively normal lifespan (Rae-Grant et al., 2011) with this disease shortened in only severe cases (Kaplan & Porter, 2011a). Although there is no cure, many therapies are available to treat symptoms such as spasticity, pain, bladder problems, fatigue, and weakness (NMSS, 2012). Lastly, while Parkinson’s symptoms tend to worsen over time (National Institute of Neurological Disorders and Stroke [NINDS], 2004), the disease is initially well-treated with medication (Haahr et al., 2010). There are no treatments capable of slowing or arresting the progression of PD; however, current treatments can very effectively relieve the symptoms, especially in the early years (University of Maryland and Medical Center, 2011). Many people never reach the advanced stages of PD because they live a normal life span and continue to receive
significant benefit from their anti-Parkinson medications (University of Maryland and Medical Center, 2011). Additionally, the influence of complications and co-morbidities may also have a significant impact on prognosis at the individual level (DeLuca & Nocentini, 2011).

**Rehabilitation and Assistive Technology for Neuromuscular Disorders**

Although NMDs are not curable, they are treatable and do respond to rehabilitation (Jamero & Dundore, 1982). Rehabilitation is an integral part of the long-term treatment of patients with neuromuscular disease (Spranger, 2008). As Cardol et al. (2002) suggest, “Thorough assessment of perceived restriction(s) in participation is essential to understand the social impact of chronic illness on a person’s life and to be able to offer tailored rehabilitation programmes according to individual needs” (p. 27).

A greater appreciation of functional limitations associated with different stages of disease progression may guide timely initiation of rehabilitation interventions, with the goal of delaying functional decline (Schenkman et al., 2011). Cardol et al. (2002) indicate that rehabilitation treatment in chronic illness ultimately aims to restore a person’s participation in society, despite persistent sequelae of illness, such as impairments and disabilities (p. 27). Ultimately, the purpose of any rehabilitation goal is to empower the individual with a disability to successfully participate in all phases of life (Brodwin et al., 2009).

The goal of assistive technology (AT) is to enhance functional independence for individuals who have disabilities. The focus, therefore, is not on the disability, but on the
remaining functional abilities people use to accomplish their chosen objectives (Brodwin et al., 2009). Rehabilitation uses several approaches to reduce the impact of a disease upon health and well-being and by increasing the range of activities a person can perform; AT is a feasible method of optimizing participation (Friederich, Bernd, & De Witte, 2010). For example, according to the authors’ responses from specialized rehabilitation centers for clients with diseases of the nervous system or mixed rehabilitation facilities, the two most frequently indicated types of assistive technology were for personal care and protection and housekeeping. For personal care and protection, they included AT for dressing and undressing, body and skin protection, personal hygiene, incontinence care, washing, bathing, and showering. For housekeeping, they included AT for eating and drinking. The authors also suggest, “The aids most frequently prescribed were bath seats, mobility aids, grab bars, and removal of door thresholds” (Friederich et al., 2010, p. 312).

Although unpredictability means loss of control and, hence, loss of independence, accommodations through devices can help prolong independence (Haar et al., 2010). Because neuromuscular disorders are progressive conditions, physical changes occur over time, requiring the ongoing need for assistive devices to maintain functionality (Muscular Dystrophy Canada, 2012). For example, for those with neuromuscular diseases, disability is reflected by fatigue from overuse of muscles, a noticeable limp, slowness of gait or inability to walk, and dyspnea (shortness of breath) (Brodwin et al., 2009). Several devices help people with disabilities (Muscular Dystrophy Canada, 2012). For
example, assistive devices range from walking aids to transfer devices to home adaptations such as ramps (Spuler et al., 2011). Additionally, ATs, such as mobility aids and memory aids, can help in self-care or household tasks (Muras, Stokes, & Cahill, 2008). Also, communication equipment devices can range from communication letter boards, to computer-based systems with sophisticated software and speech synthesizers (Muscular Dystrophy Canada, 2012). Various types of body supports called orthoses help support joints in certain positions when muscles weaken, prevent contractures if spasticity is a problem, enhance comfort, and aid in function (Muscular Dystrophy Canada, 2012).

As in many chronic diseases, individuals require ongoing care coordination, including medication, disease and symptom management, and education as well as strategies for addressing acute exacerbations (Rae-Grant et al., 2011). However, as Spuler et al. (2011) suggest, “Any future therapeutic strategy will probably only make a real difference in prognosis if the treatment is begun early in the course of the disease” (p. 5).
Chapter 3

METHODOLOGY

The vocational rehabilitation transitional manual was developed to provide Veterans with a brief synopsis of symptoms and accommodations attributed to the three most common diseases found among Veterans enrolled in Chpt 31, ILP, Myasthenia Gravis, Multiple Sclerosis, and Parkinson’s disease. The manual in this project was developed with the idea of helping SC Veterans visualize the manifestation of their progressive disease and help lessen their fear and anxiety that can come with being diagnosed with a chronic disorder. A guide such as this can help the Veteran continue meeting their independence in daily living and/or help strengthen their ability to succeed in an individualized extended evaluation program (IEEP) aimed at feasible employment.

