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Occupational Therapy Caregiver's Guide to Spinal Cord Injury

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OCCUPATIONAL THERAPY CAREGIVER'S GUIDE TO SPINAL CORD INJURY

by

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Approval Page

This Scholarly Project Paper, submitted by Kelsey Berg, MOTS and Amanda Larson, MOTS in partial fulfillment in the requirement for the Degree of Master's of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under who the work has been done and is hereby approved.



Faculty Advisor



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ABSTRACT

In 2006, it was estimated that there were 253,000 Americans living with spinal cord injuries (SCI) (Spinal Cord Injury Information Network, 2003, p. 1). Current literature suggests that individuals are transitioning into the community earlier with the majority of care being provided by informal caregivers (Boschen, Tonack, & Gargaro, 2005). These caregivers are often unprepared for the major role they will be assuming in the care of their loved one and often their health and well-being is compromised due to the overwhelming nature of caregiving.

A comprehensive literature review was conducted to explore and identify the needs of caregivers. Topics researched included spinal cord injury (SCI), treatments, caregiving, caregiver needs and interventions, and caregiver resources. In addition, the literature was reviewed regarding best practice strategies to deal with the changing needs and lifestyles the family may experience. The literature review revealed that there were few resources examining caregivers of individuals with SCI, many of the needs of the caregiver were identified and shown to be underserved.

Based upon the literature review, the *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* has been developed to assist caregivers in performing their new role of primary caregiver. It provides them with information on basic patient care guidelines as well as information on the caregiver's physical and psychosocial well-being. The guide also provides the caregiver with information on the importance of

continuing their prior occupations along with their new occupations. Lastly, the guide will provide the caregiver with a list of resources that may be useful in trying times such as the benefits of respite care.

The authors hope that the guide will begin to bridge the gap faced by caregivers of individuals with spinal cord injury. It is hoped that unifying the resources and strategies in the guide will decrease the caregivers stress so he or she can be in a more healthy and supportive role during the recovery process.

CHAPTER I

INTRODUCTION

Each year there are approximately 11,000 new spinal cord injuries (Spinal Cord Injury Information Network, 2003, p. 1). In 2004, there were nearly 30 million people serving as caregivers in the United States alone (National Family Caregivers Association and Family Caregiver Alliance, 2006, p. 1). Not only is it hard for the family to accept the injury their loved one has suffered but, they are also expected to be responsible for their loved one's health and wellbeing and often they are very unprepared for this role.

Currently, there are several major problems being faced by caregivers of individuals with spinal cord injury. First, due to the nature of shorter rehabilitation stays, therapists must choose the most important interventions to address, while less vital information may not be covered, leaving the patient and their caregiver less prepared to return to the community. Caregiver manuals are currently available for caring for individuals with many different diagnoses including spinal cord injury. There is not a specific guide that encompasses many of the difficulties faced by caregivers of individuals with spinal cord injuries. In addition, the available guides are not developed for use specifically by an occupational therapist. Occupational therapists have the skills needed to be in the forefront of assisting caregivers.

A comprehensive literature review was conducted to explore and identify the unique needs of caregivers of individuals with spinal cord injury. This led to the

development of the *Occupational Therapy Caregiver's Guide to Spinal Cord Injury*.

This guide is based on evidence-based research and is designed to provide occupational therapists with a tool to help minimize the burden that is experienced by caregivers. The sections in this guide include:

- ❖ Introduction
- ❖ Caring for Yourself
- ❖ Medical Management
- ❖ Adaptation
- ❖ Resource list

The *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* is to be used by OT's when treating spinal cord injury clients and their caregiver during rehabilitation and community reintegration.

The theory chosen to help guide the production of this product was Malcolm Knowles Adult Learning Theory of Andragogy. This theory makes the following assumptions about adult learning: (1) Adults need to know why they need to learn something, (2) Adults need to learn experientially, (3) Adults approach learning as problem-solving, and (4) Adults learn best when the topic is of immediate value (Brueggeman, 2006; Padberg, 1990). The first assumption was used to develop the introduction to the guide, when explaining to the caregiver the importance of the role they are partaking in. The second assumption comes into play when the caregiver uses information from the guide and previous experiences to provide better care for their loved one. The third assumption was addressed within problem based worksheets that ask the caregiver to assess their own situation and develop possible solutions. The fourth

assumption was used when creating all sections of the guide because the topics of each section were identified in the literature review as being of immediate value to the caregiver.

Occupational therapists have the skills needed to empower the caregiver to be an active learner and problem solver. The *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* will serve as a tool for the caregiver to aid in their independent problem solving with the therapist to facilitate this interaction.

The chapters of this scholarly project are presented in the following order:

- ❖ Chapter II – A review of literature presenting information on spinal cord injury (SCI), treatments, caregiving, caregiver needs and interventions, caregiver resources, and occupational therapy's role was conducted. Also included in this chapter is a description of the *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* and the theory that was used in its design.
- ❖ Chapter III – The methodology used to gather information for the development of the *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* is outlined in this chapter.
- ❖ Chapter IV – Presented in this chapter is an introduction to the product and the product in its entirety.
- ❖ Chapter V – Includes a summary of the information obtained and presented throughout the *Occupational Therapy Caregiver's Guide to Spinal Cord Injury*.
- ❖ References

CHAPTER II

LITERATURE REVIEW

Introduction

In 2006, it was estimated that there were 253,000 Americans living with spinal cord injuries (SCI) (Spinal Cord Injury Information Network, 2003, p. 1). Current literature suggests that individuals are transitioning into the community earlier with the majority of care being provided by informal caregivers (Boschen, Tonack, & Gargaro, 2005).

Rehabilitation stays are increasingly short, the coping/adjustment process is often prolonged. Patients and their families are likely only beginning to comprehend what has happened to them at the time of discharge. It is likely that the bulk of emotional care and support, therefore, will be the responsibility of the caregiver (Richards & Shewchuk, 1996, p. 2).

During the rehabilitation stay caregivers may not understand how important their own health and wellbeing is in relation to adequately caring for their loved one. At this time, they also may not be thinking into the future when they will be responsible for identifying signs of injury or illness experienced by the individual with the SCI. Therefore, education must be provided to both the patient and caregiver during and following the rehabilitation stay (Manns & May, 2007).

A literature review was conducted to identify the needs of the caregiver and the best practice strategies and resources to deal with the changing needs and lifestyle the

family will experience. Although numerous websites and guides are available to the individuals with a SCI and their families, there is not a guide specific to treating the occupational and psychosocial needs of the caregiver from an occupational therapy (OT) perspective. Current literature supports a need for training and follow-up education of the caregiver subsequent to the rehabilitation phase (Boschen et al., 2005; Elliot, Kurylo, & Lindsey, 1998; Grey, Horowitz, O' Sullivan, Kharasch Behr, & Abreu, 2007; Manns & May, 2007; Moghimi, 2007).

Based upon the results of this current literature review, an occupational therapy based guide was developed. The *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* was designed to specifically address the needs of the caregiver during the patient's transition from rehab to the community and will also include basic home program guidelines. The following information was gleaned from the research literature: defining the caregiver; the caregiver's roles and responsibilities; the issues and needs of the caregiver as well as the role of the OT and OT services in this process. The review of literature will culminate with the presentation of the *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* as an effective resource tool to facilitate a more positive and healthy transition for both the client and their loved ones.

Caregiver

Who is the Caregiver?

Individuals with spinal cord injury often receive support from family and friends who are considered to be informal caregivers. For the purpose of this project, an informal caregiver is defined as any person who regularly provides physical care and emotional support to a person who has suffered a spinal cord injury and who is not paid

to do so (Elliott et al., 1998; Gray et al., 2007; Raj, Manigandan, & Jacob, 2006).

Formal caregivers are those individuals who have received formal training and who are paid for their services (Gray et al., 2007). This scholarly project will primarily focus on the informal caregiver's since they are the untrained caregiver in need of the most education, training, and support. The term caregiver will be used synonymously with informal caregiver.

In a study on the psychological wellbeing of caregivers, Manigandan et al. found that 52.6 percent of caregivers were spouses and 28.9 percent were parents. Richards and Shewchuk (1996); Unalan et al. (2001); and Blanes, Carmagnani, and Ferreira (2007) all found that approximately 80% of caregivers who participated in these studies were female with an age ranging from young to old. Most caregivers in these same studies reported having at or below a high school education with very few having college educations (Richards & Shewchuk, 1996; Blanes, et al., 2007).

Caregivers Roles

Caregivers of people with a SCI face a unique role in relation to many other caregivers, because clients with SCI have longer life expectancies than many other diagnoses. The caregiver is expected to perform their role as the primary caregiver for an indefinite length of time (Elliot et al., 1998).

It is often forgotten that, in addition to gaining a tremendous new role as a caregiver, the individual is also losing many roles that were previously very important to them. For instance, they may have to quit working or change jobs and they may not have as much time for the leisure activities that they previously enjoyed (Elliot et al., 1998). Due to these life changes, the caregiver's social system may also change during a time

when they are in need of the most social support (Borg & Hallberg, 2006; Sheija & Manigandan, 2005). It is obvious that the relationship between the individual with the newly acquired SCI and the family member who takes on the role as the primary caregiver will change.

Although caregivers are often involved in the acute rehabilitation phase, they are not always prepared for the large role they must assume. It can often be very difficult to adjust to being more of a teacher and supervisor to their loved one. Caregivers are often a critical link during the rehabilitation process, yet the focus is often entirely placed on the patient.

Caregivers Responsibilities

The caregiver is often responsible for making sure that the individual that they are caring for follows their daily routines and makes good decisions about their lifestyle so that their health isn't compromised (Elliot et al., 1998). When a problem arises, the caregiver is in charge of seeking the correct treatment. Caregivers must be educated to detect signs and symptoms of secondary complications. Prevention and early intervention is necessary for a positive health outcome to procure. Elliot and Shewchuk (2001) suggest that problem solving by both the caregiver and the care recipient is key in preventing secondary complications.

Due to the shortened nature of acute rehabilitation, therapists are often forced to prioritize interventions. Caregivers are frequently educated during the rehabilitation stage for supportive care in a group setting with minimal to no opportunity for hands-on practice. Boschen et al. (2005) found that there are fewer opportunities to provide education and guidance to the caregiver involving their newly acquired role. This makes

it difficult to prepare the caregiver to face the many challenges that caregiving entails. At the time of discharge, caregivers are often expected to be competent in range of motion (ROM), positioning, pressure relief, assistance in activities of daily living (ADL), and the use of equipment (Atkins, 2002).

Caregivers have numerous responsibilities and often neglect their own personal wellbeing. Richards and Shewchuk (1996) found that caregivers spend an average of 10.3 hours per day fulfilling their responsibilities. In order for caregivers to provide adequate care, they need to be taking care of themselves.

Caregivers Needs

Caregivers who have not been well prepared for their role and responsibilities in discharge care, without adequate resources, struggle to deal with the issues their loved one is experiencing, as well as their own. In Post et al. (2005), it was found that many spouses who were providing care experienced high burden of support. Post et al. (2005) suggest that the burden is higher if; 1) the injury is more severe, 2) the injury is recent, and 3) the caregiver is responsible for a majority of the client's ADL care. The review of literature identified caregiver needs in the areas of: emotional, physical, knowledge, support systems, and accessing healthcare professional assistance. Each of these areas will be presented and discussed in the following section.

Emotional: In a study by Raj et al. (2006), 53% of the caregivers were documented as having psychiatric disorders, the most common being depression and anxiety. High levels of stress, degeneration of health, increase in feelings of depression, and lower life satisfaction are all contributors to the caregiver's burden. If not dealt with,

it can result in nursing home placement of the individual with SCI. For these reasons prevention of caregiver burnout should be an integral part of the lifelong care process.