The author’s interest in the challenges faced by SC Veterans diagnosed with progressive diseases first began in 2011 during work-study experience with the Department of Veterans Affairs, Vocational Rehabilitation & Employment (VR&E), Oakland regional division, Sacramento satellite office. During the author’s participation in working with independent living in-home evaluations while under the guidance of Jan Rollings-Rapoza MSC, VRC, she learned that no information was available as a quick reference manual addressing the chronological manifestation of these diseases, such as symptomology, functionality, medical and emotional needs, psychosocial impact, and needs in technological accommodations.
The research involved a review of the three most common diseases found among SC Veterans enrolled in an ILP through VBA data source CWINRS (2012), peer-reviewed journals, books, and websites. Also, personal discussions with VR&E counselors through the year of 2011-2012 were done to retrieve information. The literature review occurred during 2012. The author’s first interview with Jan Rollings-Rapoza, a VRC for the Department of Veteran affairs, occurred August 13, 2012; additional contacts were made with her throughout the development of the manual. A personal interview with Dr. Norman Corson, Assistant VR&E Officer occurred on September 3, 2012 to assist with statistical information. Throughout 2011 and 2012, this author also had the privilege to speak with several SC Veterans who had been diagnosed with one of the three most common neuromuscular disorders. Conversations with these Veterans provided much knowledge and insight about their own specific experiences with their disease. Several discussions with Dorothy Devereux of Vocational Resource Services during the Fall of 2012 provided valuable information and resources in reference to assistive technologies for neuromuscular disorders. For an additional reference, contact was made in July 2012 with Maria Hernandez, case manager with experience in ILP services with the Department of Rehabilitation for the State of California. During discussions with Ms. Hernandez, it was revealed that she was unaware of any such information providing a brief synopsis of symptoms and accommodations for those with neuromuscular disorders.
During the Fall 2012 semester, this author met with her advisor several times for
draft evaluation, annotations, and suggestions. In November 2012, after final review and
evaluation, this project and manual was presented to Guy Deaner, Ph.D. for review and
appears in its final form.
Chapter 4

SUMMARY AND RECOMMENDATIONS

Summary

The development and culmination of the author’s work is a manual entitled *A Vocational Rehabilitation Transitional Manual for Veterans with Neuromuscular Disorders* (see Appendix). This manual is a foundation to provide SC Veterans a reference through which to gain knowledge and understanding of the needs and accommodations they may require while living with a neuromuscular disorder. Although the severity of a Veteran’s neuromuscular disability may displace them from employment many times, education and insight about the progressive stages of their disease can help increase their medical, psychological, social, and vocational capabilities, leading to a successful vocational rehabilitation training program.

It is the author’s hope that with the use of this manual, the Veterans will find the most recent information on accommodations and assistive devices needed to better understand the progression of their diagnoses of Myasthenia Gravis (MG), Multiple Sclerosis (MS), or Parkinson’s disease (PD). This manual may also allow Veterans to better prepare for future potential challenges in order to meet their independence in daily living or help strengthen their ability to succeed in an individualized extended evaluation program (IEEP) aimed at possible employment.
Recommendations

“Knowledge of the history, onset, and course of a disease process is significant in rehabilitation” (Brodwin et al., 2009, p. 286). Due to Brodwin et al.’s statement and to the continued advances in technology, it is the recommendation of this author that a revision of the manual be accomplished and a periodic update be considered. Also, since this manual only emphasizes the scope of meeting independent living needs as well as needs necessary to help Veterans strengthen their ability to succeed in an IEEP, the need for a manual directed solely at employment needs of Veterans with neuromuscular disorders should be considered.

Due to the vast array of progressive and debilitating diseases with which SC Veterans can potentially be diagnosed, future research should be directed toward additional disorders that can pose a challenge to the Veterans’ independent living needs or employment goals. Additionally, Veterans who are SC and found entitled to ILP services do not have the financial hardship in meeting their medical needs compared to those who do not qualify for ILP services under VA care. Therefore, a manual directed toward addressing affordable accommodations in providing assistive technology and/or alternatives for those with progressive neuromuscular disorders could very well be considered a valuable resource for not only those diagnosed with such a disease but for family members and caregivers as well.

Providing a transitional manual for three types of neuromuscular disorders, such as the manual presented, required extensive research that limited the concentration of
information that could be incorporated into this manual. It is recommended that research and focus of only one specific disorder be considered as to allow the author to provide a more extensive analysis of the medical, psychosocial, functional, and vocational needs of Veterans with a progressive neuromuscular disease, thus allowing for better insight and knowledge for the Veteran.

This project is focused on providing SC Veterans knowledge and guidance about accommodations and needs for specific neuromuscular disorders within the state of California. Other states may need to develop a comparable manual for their individual state since the diseases of MG, MS, and PD can be presumed by the VA to have a relation to certain herbicide agents and environmental exposures. Other public and private entities providing vocational services to those with progressive disabilities may also be interested in the development of a transitional manual.

The manual designed in the Appendix does contain some author bias due to the author’s experience in working with the Department of Veterans Affairs, VR&E. The development of a manual of this same nature by another individual may suggest a different viewpoint.
APPENDIX

A Vocational Rehabilitation Transitional Manual for Veterans with Neuromuscular Disorders
Providing Awareness and Knowledge

A Vocational Rehabilitation Transitional Manual for Veterans with Neuromuscular Disorders
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ABOUT THE COVER

The American flag and eagle placed on the cover is in honor of all active duty military and Veterans for their pride, dedication, and achievements. It also signifies those who had the courage to sacrifice their lives in defending honor, duty, and country. Many service connected (SC) Veterans living with a disability such as a neuromuscular disorder continue with the same level of pride and dedication to be able to gain continued achievement by living a productive and fulfilling life. The cover resembles the importance of their plight in needing to accommodate challenges to meet their independence in daily living or to help strengthen their ability to succeed in vocational training.
PREFACE

In developing this manual, it became evident there was a need for a comprehensive resource for SC Veterans to use as a reference for information and guidance on neuromuscular disorders. There are a multitude of references, books, and materials published about the disorders of Myasthenia Gravis (MG), Multiple Sclerosis (MS), and Parkinson’s disease (PD); however, the amount of material quickly becomes overwhelming. For the SC Veteran, it is important to have readily available informational access for them to draw upon as they live with the progression of their neuromuscular disorder. Veterans diagnosed with such diseases will have many questions. How can I cope with my diagnosis? What will my family and friends think? How will my neuromuscular disorder affect my independent living needs? How can my needs be accommodated to be successful in my desired vocational goal?

This manual is not meant to embody all aspects of MG, MS, and PD. The intent and design is to be a quick resource for Veterans to recognize current and future challenges found in meeting the needs of their disease in areas such as symptomology, functionality, psychosocial, emotional/spiritual, and assistive technology. Although a neuromuscular disease is not curable, it is treatable and can be successfully managed.
INTRODUCTION

This manual has been developed for SC Veterans enrolled in ILP services who have been diagnosed with one of the “three most common neuromuscular disorders” of a progressive, muscular symptomatic nature, more specifically, disorders of MG, MS, and PD. Due to the presumptive service connection status of these disorders and the high prevalence among Veterans, the author found it appropriate to focus specifically on these disorders. This manual has been developed to familiarize the Veteran in areas of commonalities found among these disorders such as symptomology, functionality, psychosocial needs, and needs in assistive technologies. This transitional manual can help guide SC Veterans in meeting their independence in daily living or to help strengthen their ability to succeed in an individualized evaluation program aimed at possible employment.

Understanding the manifestation of a neuromuscular disease can lessen fear and anxiety that can come with being diagnosed and can provide better visualization for a projected outcome. Neuromuscular disorder is a broad term that encompasses many different syndromes and diseases that either directly or indirectly impair the function of the skeletal muscles, the muscles that move the limbs and trunk (The Cooperative International Neuromuscular Research Group [CINRG], 2012, p.1). Because of the sheer size and scope of these diseases, this author is not providing an exhaustive guide on all specified, relevant, and multidimensional aspects related to MG, MS, and PD.
For a service connected (SC) Veteran newly diagnosed with a progressive neuromuscular disease of MG, MS, or PD, it can be a time of uncertainty and fear. The symptoms of the disease felt over the past several months may make you wonder “What may happen next?” Better understanding and common knowledge about the progression of your neuromuscular disease can ease fear and anxiety.

To begin with, it is important to remember that the majority of the time, the disorders MG, MS, and PD do not adversely affect life expectancy. Although these disorders are not curable and many challenges will develop through the progression of such a disease, life expectancy can be nearly the same as an otherwise normal individual and symptoms can be treatable. Although some symptoms of MG, MS, and PD can be life-threatening, much of the time, there are ways in which to manage these symptoms. Having access to good information, the right treatments and attitude, and support from both family and friends can have great benefits on living a productive life with a neuromuscular disease.

It is easiest to categorize these neuromuscular disorders as directly or indirectly affecting the motor neurons of the nervous system, which may include the muscles, nerves, or the junction between the muscles and nerves. For example, MG is considered an autoimmune disease and, although rare, considered the most common primary disorder of neuromuscular transmission. This disorder affects the neuromuscular junction (the space between the nerve ending and the muscle). Symptoms of MG occur
when normal communication between nerve receptors and muscles is interrupted at the neuromuscular junction. This interruption is caused by antibodies that destroy or block the receptors. Antibodies are important, for they are substances made by the body’s immune system to fight germs and infections. Some scientists suggest that an abnormal thymus gland (a small gland located under the breastbone) may be responsible for the immune system attacking the receptors attached to the muscle. Although MG can be progressive, for some, surgery to remove the thymus may result in permanent remission or a decreased need for medicines. Most individuals with MG have a normal life expectancy. The etiology is unclear with regard to causes of MG; however, research suggests it is a multifactorial disease, and may have a slight genetic predisposition, viral or bacterial factor. Congress has determined MG a presumptive service connected condition, therefore suggesting influential factors of environmental exposure.