Physical: Caregivers are at high risk for physical ailments as reported by Borg and Hallberg (2006), who found that almost half of all caregivers rated their overall health as poor to fair. Blanes et al. (2007) reported that caregivers make more visits to the doctor and have an increased incidence of psychiatric morbidity when compared to the general population. This study also found that caregivers have a tendency to meet with friends less often due to their role as primary caregiver. All of the above mentioned factors contribute to the low life satisfaction that is often experienced by caregivers (Borg & Hallberg, 2006).

Knowledge: The caregiver is an integral part of the information seeking process and often the one responsible for detecting and reacting to various problems related to the injury or secondary complications. The literature shows that there is a need for resources that are accessible to both the patient and the caregiver. “Accessing and using information related to topics such as health, technology, housing, attendant services, respite care, and peer support remains an elusive task for many support providers” (Unalan et al., 2001, p. 403).

Caregivers must be able to seek, identify and use appropriate information when preventing, detecting, and solving problems associated with the injury. Information should be accessible but also reliable and many have expressed feelings of difficulty when attempting to access information that is readily available. Many of the participants spoke of using the internet as their main resource after rehabilitation because they did not

retain the information they had received during their rehabilitation (Manns and May, 2007).

Not only is information important, how and when it is presented is also important. Manns and May (2007), found that individuals and caregivers feel that they are given too much information when at the rehabilitation center. One individual, who suffered a spinal cord injury, stated that the information that is given to both him and his caregiver should be spread out over a longer period of time (Manns & May, 2007). Upon the return home, the client and caregiver encounter new situations that require problem solving and individuals resort to digging up old information or searching for new.

Support Systems: In a study on life satisfaction of caregivers, Borg and Hallberg (2006) suggest that receiving adequate support from others can help to increase a caregiver's contentment; however, many caregivers are receiving very low levels of support. Boschen et al. (2005) found that ignoring the importance of emotional wellbeing for both the patient and the caregiver is poor practice technique, therefore, efforts to increase the support of both parties is imperative. Research suggests that additional resources and support networks need to be readily available to reduce the emotional instability and burnout experienced by primary caregivers (Post et al., 2005).

Accessing Healthcare Professional Assistance: Currently, the ways in which services are being delivered require that the client must always be directly involved, making it difficult to give the caregiver the attention they need (Moghimi, 2007). This lack of attention may result in the caregiver failing to seek help when they need it. Although there are a number of resources available to caregivers they often go unutilized because they are overwhelming and difficult to access. Moghimi (2007) found that

although caregivers were supplied with resources very few of them used the resources or sought out assistance. Because the caregivers are untrained they are not providing the highest level of care possible, which can lead to more money spent on healthcare for the care recipient as well as themselves. It has been found in populations not specific to SCI, that providing training to family caregivers reduced costs for care, improved life satisfaction, and decreased family burden (Patel, Knapp, Evans, Perez, & Kalra, 2004).

Family caregivers operate as an integral component of the health care delivery system and are responsible for a wide range of services that, in the past, were provided formally by traditional health care providers and usually have to be given for an indefinite period (Post, Bloeman, De Witte, 2005, p. 311).

As presented thus far, in order for the client and family to make a good adjustment, the caregiver needs training and education. This training and education needs to come from all healthcare professionals including OT.

Occupational Therapy's Role

Occupational therapists are an integral part of the rehabilitation phase of recovery and therefore have an obligation to provide support to the patient and caregiver as they transition into the community. This phase of rehabilitation is termed "community re-integration" and involves learning to deal with the disability and the effects it has on functioning in daily activities (Forchheimer & Tate, 2004).

The Occupation of Caregiving

Historically, OT has focused on how individuals complete daily occupations, the meaning these occupations have in their lives, and the fulfillment they receive from participating (Law, 2002). A main goal of occupational therapy is to assist individuals, with or without disabilities, in performing occupations or tasks that are necessary and meaningful for the job of living (Clark, Corcoran, & Gitlin, 1995).

Pierce, (2000) described occupations such as caregiving as a “co-occupation” since they can only occur with someone else. Caregiver’s are often times forced into the job of caregiving with little time to prepare and minimal training. These caregivers previously had set roles and routines that involved occupations that were meaningful and fulfilling to them. With the new occupation of caregiving, caregivers are finding it difficult to balance their new role with their previous roles, causing an inner struggle (Gray et al., 2007). As with all new occupations, caregiving presents with many challenges that are unique to each person. Due to the client-centered and occupation-based approaches that occupational therapists provide, many of these unique needs can be addressed, resulting in higher satisfaction of the caregiver and an increase in the quality of care provided to the care recipient.

Therapist/Caregiver Relationship

The caregiver no longer needs to be the hidden client or the hidden healthcare provider, but rather needs to be seen as a vital member of the team (Moghimi, 2007). Clark et al. (1995) suggests that the caregiver be viewed as a “lay practitioner” because often caregivers are hesitant to offer their input. The reason for this hesitancy is because caregivers are used to medical professionals being responsible for all treatment and recommendations. By giving caregivers this power it will be easier for them to develop greater participation and problem solving skills. The ultimate decision making power is held by the client and their family so it is important to include and respect their concerns and wishes (Moghimi, 2007).

Occupational therapists can aid in this power shift by giving up some of the power and working with the interdisciplinary team to do the same. The development of a strong

therapeutic relationship between the therapist and the family will ensure that proper attention and respect is given to the caregiver. This can allow the caregiver to come into the role of “lay practitioner” and will assist in creating a positive outcome for the care recipient. By building a strong relationship, the OT forms a better understanding of the caregiver and their occupations and can more appropriately advocate for and treat the family. This feeling of empowerment is essential for successful community reintegration for both the client and his or her caregivers.

Community Reintegration

In rehabilitation settings, SCI patients and their caregivers are practicing the *skills of living* in an optimal environment with healthcare professionals or “formal caregivers” there to advise them. Upon returning home the environment may not be as ideal and healthcare professionals are not present. In a study by Manns and May (2007), it is suggested that the service delivery of patient and caregiver education may become more beneficial if it is presented to the patient and caregiver after the return home to the community.

Occupational therapists are well equipped to bridge the gap between rehabilitation and community reintegration by providing caregivers and their loved ones with the skills to be successful. These skills include educating, training, and facilitating problem solving for caregiver’s so that they are better able to care for themselves and the receiver of care (Gray et al., 2007).

As with all new occupations, caregiving presents with many challenges that are unique to each person. Due to the client-centered and occupation-based approaches that occupational therapists provide, many of these unique needs can be addressed, resulting

in higher satisfaction of the caregiver and an increase in the quality of care provided to the care recipient. For this reason, the *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* was developed.

Caregiver's Guide

Thorough education and training is necessary to empower the caregiver to adequately care for their loved one as well as themselves (Moghimi, 2007). The training and education that OT's provide can contribute to increased feelings of competence and confidence. It is important for the caregiver to develop these feelings of mastery through training and education and enabling them to problem solve and care for their loved one. Through development of these problem solving skills the caregiver can use this sense of power when they encounter unexpected events (Moghimi, 2007). "In the care, concern and support of the client's we work with, occupational therapists have an obligation to help caregivers shape their own occupation, and their family members' lives" (Moghimi, 2007, p. 280).

Purpose and Design

The purpose of the education and training provided by the *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* is to ensure that caregiver's know how to take care of themselves, adequately care for their loved one and how to confidently respond in many situations. Skilled OT's are to present the material in the guide to caregiver's of individuals who have experienced a spinal cord injury when the client and caregiver are participating in rehabilitation in preparation for a more successful transition home.

The guide is designed to assist caregivers in performing their new role of primary caregiver more successfully. Information is included that can help the caregiver to

understand how important their health and well-being is as well as the care recipients. It provides information on basic patient care guidelines as well as the caregiver's physical and psychosocial well-being. The guide provides the caregiver with information on the importance of continuing their old occupations along with their new occupations. Lastly, the guide will provide the caregiver with a list of resources that may be useful in trying times such as the benefits of respite care.

The following is an outline of the *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* to be presented in its entirety in Chapter IV:

Occupational Therapy Caregiver's Guide to Spinal Cord Injury

Introduction

Section I: Caring for Yourself

- Balance of occupations
- Respite care
- Emotional well-being
- Physical health

Section II: Medical Management

- Important words
- Common health complications
- Basic patient care guidelines

Section III: Adaptation

- Home modifications
- Community access
- Assistive technology support

Section IV: Resource list

Theoretical Framework

Adult Learning Theory

The theoretical framework that will guide the design and layout of this scholarly project is based upon Malcolm Knowles Adult Learning Theory of Andragogy under the

umbrellas of Constructivism and Humanism. Andragogy makes the following assumptions about the design of learning: (1) Adults need to know why they need to learn something, (2) Adults need to learn experientially, (3) Adults approach learning as problem-solving, and (4) Adults learn best when the topic is of immediate value (Brueggeman, 2006; Padberg, 1990).

Knowles believes that the adult learner brings life experiences to learning. Adults prefer self-directed and self-designed learning projects over group learning experiences led by a professional, they select more than one medium for learning, and they desire to control pace and start/stop time. The Caregivers Guide provides that as well as the learner/caregiver with the information and resources that they can access when and if they need it.

The four assumptions that Knowles uses in his theoretical framework about adult learners are (Brueggeman, 2006; Padberg, 1990):

1. Adults are independent learners: they are generally willing to engage in learning experiences before, after, or even during the actual life change event. The learning experiences adults seek out on their own are directly related – at least in their perception - to the life-change events that triggered the seeking. Once convinced that the change is a certainty, adults will engage in any learning that promises to help them cope with the transition.
2. Adults have past experiences that can be used for new learning. They need to be able to integrate new ideas with what they already know if they are going to keep - and use - the new information.
3. Adults' readiness to learn develops from problems across the life span: they seek out learning experiences in order to cope with specific life changing events--e.g., marriage, divorce, a new job, a promotion, being fired, retiring, losing a loved one, moving to a new city. The more life change events an adult encounters, the more likely he or she is to seek out learning opportunities.
4. Adults use problem-based learning: just as stress increases as life-change events accumulate, the motivation to cope with change through engagement in a learning experience increases.

The purpose of using an adult learning theory is that the guide needs to be designed based upon adult learning theory assumptions and principles to meet the adult learning needs of the caregiver. The *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* will be organized incorporating the four assumptions from Malcolm Knowles' Theory of Andragogy. The guide is written to allow the caregiver to obtain a sense of independence and control over their learning.

The handbook will be provided to the caregiver and client by an occupational therapist who serves as a facilitator rather than the "authority". This is essential to developing a positive relationship between the OT and the caregiver.

It is vital that the occupational therapist obtain an occupational profile of the patient and their caregiver in order to have an understanding of some of the past experiences of the caregiver. This ties into Malcolm Knowles' assumption of using past experiences to enhance learning. Difficult life experiences require coping and adjustment, and according to the adult learning principles these trying life experiences produce an optimal time for learning that some have called "teachable moments" (Padberg, 1990). Adults are most motivated to learn when they have a sense of control in deciding the content of what their specific problems are that need to be addressed. For this reason, the therapist must empower the caregiver to be an active learner and problem solver. The guide serves as a tool for the caregiver to aid in their independent problem solving with the therapist facilitating this interaction.

Summary

The *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* is essential in beginning the trend of meeting the needs of caregivers by the occupational therapy

profession. Occupational therapists have a wide array of skills to assist all aspects of the caregiver's health and well-being enabling them to better care for their loved one. As healthcare costs continue to rise, preventative treatment is becoming more necessary and as this is proven to be cost effective, it is predicted that the third party payers will begin to consider reimbursement for this type of intervention.

The *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* is a necessary step toward bridging the gap faced by caregivers of individuals with spinal cord injury. It strives to address the unique needs, roles, and responsibilities experienced by providing educational materials for the occupational therapist to utilize with caregivers. It is vital that the OT uses client-centered practice when presenting the guide since each caregiver will have unique needs and challenges and require distinctive training.

The methodology of the *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* is presented in Chapter III.

CHAPTER III

METHODOLOGY

The process for developing the *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* began with a comprehensive literature review. Several resources were used to access literature about the topic including the Harley French Library and the Spinal Cord Injury Information Network. Topics researched included spinal cord injury (SCI), treatments, caregiving, caregiver needs and interventions, caregiver resources, and occupational therapy's role.

The literature review suggested that there is a lack of research regarding caregivers of individuals with SCI. There was however, an abundance of information about SCI revolving around the patients needs. Research does exist regarding caregiving, but much of it is geared toward the elderly and other specific diagnoses. In addition, there was very little research that involved occupational therapy's role in the treatment of caregivers. From the limited information available on SCI, caregivers, occupational therapy, and the limited resources examining caregivers of individuals with SCI, many of the needs of the caregiver were identified and shown to be under served. Based on the literature review, an outline was developed to target the needs of the caregiver in their role as primary caregiver.

In the development of the *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* Malcolm Knowles Adult Learning Theory of Andragogy was used to guide

the process. The four assumptions of the model are 1) adults need to know why they are learning, 2) adults learn through past experiences, 3) adults are problem based learners, and 4) adults learn best when the problem is of immediate concern (Brueggeman, 2006; Padberg, 1990). This theory was chosen to meet the needs of the adult learner more effectively. This theory allows the design of the guide to enable the caregiver to have a sense of independence and control over their learning.

The *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* is designed to assist caregivers in performing their new role of primary caregiver. Information is included that can help the caregiver to understand how important their health and well-being is as well as the care recipients. The guide provides the caregiver with important information on the importance of continuing their prior occupations along with their new occupations. It provides information on basic patient care guidelines as well as the caregiver's physical and psychosocial well-being. Lastly, the guide will provide the caregiver with a list of resources that may be useful in trying times such as the benefits of respite care.

The authors hope that the *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* will begin to bridge the gap faced by caregivers of individuals with spinal cord injury. The guide will address the unique needs, roles, and responsibilities experienced by caregivers and provide education materials for the occupational therapist to utilize in treating this important and often forgotten about group.

CHAPTER IV

THE PRODUCT

Introduction

A literature review was conducted to identify the needs of the caregiver and the best practice strategies and resources to deal with the changing needs and lifestyle the family will experience. Although there is significant information and resources available, there is not a guide specific to treating the occupational and psychosocial needs of the caregiver from an occupational therapy (OT) perspective. Current literature supports a need for training and follow-up education of the caregiver subsequent to the rehabilitation phase (Boschen et al., 2005; Elliot, Kurylo, & Lindsey, 1998; Grey, Horowitz, O'Sullivan, Kharasch-Behr, & Abru, 2007; Manns & May, 2007; Moghimi, 2007).

The literature review identified the following areas of need for the caregiver: 1) emotional support; 2) physical wellbeing; 3) knowledge about caring for an individual with a spinal cord injury; and 4) accessing healthcare professional assistance. By addressing these needs and providing the guide to caregivers, they should be better equipped to provide optimal care while living a healthy and satisfying life.

Based upon the results of this current literature review, an occupational therapy based guide was developed. The *Occupational Therapy Caregiver's Guide to Spinal*

Cord Injury was designed to specifically address the needs of the caregiver during the patient's transition from rehab to the community and will also include basic home program guidelines. It is hoped that the *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* is an effective resource tool to facilitate a more positive and healthy transition for both the client and their loved ones.

Theoretical Design

This product, *Occupational Therapy Caregiver's Guide to Spinal Cord Injury*, was designed utilizing Malcolm Knowles Adult Learning Theory. This theory is based on ideas of Constructivism and Humanism. Andragogy makes the following assumptions about the design of learning: (1) Adults need to know why they need to learn something, (2) Adults need to learn experientially, (3) Adults approach learning as problem-solving, and (4) Adults learn best when the topic is of immediate value (Brueggeman, 2006; Padberg, 1990).

Knowles believes that the adult learner brings life experiences to learning. Adults prefer self-directed and self-designed learning projects over group learning experiences led by a professional, they select more than one medium for learning, and they desire to control pace and start/stop time. The *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* provides the learner/caregiver with information and resources that they can access when and if they need it.

The four assumptions that Knowles uses in his theoretical framework about adult learners are (Brueggeman, 2006; Padberg, 1990):

5. Adults are independent learners: they are generally willing to engage in learning experiences before, after, or even during the actual life change event. The learning experiences adults seek out on their own are directly related – at least in their perception - to the life-change events that

triggered the seeking. Once convinced that the change is a certainty, adults will engage in any learning that promises to help them cope with the transition.

6. Adults have past experiences that can be used for new learning. They need to be able to integrate new ideas with what they already know if they are going to keep - and use - the new information.
7. Adults' readiness to learn develops from problems across the life span: they seek out learning experiences in order to cope with specific life changing events--e.g., marriage, divorce, a new job, a promotion, being fired, retiring, losing a loved one, moving to a new city. The more life change events an adult encounters, the more likely he or she is to seek out learning opportunities.
8. Adults use problem-based learning: just as stress increases as life-change events accumulate, the motivation to cope with change through engagement in a learning experience increases.

The *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* is

organized by incorporating the four assumptions from Malcolm Knowles' Theory of Andragogy. The guide is written to allow the caregiver to gain a sense of independence and control over their learning.

The handbook will be provided to the caregiver and client by an occupational therapist who serves as a facilitator rather than the "authority". This is essential to developing a partner relationship between the OT and caregiver. It is vital that the occupational therapist obtain an occupational profile of the patient and their caregiver in order to have an understanding of some of the past experiences of the caregiver to enhance learning. Difficult life experiences require coping and adjustment, and according to the adult learning principles these trying life experiences produce an optimal time for learning that some have called "teachable moments" (Padberg, 1990). Adults are most motivated to learn when they have a sense of control in deciding the content of what their specific problems are that need to be addressed. For this reason, the therapist

must empower the caregiver to be an active learner and problem solver. The *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* serves as a tool for the caregiver to aid in their independent problem solving with the therapist facilitating this interaction.

Program Implementation

Skilled OT's are to present the material in the guide to caregiver's of individuals with spinal cord injury when the client and caregiver are participating in rehabilitation in preparation for a more successful transition home. The occupational therapist will seek to provide the caregiver with the necessary tools to be an effective and independent problem solver with the caregiver directing the intervention. Each client will be unique therefore the OT will tailor treatment to their specific needs with the guide serving as a resource.

Product Description

The *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* is an educational and training tool designed to ensure that caregiver's know how to adequately care for themselves as well as their loved one and how to confidently respond in many situations. It is designed to assist caregivers in performing their new role of primary caregiver more successfully. Information is included that can help the caregiver to understand how important their health and well-being is as well as the care recipients. The guide provides the caregiver with information on the importance of continuing their prior occupations. It provides information on basic patient care guidelines as well as the caregiver's physical and psychosocial well-being. Lastly, the guide will provide the

caregiver with a list of resources that may be useful in trying times such as the benefits of respite care.

The following is an outline of the *Occupational Therapy Caregiver's Guide to Spinal Cord Injury*:

Occupational Therapy Caregiver's Guide to Spinal Cord Injury

Introduction

Section I: Caring for Yourself

- Balance of occupations
- Respite care
- Emotional well-being
- Physical health

Section II: Medical Management

- Important terms
- Common health complications, prevention, and solutions
- Basic Patient care guidelines

Section III: Adaptation

- Home modifications
- Community access
- Assistive Technology support

Section IV: Resource list

Occupational Therapy Caregiver's Guide to Spinal Cord Injury



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INTRODUCTION

You have been provided with the *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* by your occupational therapist. The goal of this guide is to provide you with:

- ❖ Helpful information on how to take care of yourself and your loved one. In order to take care of your loved one, you need to take care of your own physical and mental wellbeing.
- ❖ Information about the basic medical management you will need to know to care for your loved one with a spinal cord injury.
- ❖ Adaptations that you can make to your home and other areas, and
- ❖ A resource list so you can find more information if you need to.

Your occupational therapist (OT) will be teaching you how to use the *Occupational Therapy Caregiver's Guide to Spinal Cord Injury*. You and the OT will figure out what you need to problem solve through everyday concerns and problems you may have as you try to help your loved one. The information used to develop this guide comes from professional journals and text books. The list of these journals and texts are located in the resources and reference list if you need more information.

People who have a spinal cord injury (SCI) will often live longer than people who have other medical problems. So, those of you who help someone with a SCI face a unique role in relation to many other caregivers. You, as the primary caregiver, will have this role for an indefinite length of time. For this reason, it is extremely important for you to learn how to keep a balance of the many roles you have so that you and your family can be in a positive and supportive place.

REHAB DISCHARGE CHECKLIST

This section provides you with a checklist to use when preparing to be discharged from rehabilitation. It is intended to help you feel that you are prepared for this transition. The questions on the list will ensure that all steps have been addressed and help you and your loved one feel more comfortable and confident in the return home. There may be some things that are not on this list that are important to you so add to this list as you wish.

Checklist

- 1. Do I have a list of names and numbers to call for information?**

	Name	Number
Dr.		
Nurse		
OT		
PT		
Other		

- 2. Do I feel I can transfer my loved one from:**

The wheelchair _____

The bed _____

The bathroom _____

If no, make sure to ask a doctor or therapist to address this before leaving the hospital.

- 3. Do I feel I can do the exercises?**

Arms _____

Legs _____

- 4. Have I scheduled a home evaluation?**

Yes _____

No _____

Need to do by _____

5. Do I know how to take my loved ones blood pressure if I need to?

Yes _____

No _____

6. Do I feel I can correctly carry out my loved ones catheter hygiene?

Yes _____

No _____

7. Do I understand my loved ones pressure relief schedule?

Yes _____

No _____

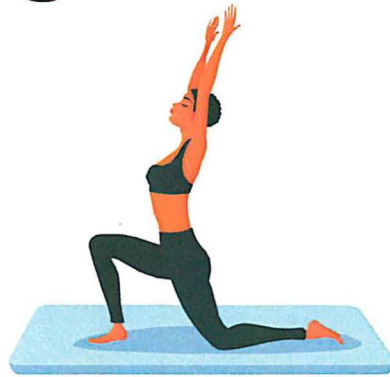
8. Have I received a handicap-parking sticker?

Yes _____

No _____

9. Do I know and have what I need at home before my loved one comes home?

Caring for Yourself



BALANCE OF OCCUPATIONS AND ROLES

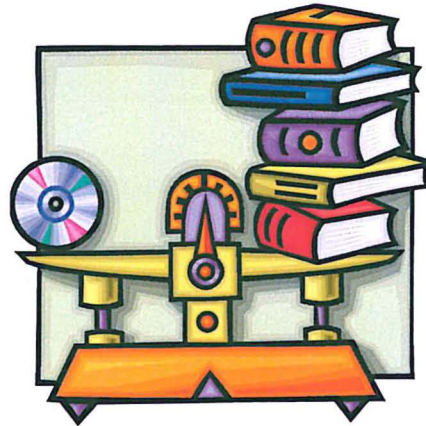
This section will give you information about the importance of having a balance in your occupations and roles. This section will also provide ideas and activities to help you balance your roles and occupations to create a more balanced day.