Like MG, MS is also categorized as an autoimmune disease; however, it is considered a disease of the central nervous system (CNS) and can be progressive in nature. Although MS is a disease of the CNS, it does indirectly affect the motor neurons. With MS, the immune system turns on itself and attacks the nerve cells (axons), damaging its protective sheath called myelin, which in turn, forms scar tissue (lesions). Symptoms you can experience depend on the site and severity of these lesions. This is why you may experience different symptoms at different times. Sometimes the CNS can repair the damaged myelin; this is why relapses (noticeable symptoms) can be followed by episodes of remission (when symptoms improve or disappear altogether). Life
expectancy of people with MS is typically only 5-10 years lower than that of the unaffected population. A scale known as the Expanded Disability Status Scale can be a way of measuring physical disability for those with MS. This scale measures increments from zero to nine, with zero being no symptoms of disability and nine being confined to a bed. The majority of those with MS do not progress past level six, which is rated at “assistance required to work.” While the etiology of MS is unknown, research suggests components of either a genetic predisposition to infectious exposure to numerous viruses, bacteria, or other microbes may play a role. The disorder of MS is also considered a presumptive service connected condition for military Veterans, indicating a strong link to environmental and industrial toxins, diet or trace metal exposures.

Lastly, PD shares some commonalities of MG and MS in that it is considered by most research studies to have an autoimmune component. Like MS, PD is considered a degenerative disease of the CNS; however, it indirectly affects the muscles and is progressive in nature. With PD, brain cells that produce dopamine (which is a neurotransmitter) gradually die in an area of the brain called the substantia nigra. Dopamine is responsible for sending messages to the areas of the brain that deal with muscle activity and movement. When this neurotransmitter area dies, the brain starts to lose the ability to tell the body when and how to move. This manifestation is what is responsible for creating tremors, the classic and typically first noticeable signs of PD. Although PD is considered a serious progressive condition, it is not considered a fatal
illness. Those who have PD usually have the same life expectancy as people without the disease.

Although there is no cure, treatments can help ease symptoms. It is also important to be mindful about the disease progression and its advanced stages due to life-threatening complications such as falls, pneumonia, and choking. The Hoehn Yahr is a widely used scale providing a general estimate of clinical function in PD (Goetz et al., 2004). It is a rating scale from zero to five that can help define the broad description and determine various stages of PD. Although thinking about the progression of this disease can be frightening, proper treatments can help you to live a full, productive life for years to come. Risk factors of PD may include genetic predisposition as well as age. The strongest indicator suggests chronic exposure to environmental toxins may increase the risk of PD. Exposure to certain pesticides and herbicides can double the risk of developing Parkinson's disease. Because research suggests such a strong indication to toxin exposure, PD has been determined by Congress to be a presumptive service connected condition.

COMMON SYMPTOMOLOGY AND FUNCTIONALITIES

The diseases of MG, MS, and PD are found to have common, muscular symptomatic characteristics affecting the muscles and nerves. For Veterans diagnosed with one of the three most common neuromuscular disorders, some may experience symptoms differently and in different combinations. Depending on time of diagnosis, and stage of progression, some symptoms may be mild and for others they may be more
severe. Sometimes just one symptom may appear while other people may have many symptoms. Major symptoms may disappear while others will have permanent and progressive symptoms. These include common symptoms such as:

- Low muscle tone
- Delayed motor milestones like delayed walking or abnormal gait
- Muscle weakness, atrophy, twitching, or rippling

For example, the symptoms of MG progress very differently for each person. This disorder causes weakness of the voluntary muscles (muscles under your control; you think about moving your arm and it moves), is progressive in nature, and fluctuates in severity. For those with MG, muscle weakness tend to worsen with activity and improve with rest. The symptoms of MG tend to progress over time, usually reaching their worst within a few years after the onset of disease. However, for many diagnosed with MG, it can be effectively managed with little impact on life expectancy with the appropriate treatment. In more than half the people who develop MG, their first signs and symptoms involve eye problems, such as:

- Drooping of one or both eyelids (ptosis)
- Double vision (diplopia), which can be horizontal or vertical (see Figure 1)
In addition to eye problems, additional symptoms of MG involve neck muscles and difficulties with:

- Altered speaking
- Difficulty swallowing
- Problem chewing
- Limited facial expressions

Other areas affected by MG include limb muscles affecting walking, using your arms and hands, and holding up your head. Crisis situations in which muscle weakness involves the breathing muscles may occur without warning with under or overuse of medications. Hospitalization and assistance with breathing may be required during these attacks; however, these attacks seldom last longer than a few weeks.