The word occupation is talking about all activities that you do during your day. Examples of occupations

are: showering, working, going to school, cooking, brushing your hair, and driving. These are activities that are important to you and that you value.

A role is a set of behaviors that are socially accepted. Some examples of roles are: wife, husband, mother, father, employee, friend, and caregiver.

Occupational or role imbalance can happen when you spend a lot of time doing only one or two occupations or roles and stop doing other things that you once enjoyed or needed to do. Occupations that are commonly stopped are social, recreational and leisure activities (such as dancing, reading, and listening to music). Certain



roles may become less important because other roles become a priority. For example, you may see the caregiving role as more important than roles that were once so important to you. It is important for you to continue to participate in the activities you enjoy in life to keep a healthy balance.

Having an occupational and role balance can help you feel better about yourself and the situation, which means you will stay healthier. A good way to make sure that you do continue to take time for yourself and fulfill your life roles is to have set times in which you perform these activities. On the next page there is an activity that will help you to identify your roles and how satisfied you are with them.

Role Exploration Sheet

What roles do you have, please check all that apply?

Mother		Grandparent	
Father		Employee	
Sister		Employer	
Brother		Friend	
Aunt		Home maintainer	
Uncle		Caregiver	
Other		Other	

1. Do you feel that you are able to do all that you need to do in each of the areas you have checked? Are there things you are not happy with or things you are not doing at all (i.e. visiting with friends, taking time to relax)?

2. What are some ideas/things that you could do to get a better balance between your roles (i.e. setting aside a few hours each week to do the things you enjoy)?



If you are having a hard time trying to keep a healthy occupational balance, the Activity Wheel may be able to help you look at your daily schedule. One way to see the changes you have is to fill out the Wheel twice, once with your daily schedule before you became a caregiver. Then fill out another Wheel that show how your day is now, as a caregiver. This will give you a good idea of what things have changed and also how to keep thinking of ideas on how to start adding things you used to enjoy back in to your new daily schedule. It may not happen all at once and some days it may not happen at all. The important thing to remember is to always keep it in your mind that your time is also important and you are important too.

Take time now, with your OT, to fill in the Activity Wheel worksheet on pages 15-16. When you are done, please answer these questions.

Is there an imbalance? _____ Yes _____ No

If yes, what are some ways you could help to balance your schedule? (i.e. I will take an hour everyday to visit with friends and family)

What are some resources to help you get a healthy balance of activities? (i.e. Making a schedule that includes time for myself)



Activity Wheel (before caregiving)

How many hours do you spend sleeping each night? _____

How many hours a day do you spend at your job? _____

How many hours a day do you spend doing caregiving tasks? _____

How many hours do you spend cooking and eating each day? _____

Are you eating healthy? _____

How many hours a day do you spend doing your self-care tasks such as dressing and bathing? _____

How many hours a day do you spend visiting or spending time with friends? _____

How many hours a day do you spend relaxing? _____

How many hours a day do you spend exercising? _____

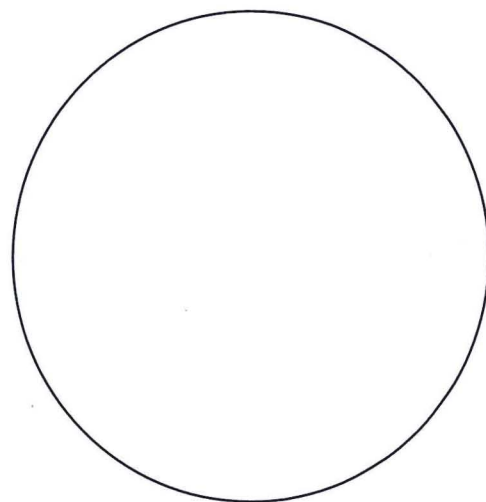
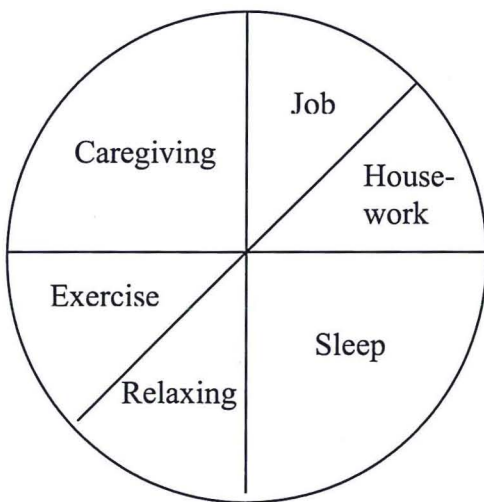
Other _____

Total Hours _____

Are there any hours left unaccounted for (subtract your total number of hours from 24)? _____

Fill in the circle below.

Example:





Activity Wheel (as a caregiver)

How many hours do you spend sleeping each night? _____

How many hours a day do you spend at your job? _____

How many hours a day do you spend doing caregiving tasks? _____

How many hours do you spend cooking and eating each day? _____

Are you eating healthy? _____

How many hours a day do you spend doing your self-care tasks such as dressing and bathing? _____

How many hours a day do you spend visiting or spending time with friends? _____

How many hours a day do you spend relaxing? _____

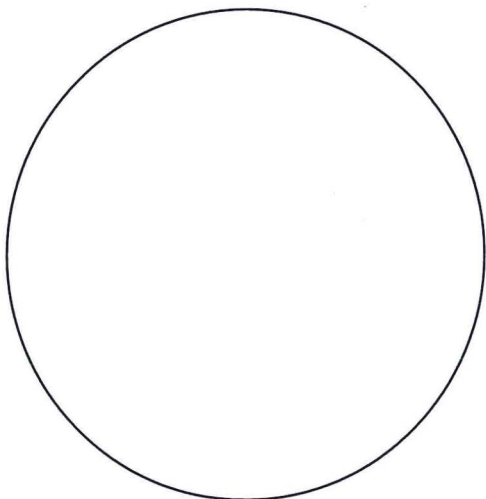
How many hours a day do you spend exercising? _____

Other _____

Total Hours _____

Are there any hours left unaccounted for (subtract your total number of hours from 24)? _____

Fill in the circle below.

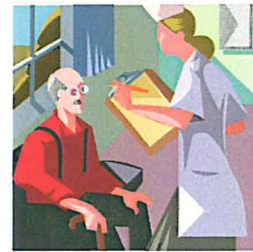


Now go back up and complete the questions about the Activity Wheel on pages 11-12.

RESPIRE CARE

This section provides you with information on respite care. The benefits of respite care are included and how you can find and use it in your community.

Respite care is a service that gives you a rest or break from caring from your loved one. It is a good way to help your family through difficult times. Family caregivers report having chronic health conditions such as depression, anxiety, and back problems almost twice as much as non-caregivers (National Respite Coalition, 2005). Your chances of developing a chronic condition can be decreased by taking care of yourself and one way to do this is by using respite services.



Benefits of respite care include:

- ❖ Having time to do things for yourself
- ❖ Decreasing stress by having a break or time to relax
- ❖ A chance to get new ideas from the respite provider
- ❖ A break for your loved one as well
- ❖ A time for you to socialize with friends

How to find respite services in your community:

- ❖ Ask your loved ones physician, occupational therapist, physical therapist, or social worker
- ❖ Use the internet
- ❖ Ask family and friends to spend time with your loved one
- ❖ Contact home health agencies in your area
- ❖ The yellow pages
- ❖ If you join a support group, ask members

EMOTIONAL WELL-BEING

This section will talk about how to deal with stress and includes several different activities that will help you to identify and get rid of stress. Also included in this section are techniques/ideas to help you relax, information about counseling services, and the steps to solve a problem. Examples and activities are provided for you.

Stress Management

Stress is a normal reaction to change. Physical signs of stress are headaches, feeling really warm or really cold, tense muscles, fast breathing, tiredness, dizziness, and light headedness. Mental signs of stress are: sadness, a hard time concentrating, irritability, anxiety, and forgetfulness. It is important for you to keep your life as stress free as possible and have some good ways to deal with stress.

Ideas to deal with stress:

- ❖ Know the signs of stress such as the examples listed above
- ❖ Figure out what is causing your stress
- ❖ Develop a schedule to avoid getting too tired
- ❖ Schedule to take time for yourself (even 20 minutes a couple times a day)
- ❖ Never be afraid to ask for help

- ❖ Have someone that you can talk to
- ❖ Write in a journal as a healthy way to express your feelings
- ❖ Get enough sleep
- ❖ Have a good sense of humor



See pages 21-28 for additional ideas.

1. Page 21 gives you a listing of stress symptoms. If you have a lot of checks you are under a lot of stress.
2. Pages 22-25 give you a list of ideas to help you decrease your stress. Some may work for you and some may not. Keep trying to figure out what works best.
3. Pages 26-28 give you ideas on how to relax. If you do not understand these ask your OT for more information or more examples.

Another way to keep your stress levels down is to have a good support network. A support network is a group of people that you can talk to or depend on for help. Often this group of people includes



family, friends, or people who have been in similar situations to you. If you do not have a strong support network there are ways to finding one. Support groups on the internet are a great solution. There are several sites to help caregivers. See page 70-76 for sites that

provide these services. If you do not have access to the internet, you can ask your local healthcare provider for a list of groups or support services that they provide. Your local hospital may have ideas.

STRESS SYMPTOM CHECKLIST

- 1. Buzzing or ringing in the ears
- 2. Fatigue I can't account for
- 3. Dizziness
- 4. Blushing
- 5. Sweating (other than from exercise or caused by physical environment)
- 6. Peculiar numbness of any part of body
- 7. Unexplained heightened sensitivity of any part of the body
- 8. Stiffness or pain of muscle or joints (not due to exercise)
- 9. Intestinal disturbance
- 10. Stomach complaints
- 11. Breathing difficulties (not caused by disease)
- 12. Itching (I can't explain)
- 13. Urinary problems or complaints
- 14. Visual disturbances
- 15. Pain (I can't explain)
- 16. Nervous mannerisms (e.g., flinching, "tics," nail biting, drumming fingers)
- 17. Restlessness
- 18. Tearfulness
- 19. Irritability
- 20. Confusion
- 21. Trouble concentrating
- 22. Insomnia
- 23. Diarrhea
- 24. Headaches
- 25. Fever blisters
- 26. Hunger or lack of appetite
- 27. Clumsiness, fainting, trembling
- 28. Heart palpitations
- 29. Forgetfulness
- 30. Immobilization
- 31. Constipation
- 32. Excessive sleep
- 33. Coldness of extremities
- 34. Dry mouth

101 WAYS TO COPE WITH STRESS

1. Get up earlier
2. Prepare ahead
3. Avoid tight clothes
4. Avoid chemical aids
5. Set appointments
6. Write it down
7. Practice preventive maintenance
8. Make duplicate keys
9. Say "NO" more often
10. Set priorities
11. Avoid negative people
12. Use time wisely
13. Simplify meals
14. Copy important papers
15. Anticipate needs
16. Make repairs
17. Get help with jobs you dislike
18. Break down large tasks
19. Look at problems as challenges
20. Look at challenges differently
21. Unclutter your life
22. Smile
23. Prepare for rain
24. Tickle a baby
25. Pet a dog/cat
26. Don't know all the answers
27. Look for the silver lining
28. Say something nice
29. Teach a kid to fly a kite
30. Walk in the rain
31. Schedule play time
32. Take a bubble bath
33. Be aware of your decisions
34. Believe in yourself
35. Stop talking negatively
36. Visualize winning
37. Develop a sense of humor
38. Stop thinking tomorrow will be better
39. Have goals
40. Dance a jig
41. Say hello to a stranger
42. Ask a friend for a hug
43. Look at the stars
44. Breathe slowly
45. Whistle a tune
46. Read a poem
47. Listen to a symphony
48. Watch a ballet
49. Read a story
50. Do something new
51. Buy a flower
52. Smell a flower
53. Find support
54. Find a "vent" partner
55. Do it today
56. Be optimistic
57. Put safety first
58. Do things in moderation
59. Note your appearance
60. Strive for excellence, not perfection
61. Stretch your limits
62. Enjoy art
63. Hum a jingle
64. Maintain your weight
65. Plant a tree
66. Feed the birds
67. Practice grace
68. Stretch
69. Have a plan "B"
70. Doodle
71. Learn a joke
72. Know your feelings
73. Meet your needs
74. Know your limits
75. Say "Have a good day" in pig Latin
76. Throw a paper airplane
77. Exercise
78. Learn a new song
79. Get to work earlier
80. Clean a closet
81. Play with a child

82. Go on a picnic
83. Drive a different route to work
84. Leave work (class) early
85. Put air freshener in your car
86. Watch a movie and eat popcorn
87. Write a far away friend
88. Scream at a ball game
89. Eat a meal by candlelight
90. Recognize the importance of unconditional love
91. Remember stress is an attitude
92. Keep a journal
93. Share a monster smile
94. Remember your options
95. Build a support network
96. Quit trying to fix others
97. Get enough sleep
98. Talk less and listen more
99. Praise others
100. Stop a bad habit
- 101. RELAX. TAKE EACH DAY AT A TIME...YOU HAVE THE REST OF YOUR LIFE TO LIVE**

STRESS: HOW TO HANDLE IT

1. **TALK IT OUT** – When tensions build up, try discussing the problem with a close friend or with the people involved.
2. **ESCAPE FOR A WHILE** – Don't wait until you've lost control. Act while you are still able to decide for yourself.
3. **TAKE A BREAK** – A change of pace, no matter how short, can give you a new outlook on an old problem.
4. **EXERCISE REGULARLY** – Any sport will help you relax and let off steam.
5. How about swimming, tennis, bicycling, jogging – you can reduce stress while having fun!
6. **EAT PROPERLY** – Your nutritional needs increase when you are under stress. You need protein, vitamins, and minerals to repair damage caused by stress.
7. **AVOID STRESS** – Many changes at once can result in increased stress. When you can, plan to avoid too many big changes at the same time.
8. **PLAN YOUR WORK** – Tension and anxiety really build up when your work seems endless. Plan your work to use time and energy more effectively.
9. **POSSIBLE RESOLUTION OF STRESSFUL SITUATIONS** – Learn to be an effective problem solver.
10. **TAKE ONE THING AT A TIME** – When work seems endless, tension and anxiety really build up. Planning can help you reduce stress as you use your time and energy more effectively.
11. **SHUN THE “SUPERMAN” or “SUPERWOMAN” URGE** – Be realistic. People who expect too much of themselves can become tense if their plans don't work out. Set practical goals.
12. **GO EASY WITH YOUR CRITICISM** – Too much criticism of others and of yourself can lead to frustration. Instead of criticizing, search for good points.
13. **ACCEPT WHAT YOU CANNOT CHANGE** – When a problem is beyond your control, learn to recognize and accept it. It beats spinning your wheels and getting nowhere.

14. GIVE IN OCCASIONALLY – It's not always urgent to be right. If you yield, others probably will too. Working out disagreements with others will help you reduce and even avoid stressful situations.
15. GIVE THE OTHER FELLOW A BREAK – Competition is contagious, but so is cooperation. Giving the other fellow a break can make things easier for you too.
16. LEARN TO RELAX – Everyone needs and deserves some relaxation. Just a few minutes of peace and quiet each day make a big difference! Try it
17. GET RID OF YOUR ANGER – Anger is a normal emotion. You use it to combat attack. Anger becomes a problem only when it's unreasonable – out of control. It not only hurts others but also you.
18. DO SOMETHING FOR SOMEONE ELSE – It breaks the stranglehold of your moodiness, and brings a feeling of strength.
19. THINK POSITIVE.– CHANGE ATTITUDE – Be positive and optimistic.
20. LEARN HOW TO HAVE FUN – Learn how to play!
21. DEVELOP A SENSE OF HUMOR – Laughter is good for the soul!
22. QUIT FEELING SORRY FOR YOURSELF.
23. IF YOU NEED HELP, GET AN EXPERT – When stress gets out of hand, professional help is available to you in your community. People who handle stress well tend to have the characteristics listed below.
24. Strive to develop these characteristics.
 - a. He/she views change as a challenge, not as a threat.
 - b. The person feels committed to something he/she is involved with (in personal life, on the job, or both).
 - c. The person feels a sense of control – realizes that he/she is ultimately in control of their own life and situations to be dealt with.

Relaxation Techniques

A great way to deal with stress is to practice relaxation techniques. Benefits of relaxation include:



- ❖ A slower heart rate
- ❖ Lower blood pressure
- ❖ A normal breathing rate
- ❖ Reduced need for oxygen
- ❖ Increase in blood flow
- ❖ Reduced muscle tension
- ❖ Fewer headaches
- ❖ Less back pain
- ❖ You have fewer emotional responses (i.e. crying, anger outbursts, sadness)
- ❖ You have more energy
- ❖ You can concentrate on things better
- ❖ You can handle problems much better
- ❖ You can do your daily activities much easier

Types of relaxation techniques:

- ❖ **Breathing Exercises:** Often times when under stress individuals forget to breathe normally. They may breathe too fast and make their hearts work harder. In times of stress it may be helpful to practice deep and slow breathing. One thing you can do is abdominal breathing. You start by putting your hands on your stomach so you can feel your stomach rise and fall as you breathe. It may also help to repeat words or numbers in your head to help you concentrate on your breathing. For example, thinking the word “relax” on every inhale and exhale.
- ❖ **Progressive Muscle Relaxation:** This is where you tighten and relax muscles in the body from head to toe. An example of tighten and relax is when you make a fist (tighten) and spread fingers open (relax). This can help you feel less tense by relaxing the body to help relax the mind. This is a good technique for people who have trouble relaxing, because it is something that you are doing and not just thinking.



- ❖ Visualization: This is where you think about things that are pleasant or relaxing. This may help you to relieve stress. You may want to sit or lie down in a quiet area and close your eyes. It may also be helpful to include different sounds and smells. For example if you are thinking about a forest you could burn a pine scented candle and listen to a nature CD.

Other common relaxation techniques include:

- ❖ Yoga
- ❖ Tai Chi
- ❖ Music
- ❖ Exercise
- ❖ Meditation
- ❖ Hypnosis
- ❖ Massage

You can learn more about relaxation from the internet, searching the yellow pages to see if there is a provider in your community, or ask someone at your rehabilitation facility.

Counseling Services

You also benefit from seeing a counselor to help you feel like you are staying on track. Some people think seeing a counselor is a sign of weakness but it may actually help you to deal with the struggles that come with being a caregiver. Don't be afraid to give this a try. You can find a local counselor by contacting your local counseling service. There are many counselors that charge only what you can afford. There are also state agencies where counseling can be found.



PHYSICAL HEALTH

This section will help you find the best ways to take care of your own physical health. It includes a list of things to do and things to do not do when transferring your loved one from one position/place to another.

For you to give the best care to your loved one, it is important that you are healthy. One way for you to stay healthy, is to use proper body mechanics when lifting and moving your loved one. Body mechanics is the way you use your body to do physical tasks. Proper body mechanics will help to prevent you from becoming injured especially your back. Some of these ideas are listed below in the transferring do's and do not's.

Things to do when transferring

- ❖ **Do** get training before your loved one leaves the hospital so you feel comfortable and safe doing it
- ❖ **Do** lock the wheelchair brakes
- ❖ **Do** tell the person that you are moving them
- ❖ **Do** remember to unfasten all seat belts and harnesses



- ❖ **Do** use a transfer belt on the person being transferred (you must be trained on the right way to use a transfer belt)
- ❖ **Do** have a stable and clutter free transfer surface (clean off the bed, wheelchair, car, and other areas)
- ❖ **Do** keep your feet shoulder width apart for a wide base so that you are balanced when you move 
- ❖ **Do** keep your back and spine as straight as possible
- ❖ **Do** use your legs when lifting (bending at the knees)
- ❖ **Do** bend your knees when you lift the person
- ❖ **Do** completely lift the person before turning
- ❖ **Do** take small steps to turn
- ❖ **Do** ask for help!

Things to not do when transferring

- ❖ **Do Not** transfer someone by pulling on their arms
- ❖ **Do Not** use your back to lift (bending only at the trunk)
- ❖ **Do Not** twist your back when lifting or moving the person
- ❖ **Do Not** attempt more than you are capable of (if you think you can not do it, don't)



Ways to stay healthy are:

- ❖ exercise regularly (three times per week)
- ❖ eat a well balanced diet
- ❖ stay as stress free as possible
- ❖ get regular check-ups, and
- ❖ remember to enjoy each day



PROBLEM SOLVING

Steps to Help Me Solve Problems

The next section gives you some steps to help you solve problems so that you can hopefully decrease your stress. When you have a problem that you feel can not be solved, use the problem solving worksheet that is on page 34 to help you work through the problem. There is a sample problem solving worksheet on page 35 to give you an example to correctly fill it out. If the worksheet does not help you find possible answers, do not hesitate to ask someone else for help.



Problem Solving

1. What is/are the problem area/s.

2. Which one is most important to you right now?

3. How do you want to deal with the problem?

4. What are some choices you have?

5. What are some things you could do?

6. Make a plan.

7. How is it going?

8. Could you use this idea or ideas with other problems?

Problem Solving Example

This is an example of how the problem solving process can work.

1. Problem areas.

- Bathing
- Transferring to toilet
- Leaving the house for an appointment

2. Most Important.

- Going somewhere

3. Dealing with the problem.

- Currently, it is unorganized and is causing stress.
- Nothing is ever planned ahead which makes us late for appointments.

5. Choices.

- Create a schedule.
- Get ready earlier to allow more time.
- Hire someone to help.
- Schedule appointments at a different time that is easier such as the afternoon.

6. Ways to solve the problem.

- We could use an alarm to make sure we have enough time to get ready. We could also ask several people to help.

7. The plan.

- Create a schedule that will be posted on the refrigerator of all appointments for the week. The schedule will include the time and place of the appointment and also who is responsible for driving. We will look at the schedule the evening before and determine what we can do that night and also determine the time we need to start preparing to leave the next day. We will then set an alarm for that time. Once the alarm goes off we will start preparing and hopefully will be prepared to leave on time.

8. How is it going?

- After using the schedule for a few weeks, we will see if it is working and what changes need to be made.

9. Use with other problems.

- The alarm and schedule could be useful in other areas.

Medical Management



IMPORTANT WORDS

In this section you will learn about words that you are going to hear from doctors and therapists. It is important to know what the words mean so that you can understand what is



being said. Knowing these words will also help you to feel a sense of control during this time. If at any time the doctors or therapists use words that you do not know and they are not listed here, make sure you ask them to explain or give you resources that will help you understand.

Medical Words

Nerve: It looks like a cord and has many nerve fibers that carry signals and messages between the brain and the different parts of the body.

Spinal Cord: Is the largest nerve in the body and is surrounded and protected by bony structures (back bone). It is located at the base of the brain and goes down the back to about your waist.