Much like MG, MS progresses very differently for each person and can have many of the same characteristics of MG. However, unlike MG, exercise can provide
helpful benefits to those with MS. Although there are no symptoms in the beginning stages, damage to the CNS may still be progressing. After a diagnosis, you may experience symptoms such as numbness, tingling, or vision loss. At times, early in the disease, you may have complete relapses in your first years after a diagnosis. Especially early in the disease, it is not uncommon for several years go by between relapses. Later, as MS progresses, you may experience tremors as well as difficulty with coordination and walking. During this time, relapses may become more frequent and it may be more difficult to recover. Typically, the more relapses one has in the first two years of their disease will affect the number of years before a person will need accommodations for ambulation or assistive technology. The more relapses within the first two years may lead to faster progression. Through the stages of progression, you may experience many, if not all, of the following symptoms to some degree:

![Diagram showing relapse frequency over years](image)

Source: MS Active Source (2012)

*Figure A2. Fewer relapses indicate greater independence with Multiple Sclerosis*
Fatigue, weakness, visual disorders, numbness, dizziness and vertigo, bladder and bowel dysfunction, impaired mobility, sexual dysfunction, slurred speech and swallowing disorders, tremors and spasticity (leg stiffness), chronic aching pain, depression, and mild cognitive and memory difficulties are most often exacerbated by extreme fatigue which can worsen during an increase in temperature. The symptoms of PD do have many of the same symptomatic characteristics as MG and MS. Although the disease of PD is progressive in nature and will get worse over time, it is not considered fatal and the progression of symptoms can take 20 years or even longer; however, the rate of progression does vary from person to person. Each person with PD will experience symptoms differently, as well. For many, the most common symptoms include tremor-like movements; although, others may not have tremors but may have problems with balance. Also for some, the disease may progress quickly and in others it may not. Generally, individuals will have initial symptoms that only affect one side of their body for a number of years; however, the symptoms will, in time, begin on the other side as well. Some of the more common motor symptoms include:

- Tremors
- Loss of balance
- Stiffness and rigid limbs
- Walking problems
- Slow movement (bradykinesia)
Advanced stages of PD can consist of memory loss, stooped posture and freezing, mask-like expressions and unwanted accelerations, sleep disturbances, speech difficulties and drooling, breathing and swallowing problems, and urinary incontinence. Research has suggested that non-motor symptoms (those not involving movement) can precede motor symptoms and a PD diagnosis by years. These recognizable symptoms include:

- Loss of smell
- REM behavior disorder (a sleep disorder)
- Cognitive disorders (neuropsychiatric disturbances)
- Orthostatic hypotension (low blood pressure when standing up)

There is no cure for PD and the progressive nature can be frightening; however, proper treatments can help a person live a full and productive life.

**PSYCHOSOCIAL FACTORS**

When newly diagnosed with a neuromuscular disorder, you may experience confusion, anxiety, or even a sense of anger. New choices need to be made and tasks may feel overwhelming. You may need some time to adjust to the new diagnosis. Most family and friends will try to be supportive, but at times they might not know what to do. Eventually, once you learn about the disease and treatment options, you can begin to develop a plan toward living a new life with the disorder. You may find yourself living and adjusting to a “new normal.”

Psychosocial factors are determinants of health and well being and should be taken into consideration when adjusting to a diagnosis of MG, MS, or PD. The term
psychosocial refers to the psychological development of the individual in relation to his or her environment and/or the influence of social factors on mental health and behavior (University of Washington Alcohol and Drug Abuse Institute, 2011). These factors include such areas as physical, social, and mental (emotional, spiritual) aspects and differ from person to person. For example, extreme fatigue can often make physical symptoms worse among those with neuromuscular disorders. Social arenas such as culture, value beliefs, and economic condition all play an important role in the management of living with a neuromuscular disorder. Emotional status, anxiety level, and perception about health and illness will play an intricate part as well.

It is important to remember the following:

- The impact on stress and health can affect the body’s immune response
- Social environment has a strong connection to influencing health.
- Communication and interpersonal skills are essential to the activities of daily living
- Anxiety level affects the ability to breath, eat, and drink

When addressing your physical, social, and mental needs, you might want to consider support groups that can address your own life stage and reflect your stage of development (i.e., age, sexuality, role in family or even family status). Support groups can provide information gained from experience and network of understanding. Having open discussions with family members and friends can also be beneficial. You may also want to consider researching the prospect of a service, therapy, or companion dog for
your disability. Assistance dogs can be trained to perform an impressive range of tasks including guiding; alerting to sounds; opening and closing doors; retrieval; pulling wheelchairs; providing balance support; turning lights on and off; and responding to changes in the physiological, mental, or emotional state of their human partner.

As a SC Veteran entitled to ILP services, the Veterans Health Administration (VHA) along with the Veterans Benefits Administration (VBA) can provide you with an array of social services, health services, and independent living program (ILP) services to meet your needs in coping with your neuromuscular disorder. For example, services for ILP promotes a philosophy of independent living including consumer control, peer support, self-help, self-determination, equal access, and individual and system advocacy. This can allow greater integration and full inclusion of individuals with disabilities in community leadership, empowerment, independence and productivity (University of South Florida, Colleges of Arts and Sciences, n.d.).

Lastly, it is important to note, that medication can be a major aspect in the treatment of a neuromuscular disorders. These medications may include over-the-counter drugs as well as prescribed ones. Because each neuromuscular disease has its own uniqueness in both physiological and neurotransmission properties, medication will vary based on individual and disorder.