Vertebrae: Back bones that stack on top of each other and make up the spinal column. The spinal cord is inside of the spinal column.

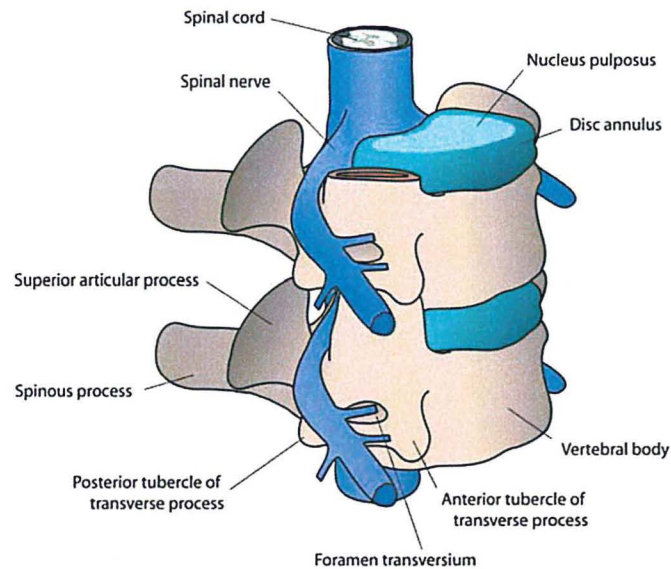


Figure 1: This figure represents two vertebrae with spinal nerves that extend from the spinal cord to send messages to the rest of the body. It is label with some of the anatomical features (www.dkimages.com/.../previews/961/50311545.jpg).

Cervical Spine: The top part of the spinal column and has 7 vertebrae. This is the part of your back bone that is located in your neck area.

Thoracic Spine: The part of the spinal column (back bone) that includes the chest area and has 12 vertebrae.

Lumbar Spine: The part of the spinal column that includes the lower back section and has 5 vertebrae. It is down near your hip area.

Sacral Spine: The bottom part of the spinal column which has 5 vertebrae and the bones are actually fused together. The last bone is called the coccyx.

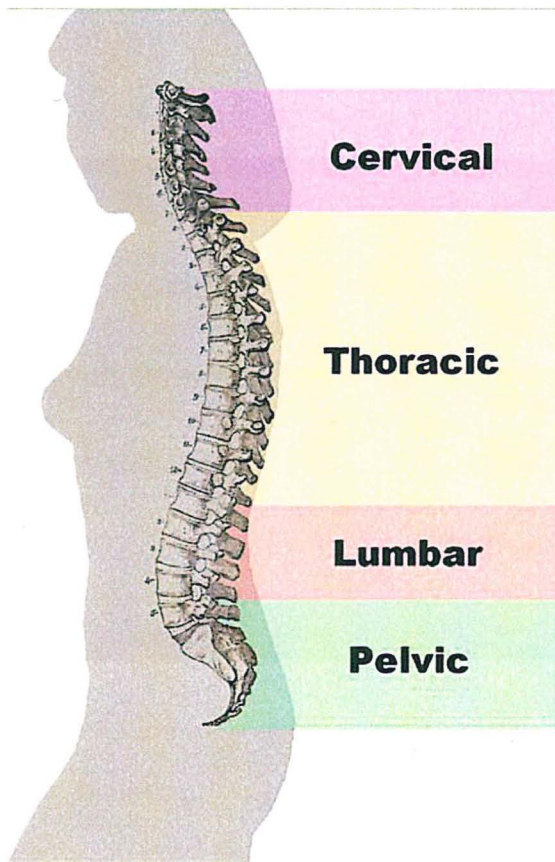


Figure 2: This figure represents the spinal column showing the cervical, thoracic, lumbar, and pelvic or sacral levels (www.upload.wikimedia.org/wiki/5/54).

Dermatome: Each area of the skin that gets messages from specific spinal nerves.

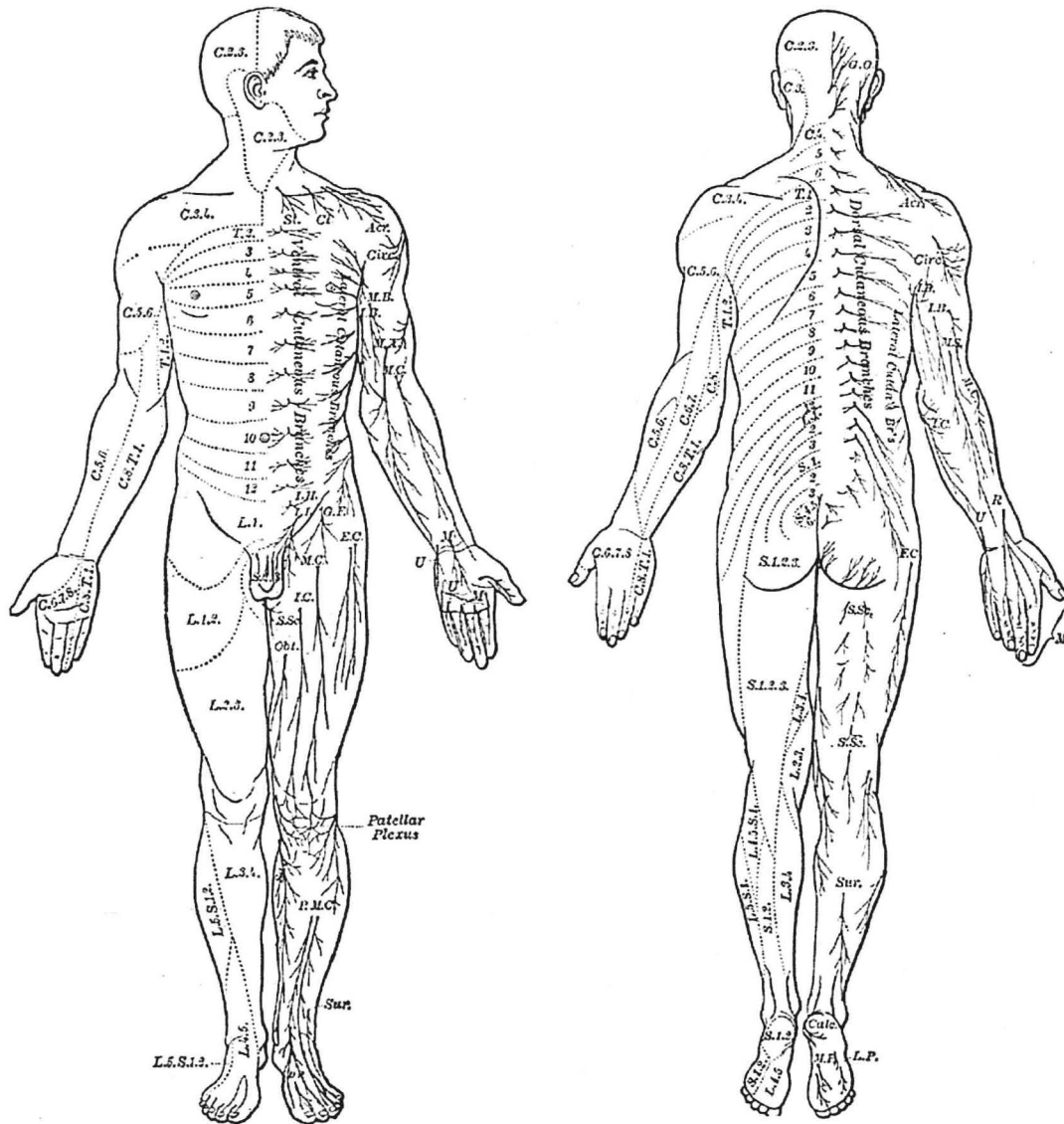


Figure 3: This figure represents a dermatome chart showing which spinal nerves give feeling to skin areas (www.thecompunder.com/images/dermatomeB.jpg).

Spinal Cord Injury: Damage to any part of the spinal cord.

Level of injury: The lowest point on the cord where there is a decrease or loss of feeling and/or movement. The higher the injury is and the closer it is to the brain, the more loss of movement and/or feeling a person has in that part of the body.

Paraplegia: Loss in movement and/or feeling after damage to the thoracic, lumbar, or sacral areas of the spinal cord (see page 39). There is possible loss of movement and feeling in the trunk, legs, and pelvic organs.

Quadriplegia (Tetraplegia): Loss of movement and/or feeling after damage to the cervical area of the spinal cord (see page 39). There is possible loss of feeling and movement in the arms, trunk, legs, and pelvic organs.

Complete Injury: Loss of movement and feeling below the level of the spinal cord injury.

Incomplete Injury: Some feeling and movement may be possible below the level of spinal cord injury.

Occupational Therapy Words

Activity: Doing a task that is goal directed and done for a purpose.

Examples include paying bills, writing a letter, and washing the dishes.

Activities of Daily Living (ADL): Activities to take care of oneself.

Some examples include bathing, dressing, eating, and personal hygiene (washing up, brushing teeth).



Adaptation: To change something so that it is easier and safe to do.

Examples include removing rugs from the floor to allow the wheelchair user to move around better, and changing the morning routine so that it does not feel rushed and everything gets done.

Body Mechanics: The way we use our body when lifting, pushing, and carrying something or someone.

Independence: Our ability to do our everyday tasks by ourselves.

For example, being able to feed oneself.



Leisure: Something we do because we enjoy it.

Occupation: All activities that people do to occupy their time. They are named, organized, valued, and have meaning.

Occupational Therapy: Therapy to help people do the day-to-day activities that are important and meaningful to their health and well-being through valued occupations.

Range of motion (ROM): The total amount of movement a person has in different body parts.

- ❖ Passive ROM is when someone else moves the body part for the person injured or sick.
- ❖ Active ROM is when the individual moves their own body part.

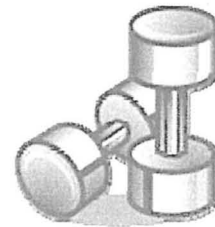
Respite Care: A service that gives you a rest or break from caring for your loved one. Examples include having a friend or family member have a set time each day when they care for your loved one or hiring someone to spend time or care for your loved one.

Role: A set of behaviors that are socially accepted. For example being a mother, daughter, and friend.

Routines: An established set of sequenced activities. A morning routine of taking a shower, brushing your teeth, and fixing your hair is an example.

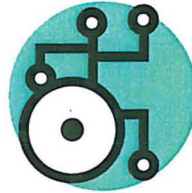
Transfer: To move a person from one surface or place to another place with or without assistance from someone else.

Wellness: A balance of physical and mental fitness in which a person feels good, rested and healthy.



Tip: Make sure your getting enough rest!

BASIC PATIENT CARE GUIDELINES



This section includes information on how to best care for your loved one. It talks about range of motion (ROM), positioning, and self-care assistance for your loved one. An exercise chart is provided to help you track your loved ones progress. It is important to follow the therapists exercise schedule.

Range of Motion (ROM)

It is important that both you and your loved one do your exercises routinely. This includes moving all of the joints to prevent them from becoming stiff and stuck, especially the joints that your loved one is unable to move on his or her own. A specific exercise program should be discussed with your loved ones doctors and therapists. It is always good to begin a routine where the range of motion exercises are completed during specific times of the day. Not doing these exercises could result in future problems. By doing the exercises, your loved one will maintain and possibly increase the amount he or she can move the joints. This may help them to become more independent in their own care.

Steps to follow to have a range of motion exercise routine:

- ❖ Speak with your loved ones doctor and therapists to make a plan
- ❖ Set a specific time in which the exercises will be carried out
- ❖ Use the Daily ROM Chart on the next page to show when the exercises were done and how well your loved one did (make copies as you need them)
- ❖ Report back to the doctor and therapist regularly



Positioning

Skin breakdown is common in individuals who have decreased or a lack of feeling/sensation in their skin. To prevent skin breakdown your loved one should follow a positioning schedule set by their doctor/therapist.

Wheelchair positioning:

- ❖ Make sure your loved one always uses the cushions and supports that have been prescribed to them
- ❖ If able, have your loved one lean forward over their feet and hold for a few minutes
- ❖ If able, have your loved one lean to one side and hold for a few minutes
- ❖ If able, have them lean to the other side and hold
- ❖ Have your loved one grab on to the armrests and push themselves up enough to relieve the pressure on the bottom
- ❖ Have your loved one wiggle in their chair regularly
- ❖ If able, have your loved one to lift up one leg and hold it for a few minutes and then do the other leg
- ❖ For individuals who use a tilt-in-space wheelchair, simply tilting the chair will provide pressure relief (you will be trained in this if your loved one has this type of chair)



*** One of these positioning ideas should be done about every 30 minutes with the wheelchair brakes locked**

COMMON HEALTH COMPLICATIONS



There are common health problems that your loved one may experience. In this section are 1) possible symptoms to look for; 2) what may be causing the problem; 3) possible ways to solve the problem; and 4) ways to prevent the problem from happening. If you feel that your loved one may be experiencing some sort of problem you can use this section to help you deal with the problem. A physician, nurse, therapist or other medical professional may give you information on these complications as well. The information and instructions provided by your physician should be followed exclusively and the information provided below can be used in addition. You should use all the information you have if your loved one is experiencing a problem. If you can not find answers or you do not feel comfortable or safe, call 911 right away.

Autonomic Dysreflexia: This is when the blood pressure goes very high in persons having injuries at the T6 level and above. It is more common in the first year of injury.

- ❖ Symptoms include:
 1. high blood pressure
 2. goose bumps
 3. paleness

4. headache
5. excessive sweating
6. nasal stuffiness
7. anxiety

❖ Causes could be:

1. having a full bladder or rectum
2. ejaculation
3. bladder spasm
4. uterine contraction
5. pressure ulcers
6. ingrown toenails
7. wound dressing changes

Tip: Don't neglect your health needs!

❖ To prevent:

1. be aware of the causes and try to avoid causes such as having a full bladder or rectum
2. for the causes that are unavoidable, know the symptoms and how to appropriately act

❖ To resolve:

1. stop the activity you are doing
3. check the blood pressure, if it is high (normal blood pressure is around 120/80, you should consult your doctor to determine your loved ones normal blood pressure and what highs and lows are a cause for concern):
 - have the person sit up with head elevated
 - loosen clothing, abdominal binder, and any other constrictive items
 - check catheter line for kinks or folds and straighten if there are any
 - continue to monitor blood pressure
 - seek medical assistance

Deep Vein Thrombosis: This is when a blood clot forms. This happens more often in a leg or the stomach/pelvic area. If the clot

comes loose it can be a threat because the clot can travel to another area and stop circulation of the blood to that area.

- ❖ To prevent:
 1. watch the legs and look for any changes in color, size, and temperature
- ❖ To resolve:
 1. contact your loved ones doctor immediately
 2. the patient will most likely need complete bed rest and will take medications to prevent the clot from traveling



Edema: Swelling that can happen when: 1) the person's body doesn't move or isn't moved often enough, 2) decreased muscle tone, and 3) abnormal pooling of blood due to decreased circulation.

- ❖ To resolve:
 1. put the individual in a position where the swollen body part is higher than the heart
 2. if swelling does not go down after a short period of time or continues to increase you may need to contact your loved ones doctor
 3. a compression devices may be prescribed by a medical professional to create pressure over the swollen area to force swelling out



Heterotrophic Ossification: This is where the body tissue gets hard (calcifies) around a joint. This happens most often in the shoulder and hip joints.

- ❖ Symptoms include:
 1. warm, swollen extremity
 2. fever
 3. limits in your loved ones movements (range of motion)

- ❖ To prevent/ resolve:
 1. correct positioning of the patient in the bed and wheelchair which is determined by your loved ones doctors and therapists
 2. exercise (see pages 46-49)

Orthostatic Hypotension: Moving to an upright position too quickly can cause the persons blood pressure to drop to dangerously low levels.

- ❖ Symptoms include:
 1. light-headedness
 2. paleness
 3. visual changes such as blurry vision
- ❖ Cause:
 1. sudden change in the persons position
- ❖ To prevent:
 1. do not change his/her position too quickly
- To resolve:
 1. check blood pressure
 2. if the person is in bed, lower the head of the bed
 3. if the person is in the wheelchair, lift their legs and watch for signs of relief such as increasing blood pressure, return of color, and normal vision
 4. if symptoms continue, recline the wheelchair so that the head is at or below the heart
 5. if symptoms have not gone away within 5-10 minutes, put the patient in bed
 6. continue to monitor blood pressure for an increase or return to normal, seek assistance if this does not happen, and do not leave the patient unattended

Pressure Ulcers (Decubitus Ulcers, Bed Sore): The skin breaks down from being in one position for too long. Common areas for skin break down are the back of the head, the shoulder blades, the bottom, and the ankles.

❖ Symptoms:

1. redness
2. bruising
3. blisters
4. wounds on the skin

❖ To prevent:

1. follow a pressure relief schedule that is set up by your loved ones doctor/therapist
2. have your loved one wear clothing that is loose fitting and does not rub against their skin
3. check skin daily for redness, bruising, or blisters
4. have your loved one eat healthy foods and have a well balanced diet
5. see page 49 for more information on pressure relief

❖ To resolve:

1. follow doctors orders
2. remove any clothing or objects that may be causing the pressure and avoid pressure on the area by changing his/her position following the schedule
3. if the wound becomes more than just a red mark, seek medical assistance
4. for quick healing, eat foods high in protein, vitamins, and minerals

.....
Urinary Tract Infection: Is a bacterial infection in the person's bladder and/or connecting parts.

❖ Symptoms:

1. strong urge to urinate
2. painful urination
3. pain in the pelvic area
4. sick feeling including body aches, fever, chills, nausea

- ❖ Cause:
 1. loss of normal bladder control
 2. drinking carbonated drinks
 3. waiting too long to empty bladder
- ❖ To prevent:
 1. drink a lot of water (at least 64 ounces a day)
 2. proper catheter hygiene will also help to prevent infection
- ❖ To resolve:
 1. if a urinary tract infection is suspected, you should call your doctor for the appropriate treatment



Adaptation



PROVIDING SELF-CARE

It is important to help in your loved ones self-care activities during the rehabilitation phase. The amount of help they need will depend on your home and your loved ones abilities.

It will be important for the rehabilitation team to complete a home evaluation prior to your loved one returning home. The home evaluation may be completed by an occupational therapist. During this evaluation some things the occupational therapist will look at are:

1. How easy it is in your home for your loved one to use a wheelchair, the bathroom, and move around the indoor and outdoor spaces.
2. How safe the home is for things you and your loved one need to do, such as bathing, and moving around the house.
3. Other housing options to match the needs and abilities of the care recipient as well as the family will be explored. This is considered when the person may choose or want to live on their own.

This home assessment is intended to make it easier for you and your family. It is important that you are involved in making decisions and telling the therapist your concerns.

Appropriate accommodations will be discussed at this time and should be made before your loved one returns home.

Accommodations are meant to make it easier for you to care for your loved one. Although these changes have been made and you have been trained in providing care, you may still experience some nervousness about being responsible for self-care assistance. Here are some tips to help make it easier for you:

- ❖ Don't put yourself in a position to be injured (for example: do not do something you have not been trained in)
- ❖ Remember to use good body mechanics
- ❖ Have your loved ones therapists number available
- ❖ Ask your loved one for feedback about how you are doing
- ❖ Use the equipment that has been provided to you
- ❖ Don't be hard on yourself
- ❖ Ask for help when you need it



HOME MODIFICATION

This section will talk about ways that your home can be modified/adjusted to make things easier and safer for both you and your loved one. The information talks about many of the different areas of a home and gives ideas that will make it easier for your loved one to get into and around the home.

Basic home modification guidelines:

Entry-ways:

- Park close to the home.
- Make sure sidewalks are wide enough, in good condition, and clutter free so the wheelchair can easily move through.
- Ramps must be installed so the wheelchair can be moved up and into the house. The ramps should be 1 foot long for every 1 inch of height. They should also be at least 36 inches wide, but 42-48 inches is recommended. You will need to get a carpenter to install the ramp before your loved ones comes home, if a ramp is necessary.

Tip: Remember to take time for yourself!



- Doorways must be 32 inches wide, but it is better if they are 36 inches wide. There should be a 60 inch space on the inside and outside of each doorway so the person has room to turn his or her wheelchair around.

Hallways:

- Clear of all clutter and loose rugs. Remove doors if possible and if not re-hang doors so that they open into a room (away from them) rather than into a hall (having to pull it towards them).
- Hallways should be at least 36 inches wide.

Family Room:

- The amount of space to turn around in a wheelchair is a 60 inch space.



- Coffee tables, rugs, and other items that clutter the area may need to be removed.
- Flooring should be made of hard material that is easy for the care recipient to get around on with a wheelchair. Carpet

should be easy to maneuver over. A tightly woven carpet is recommended rather than a long/shaggy type.

Kitchen:



- The table should be at a height that the wheelchair can fit under it.
- Keep commonly used cooking and food items in easy to reach areas for the person in the wheelchair.
- Lengthen the sink handles for easy access by the person in his or her wheelchair. You can do this by installing new handles or buying attachments that lengthen handles.
- Insulate the sink and water pipes to prevent burns when the person's wheelchair is positioned under the sink and allow room under the sink for the chair to fit under.

Bedroom:



- Depending on the person's ability to reposition themselves, a specialized bed may need to be purchased. The bed will be similar to a hospital bed that allows the person to mechanically position themselves. The bed may also include material that prevents skin breakdown.

- Clutter will need to be removed to allow for room for getting around in the wheelchair.
- The closet door may need to be adapted so that it is easy to open.
- Clothing should be stored at a level that is within reach for the person in the wheelchair.

Tip: Remember to ask for help!

Bathroom:

- The sink, toilet, and shower may need to be adapted so that the person can use them from a wheelchair.
 - A roll in shower makes it easier for the person to get in, shower, and get out.
 - A hand-held shower may need to be purchased and may need an adaptive handle depending on level of injury.
 - A bath seat may need to be purchased.
 - The toilet seat may need to be raised.
 - The flooring in the bath area should be made of a non-slip material.
 - Grab bars should be installed in the shower and around the toilet for safety.

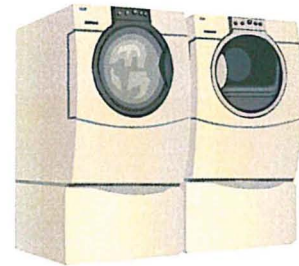


- Pump bottles for soaps will be easier to use.

* Many of these items can be purchased at your local hardware store or a medical supply store. Often there is a medical supply store at a hospital. Also, you can call your OT.

Miscellaneous:

- Light switches should be within reach when seated in the wheelchair and should be easy to use.
- If the person does laundry a front loading washer and dryer will allow greater ease when performing laundry tasks.
- The water temperature may need to be turned down if the feeling in the person's hands has been affected and they have trouble telling if the water temperature is dangerous.
- The thermostat for heating and cooling should be within reach.
- An emergency evacuation plan should be made and practiced.