EMOTIONAL ADJUSTMENT AND SPIRITUAL NEEDS

When your limitations begin to arise and functionality becomes difficult, grieving is a necessity. Remember, it is a normal process to be sad and even angry about a
limitation that can alter your life. Changes of this kind may force you to develop a
different picture of yourself and changing your self-image can be difficult. You may
have questions such as:

- Who am I now that I can no longer do things the way I used to?
- What are my goals now and what will they be in the future?
- What changes do I need to make, and what are my options?

It is important for you to remember that emotional upset is a big factor that can
worsen many neuromuscular disorders. Having a chronic disorder can be stressful and
people react to stress in different ways. You can either see it as a challenge or as a
problem. Your attitude, fears, worries, and level of self-confidence can all influence the
severity of symptoms. Emotional factors can be seen as both internal and external. Your
feelings can either be related directly to the disease process itself or influenced by
external factors. Changes that occur can be due to the disease itself, altering brain
chemistry or influenced by external factors due to one’s reaction to the situation. Some
common emotional reactions include the following:

- Denial/Disbelief
- Depression
- Stress

Although your disorder may be out of your control, your attitude about it is
something you can control. The following tips are ways in which you can help yourself
cope emotionally:
- Avoid self-criticism for it only makes things worse
- Do not let the disorder define who you are
- Find things to be grateful for
- Find a support group; it can offer a safe place to address your feelings, questions, or concerns
- Eat a proper diet and utilize proper exercise for your specific disorder
- Be your own friend; have patience with yourself

Research has shown that spiritual well being is positively correlated with life satisfaction (Brodwin, Brodwin, Howard, & Siu, 2009). Spirituality may help patients and families find deeper meaning and experience a sense of personal growth during the progression of their neuromuscular disease. Often, those who rely on their faith or spirituality tend to experience increased hope and optimism, freedom from regret, higher satisfaction with life, and feelings of inner peace. For example, Corey (2009) suggested, “For many clients in crisis, the spiritual domain offers solace, comfort, and is a major sustaining power that keeps them going when all else seems to fail” (p. 454).

Although some people prefer religious traditions or spirituality to help with feelings of optimism and hope to help them adjust to their neuromuscular condition, others may find comfort in other traditions. The importance in being proactive in activities that help with relaxation, flexibility, and balance can be emotionally beneficial. The following activities can promote such benefits:

- Meditation
• Yoga
• Tai Chi
• Art, Music Therapy

Additionally, acupuncture and massage can provide emotional well being (and physical) benefits. Psychotherapy can also help you cope with associated conditions such as depression. These treatments together can help in providing long-term success and independence in helping you adjust in your daily living needs.

ADAPTATIONS FOR FAMILY MEMBERS AND CAREGIVERS

When you have a neuromuscular disorder, everyone else in the home, on some scale, is living with the condition as well. It is important for family members, caregivers, and friends of persons with a neuromuscular disease to learn as much as possible about the disease and coping strategies in order to equip them in the knowledge that helps not only you, but everyone else, particularly early on in the disease. This can allow for a better transition during the progression of your disease. The following areas can help this transition:

• Talk about your neuromuscular disorder
• Allow your family, friends, and caregivers time to adapt to a change in lifestyle
• “Check in” with your caregivers; ask how they are doing
• Prepare for the “unexpected”
• Make it a point to focus on the positive
Many times, family members and caregivers need time to adjust. A diagnosis can place limitations on family activities, finances, and chores. Plans can get canceled at the last minute due to the care and needs of a progressive neuromuscular disorder. Also, caregiving, at times, can become all consuming without realizing it. Asking how your family members are doing during challenging periods from time to time can be an appreciated acknowledgement.

ACCOMMODATIONS AND ASSISTIVE TECHNOLOGY

Learning to cope with a change in mobility using assistive accommodations can provide great value in your journey with a neuromuscular disorder. Although living with MG, MS, or PD has its challenges, performance of basic functional activities is critical to maintaining independence and staving off disability (Schenkman et al., 2011). An effective rehabilitation program including accommodations with assistive technology (AT) can help maximize your physical and psychosocial functions.

Since the symptoms of a progressive neuromuscular disease tend to worsen as time goes on, it is important to be consistent in recognizing these physical/cognitive changes and to make adjustments accordingly. However, it is important to remember, it can take time to learn how to adjust to your new disabilities. Although you may feel anxious in the beginning about regression in your health due to your disease of MG, MS, or PD, the majority of the symptoms experienced are not considered fatal and the progression of symptoms can take many years. Many individuals diagnosed with one of the three most common neuromuscular disorders have a normal or near normal life
expectancy. Also, the degree of symptoms among individuals with a neuromuscular disorder will vary greatly, ranging from localized to generalized.

As a Veteran, you may have either just been diagnosed with a neuromuscular disorder of MG, MS, or PD and are awaiting a SC rating, or are currently a SC Veteran utilizing ILP services provided by the Veterans Administration (VA). If you are utilizing ILP services, you already know the VA’s, Vocational Rehabilitation and Employment (VR&E) program offers ILP services for Veterans with SC disabilities so severe they cannot immediately consider work (U.S. Department of Veterans Affairs, n.d.). This ILP offers services to improve the Veterans’ ability to live as independently as possible. The ILP can offer needed accommodations and AT for you to obtain independence in daily living. In the event you are able to overcome your impairments and want to participate in avenues toward possible employment, the VA can provide individualized extended evaluation services (IEEP) to accommodate this need. The purpose of an extended evaluation is to determine the current feasibility of the Veteran achieving a vocational goal, when this decision cannot reasonably be made on the basis of information developed during the initial evaluation (U.S. Government Printing Office, 2011).

While in an ILP to address and accommodate your independent living needs, it is important to take advantage of the different types of assistive technology and/or devices that can help you learn to manage everyday activities more effectively. You may have to relearn how to do tasks you used to be able to accomplish easily such as speaking, walking, grooming, and dressing, using stairs, getting in or out of the shower/tub, and
performing cognitive issues such as problem solving. This may also include learning new skills by using AT. Assistive devices will never replace the ease of human functioning; however, they can offer alternative strategies for accomplishing many of life’s tasks. AT includes any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of people with disabilities (Brodwin et al., 2009).

At times, Veterans using IL services may only need simple adaptations to help them become familiar and self-confident in learning to adjust to their disabilities. For example, physical limitations found within the mild stages of the three most common neuromuscular disorders include visual impairment and fatigue. Visual impairments can be accommodated by a portable magnifier, monocular, or binocular and fatigue can be addressed with sleep regulation or relaxation training. As the neuromuscular disease progresses, a more concentrated effort will be needed to help accommodate specified needs. For example, the moderate stages of these diseases may include unstable gait or tremors, which can be accommodated by walking canes or low-impact exercise to help maintain balance and mobility. Physical therapy can also help reduce tremor and improve coordination. The advanced stages may include AT devices to help improve disabilities such as progressed speech impairments and cognitive impairments. Accommodations for these needs may require AT devices such as high-tech voice output devices for speech impairments to personal digital assistants (PDAs, i.e., Palm Pilot),
which can provide an auditory prompting feature to assist individuals with cognitive
decline.

Progression Tables 1-3 illustrate some common progressive symptoms found
within the three most common neuromuscular disorders of Myasthenia Gravis, Multiple
Sclerosis, and Parkinson’s disease and indicate how the use of assistive technology can
help accommodate functionality. Specific symptoms each person will experience can
vary greatly.
### Table A1: Mild Stages of Myasthenia Gravis, Multiple Sclerosis and Parkinson’s Disease

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Functionality</th>
<th>Accommodations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Vision Difficulties</strong></td>
<td>• blurred/sporadic loss of vision</td>
<td>• use enlarged text</td>
</tr>
<tr>
<td></td>
<td>• color blindness</td>
<td>• pop-up pocket lens</td>
</tr>
<tr>
<td></td>
<td>• graying of vision</td>
<td>• book lights</td>
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<tr>
<td></td>
<td></td>
<td>• bold line paper</td>
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<tr>
<td><strong>Fatigue</strong></td>
<td>• feelings of sleepiness</td>
<td>• proper diet, exercise</td>
</tr>
<tr>
<td></td>
<td>• lack of energy</td>
<td>• cooling devices</td>
</tr>
<tr>
<td></td>
<td>• increased irritability</td>
<td>• dry climate</td>
</tr>
<tr>
<td></td>
<td>• inability to concentrate</td>
<td>• frequent breaks</td>
</tr>
<tr>
<td><strong>Muscle Weakness/Peripheral</strong></td>
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</tr>
<tr>
<td></td>
<td>• numbness</td>
<td>• stretching exercises</td>
</tr>
<tr>
<td></td>
<td>• resting tremors</td>
<td>• reaching devices</td>
</tr>
<tr>
<td></td>
<td>• tingling in arms/legs</td>
<td>• grip handles</td>
</tr>
<tr>
<td><strong>Speech Difficulties</strong></td>
<td>• alteration in speech</td>
<td>• mouth exercises/use of muscle group</td>
</tr>
<tr>
<td></td>
<td>• nasal tone</td>
<td>• behavior speech therapy</td>
</tr>
<tr>
<td></td>
<td>• distorted words</td>
<td></td>
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<tr>
<td><strong>Deficits in Cognition</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• forgetfulness</td>
<td>• cueing/memory aids</td>
</tr>
<tr>
<td></td>
<td>• distractibility</td>
<td>• reduce job stress</td>
</tr>
<tr>
<td></td>
<td>• concentration difficulties</td>
<td>• delegate tasks</td>
</tr>
<tr>
<td><strong>Impaired Movements</strong></td>
<td>• brief resting tremors</td>
<td>• mobility cane</td>
</tr>
<tr>
<td></td>
<td>• off –balance</td>
<td>• note taker</td>
</tr>
<tr>
<td></td>
<td>• toe drag</td>
<td>• gait training</td>
</tr>
<tr>
<td><strong>Pain</strong></td>
<td>• electrical sensation in peripheral areas</td>
<td>• reduce physical exertion</td>
</tr>
<tr>
<td></td>
<td>• feeling of pins and needles</td>
<td>• allow for flexible work schedule</td>
</tr>
</tbody>
</table>
Table A2: Moderate Stages of Myasthenia Gravis, Multiple Sclerosis and Parkinson’s Disease

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Functionality</th>
<th>Accommodations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vision Difficulties</td>
<td>holes in field of vision</td>
<td>modified keyboards</td>
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<tr>
<td></td>
<td>double vision</td>
<td>eye patch</td>
</tr>
<tr>
<td></td>
<td>jerky eye movements</td>
<td>electronic magnifier</td>
</tr>
<tr>
<td>Fatigue</td>
<td>depression</td>
<td>continue with proper diet</td>
</tr>
<tr>
<td></td>
<td>feelings of exhaustion</td>
<td>and exercise</td>
</tr>
<tr>
<td></td>
<td>acute fatigue</td>
<td>take breaks</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Yoga</td>
</tr>
<tr>
<td>Muscle Weakness</td>
<td>stiffing of muscles</td>
<td>emergency alert devices</td>
</tr>
<tr>
<td></td>
<td>difficulty with coordination</td>
<td>for home</td>
</tr>
<tr>
<td></td>
<td>foot drop</td>
<td>frequent rest</td>
</tr>
<tr>
<td></td>
<td></td>
<td>walker</td>
</tr>
<tr>
<td>Speech Difficulties</td>
<td>softness of voice</td>
<td>voice amplifier</td>
</tr>
<tr>
<td></td>
<td>monotone voice</td>
<td>augmentative</td>
</tr>
<tr>
<td></td>
<td>episodes of loudness</td>
<td>communication device</td>
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<tr>
<td>Deficits in Cognition</td>
<td>mild/memory difficulties</td>
<td>ID jewelry</td>
</tr>
<tr>
<td></td>
<td>difficulties with problem solving</td>
<td>cueing/memory aids</td>
</tr>
<tr>
<td></td>
<td></td>
<td>handheld PDA</td>
</tr>
<tr>
<td>Impaired Movements</td>
<td>limited dexterity</td>
<td>grab bars</td>
</tr>
<tr>
<td></td>
<td>stiffness in limbs and trunk</td>
<td>built-up utensils</td>
</tr>
<tr>
<td></td>
<td></td>
<td>laser case</td>
</tr>
<tr>
<td>Pain</td>
<td>pins and needles</td>
<td>avoid rapid twisting of spinal</td>
</tr>
<tr>
<td></td>
<td>burning sensation</td>
<td>column</td>
</tr>
<tr>
<td></td>
<td>neck pain</td>
<td>ergonomic work station design</td>
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Table A3: Advanced stages of Myasthenia Gravis, Multiple Sclerosis and Parkinson’s Disease

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<tr>
<th>Symptoms</th>
<th>Functionality</th>
<th>Accommodations</th>
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<tbody>
<tr>
<td>Vision Difficulties</td>
<td>• Sporadic loss of vision</td>
<td>• digital talking book player</td>
</tr>
<tr>
<td></td>
<td>• Blindness</td>
<td>• closed circuit TV</td>
</tr>
<tr>
<td></td>
<td>• eye pain</td>
<td>• pin hole glasses</td>
</tr>
<tr>
<td>Fatigue</td>
<td>• Depression</td>
<td>• Continue in a proper diet,</td>
</tr>
<tr>
<td></td>
<td>• chronic fatigue</td>
<td>• exercise/breaks</td>
</tr>
<tr>
<td></td>
<td>• hopelessness</td>
<td>• telephone headset</td>
</tr>
<tr>
<td>Muscle Weakness</td>
<td>• “masked” face expression</td>
<td>• Text-to-voice phone</td>
</tr>
<tr>
<td></td>
<td>• swallowing difficulties</td>
<td>• Text scanning software</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Tai chi</td>
</tr>
<tr>
<td>Speech Difficulties</td>
<td>• slurred speech</td>
<td>• talking switch</td>
</tr>
<tr>
<td></td>
<td>• drooling</td>
<td>• puff-n-sip phone</td>
</tr>
<tr>
<td></td>
<td>• abnormal speech pattern</td>
<td>• voice activated</td>
</tr>
<tr>
<td>Deficits in Cognition</td>
<td>• spoken or written language is often difficult</td>
<td>• ID Jewelry</td>
</tr>
<tr>
<td></td>
<td>• poor visual memory</td>
<td>• radio/tracking device</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• palm pilot</td>
</tr>
<tr>
<td>Impaired Movements</td>
<td>• head shaking</td>
<td>• electric wheelchair</td>
</tr>
<tr>
<td></td>
<td>• voluntary movement impairment</td>
<td>• foot lift assists</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• x straps</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• foot/leg orthotics</td>
</tr>
<tr>
<td>Pain</td>
<td>• chronic/severe</td>
<td>• acupuncture</td>
</tr>
<tr>
<td></td>
<td>• severe joint aching</td>
<td>• massage therapy</td>
</tr>
<tr>
<td></td>
<td>• abdominal pain</td>
<td>• meditation</td>
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