COMMUNITY ACCESS



This section explains your loved ones rights. It briefly outlines the Americans with Disabilities Act (ADA). This will give a general idea of what your

loved one is entitled to regarding benefits in the community and employment.

For further information regarding this subject, you can visit the ADA web site at www.ada.gov or contact your local advocacy group.

The Americans with Disabilities Act (ADA):

The ADA was adopted in 1990 and is meant to protect individuals with disabilities. It covers 4 main areas including:

- Title I: Employment
- Title II: Public Services
- Title III: Public Accommodations and Commercial Facilities
- Title IV: Telecommunications

Title I: Employment

Individuals with disabilities are protected against discriminative behaviors in the work place including:

- When applying for a job
- When working
- Terminating a job
- When seeking a promotion
- To get compensated or paid for hours worked
- During job training

Tip: When faced with a problem, try using the problem solving worksheet!

Employers who have more than 15 employees are required to follow these guidelines. This includes making accommodations that are reasonable and providing equal employment among people with and without disabilities.

Title II: Public Services

This protects individuals with disabilities from discrimination regarding state and local government services, programs, and activities. It also requires that public services (such as bus companies and telephone companies) make accommodations for people with disabilities regarding communication and transportation in the community.

Title III: Public Accommodations and Commercial Facilities

This requires all public places to have access and accommodations for individuals with disabilities. Restaurants, movie

theaters, motels, professional offices, retail stores, places of recreation, museums, zoos, factories, and warehouses are all included.

Tip: Be patient!

Title IV: Telecommunications

This title says that individuals with disabilities need to be able to access communication services. Frequently, a person will assist you in using the telephone and other such devices. You can access these services by contacting your local relay center located in the phone book.

General Guidelines:

It is important keep in mind that although public facilities are required to be accessible to individuals with disabilities, they are not always. It is important to make sure the place is accessible before attempting to go to it. When a situation cannot be avoided it is important to plan ahead and problem solve the best solution. Never hesitate to ask the facility for help.

Tip: Remember to use your support system!

ASSISTIVE TECHNOLOGY SUPPORT

Assistive technology is defined as any service, device, strategy, or practice that is used to help a person with a disability (Cook & Hussey, 2002). This section will give you information about different types of assistive technology. It will also briefly explain how to use and care for the equipment. Further information about assistive devices will be shared with you by the occupational therapist or another treatment team member.

Each individual with a spinal cord injury is unique. They all will need the use of various assistive devices. It is important that you and your loved one understand the device and how to use it. It is also important to be honest with the treatment team. If you do not like the device and do not think it is something you will use you should tell them. Do not be afraid to ask questions or give your ideas and opinions.

Mobility



Not everyone that suffers a spinal cord injury is going to need a wheelchair but for many a wheelchair will be necessary.

Tip: Don't get frustrated, you can use your resource list for help!

There are several different types of wheelchairs. It is important that your loved one be supplied with the correct chair during the first stages of rehabilitation. A member of the rehabilitative team will measure your loved one and will ask for his/her input on the final chair selection. The chair is very important because it will serve as your loved ones primary way of moving about.

Wheelchairs are not indestructible. They do break. It is important that you have basic knowledge of the chair so that when a problem arises you can seek the proper solution. The chair should be handled in a gentle manner. You should never force a chair to open, close, or go through a tight space.

It is also important to properly take care of the chair. This means keeping the chair clean, dry, and out of harsh weather. The chair should also be checked regularly, about once a year by your therapist or wheelchair provider. This will help to prevent costly repairs.

If the chair needs a battery to operate, you should create a battery-charging schedule. This way you will never put your loved one in a position where the battery goes dead and they cannot move.

Other Devices



There are a few different types of devices that can help a person who does not need a wheelchair.

1. One type is a walker. A walker comes in many different heights, widths, and styles. Your therapist will help make a selection that will best suit your loved one.
2. Another type of walking device that may be used is a cane or crutches. These devices also come in many different heights, widths, and styles and should be selected with the assistance of a health care professional.

Tip: Remember to laugh!

Driving and transportation



Many individuals with spinal cord injuries can relearn to drive with training from a specialized driving instructor. The specialized instructor will be able to identify the specific assistive technology the person needs for successful driving. The assessment will usually include an in-clinic portion before the actual driving portion. The in-clinic portion will consist of assessing the person's vision, perception, strength, sensation, and reaction time. With the right adaptive equipment installed, the driving part begins in the parking lot or a safe area.

If buying a car/van, it is important to ensure that it is accessible for the person to get into and out of. General guidelines are difficult to provide because every individual with a spinal cord injury is unique. Your loved ones occupational therapist and driving instructor will be better able to set guidelines for the vehicle to be purchased.

For those individuals who use manual chairs, they may be able to transfer themselves in and out of a vehicle. If they can do this, it will help to figure out the assistive technology needed for transporting the individual and the wheelchair. For individuals in power chairs, getting from the chair into a vehicle may not be as easy. These individuals may need a specialized vehicle that has a lift to move them and the chair into the inside of the vehicle.

Self-care



There are many different devices that can be used by individuals with spinal cord injuries to help them become more independent in their self-care activities. They should have received training on this equipment when they were in rehab. It is also important that you know what they have and need and receive training as well.

1. For hygiene and grooming your loved one may need to use a bath or shower chair, grab bars, hand held shower, pump bottles, and long or extended handles on sponges, tooth brushes and other items.
2. Devices such as reachers, sock aides, button hooks, zipper pulls, and shoehorns may assist your loved in dressing.
3. For cooking and eating, special silverware and dishes may make it easier for your loved one to independently cook and feed themselves. Ask your occupational therapist.

Work/education



Your loved one may be able to return to their job or to school following the injury. To do this you may need some assistive technology. There are many different types of computer programs that can help your loved one to independently do productive tasks. In addition to computer programs there are many other options available. You, your loved one, and the healthcare team should find what the individuals' wants and needs are, their abilities, and possible assistive devices to help them do what they need and want to do. If your loved

one can not return to their job your therapist can connect you to services that help individuals with disabilities find a new career path.

Leisure



Your loved one should try to do as many of the activities he or she used to enjoy. There are many solutions to help them do their activities. You should use the healthcare team, particularly your occupational therapist, as a resource in finding the devices so that your loved one can continue to be active in the things he or she enjoys doing. The Internet may also be a resource to find solutions.

Tip: Take time to complete one of the relaxation techniques!

HOW TO KNOW IF THE INTERNET WEBSITE IS A GOOD/SAFE SITE

It is important to know how to find resources that are reliable. Here are a few tips on what to look for:

- Look for sites that have **.org**, **.edu**, or **.gov** in their addresses, instead of **.com** sites.
 - Example: www.reliablesource.org
- Look for University sites and Hospital sites with Authors, Addresses, and Phone Numbers.
- If there are spelling and grammar mistakes the site may not be trustworthy.

RESOURCE LIST

- American Association of People with Disabilities
1629 K. Street NW, Suite 503
Washington, D.C. 20006
Phone: 202-457-0046, 800-840-8844
www.aapd-dc.org

This sites focus is to support those with disabilities.

- ABLEDATA
8630 Fenton Street, Suite 930
Silver Spring, MD 20910
Phone: 800-227-0216
www.abledata.com

This site provides information about assistive technology and rehabilitation equipment.

- American Paraplegia Society
75-20 Astoria Blvd.
Jackson Heights, NY 11370
Phone: 718-803-3782
www.apssci.org

This site tries to improve the quality of medical care that is provided to individuals with spinal cord injuries.

- American Spinal Injury Association
2020 Peachtree Road, NW
Atlanta, GA 30309
Phone: 404-355-9772
Fax: 404-355-1826
www.asia-spinalinjury.org

This site aims to improve care, educate, promote spinal cord injury research and improve communication with people involved in the care of individuals with spinal cord injuries.

- Americans with Disabilities Act
U.S. Department of Justice
950 Pennsylvania Avenue, NW
Washington, D.C. 20530
Phone: 800-514-0301
Fax: 202-307-1198
www.ada.gov

This site provides individuals with disabilities with information about their rights. It contains links to other resources that give information on opportunities for individuals with disabilities.

- ARCH National Respite Network
800 Eastowne Drive
Suite 105
Chapel Hill, NC 27514
Phone: 919-490-5577
Fax: 919-490-4905
www.archrespite.org

This site provides information to caregivers about respite services.

- CarePages Inc.
4043 N. Ravenswood Ave., Suite 301
Chicago, IL 60613
Phone: 866-981-4900
Fax: 773-348-4964
Telephone support line:
888-852-5521
www.carepages.com

This site provides a free space to communicate with friends and family when a loved one is receiving medical care.

- Christopher & Dana Reeve Paralysis Resource Center
636 Morris Turnpike, Suite 3A
Short Hills, NJ 07078
Phone: 800-539-7309
www.paralysis.org

This site provides resources, information, and referral services to help promote health and well-being of people living with spinal cord injuries.

- Craig Hospital
3425 S. Clarkson St.
Englewood, CO 80113
Phone: 303-789-8000
www.craighospital.org

This is the webpage for the Craig Hospital. Craig is one of the leading rehabilitation hospitals for people with spinal cord injuries. The site provides information and resources for the injured individual as well as their family.

- DisabilityInfo.gov
Phone: 800-FED-INFO
www.disabilityinfo.gov

This site provides quick and easy access to disability related information. It provides many resources.

- Disability Resource Center
US Department of Transportation
400 7th Street
S.W. Washington, D.C. 20590
Phone: 202-366-4000
www.drc.dot.gov

This site provides information on employment rights for individuals with disabilities.

- Family Caregiver Alliance
National Center on Caregiving
180 Montgomery St., Ste 1100
San Francisco, CA 94104
Phone: 800-445-8106
Fax: 415-434-3508
www.caregiver.org

This site provides information, resources, education, services and support for family caregivers. It has served caregivers for 30 years.

- National Caregivers Library
901 Moorefield Park Drive
Suite 100
Richmond, VA 23236
Phone: 804-327-1112
www.caregiverslibrary.org

This site is an online library for caregivers. It has journal articles, checklists, forms, links, and more.

- National Family Caregivers Association
10400 Connecticut Avenue, Suite 500
Kensington, MD 20895-3944
Phone: 800-896-3650
Fax: 301-942-2302
www.nfcacares.org

This site provides family caregiver's with education, support, and resources.

- National Organization on Disability
910 16th Street, N.W. Suite 600
Washington, D.C. 20006
Phone: 202-293-5960
Fax: 202-293-7999
TTY: 202-293-5968
www.nod.org

This site provides resources and information on how individuals with disabilities can get more involved in their communities.

- National Spinal cord Injury Association
6701 Democracy Boulevard
Suite 300-9
Bethesda, MD 20817
Phone: 800-962-9629
www.spinalcord.org

This site is the oldest and largest organization that provides individuals with spinal cord injuries and their families with a resource center and a peer support program.

- Paralyzed Veterans of America
801 18th Street, NW
Washington, DC 20006
Phone: 800-424-8200
<http://www.pva.org>

This site provides information on research, education, rights, accessibility, and quality of life for all individuals who have experienced a spinal cord injury.

- Spinal Cord Injury Information Network
UAB Department of Physical Medicine and Rehabilitation
Spain Rehabilitation Center
1717 6th Avenue S.
Birmingham, AL 35233-7330
Phone: 205-934-3450
www.spinalcord.uab.edu

This site provides information and statistics about spinal cord injury topics and also provides opportunities for individuals with SCI to participate in current research studies.

- Spinal Cord Injury Peer Information Library on Technology (SCI PILOT)
c/o Toronto Rehabilitation Institute
520 Southerland Dr.
Toronto, Ontario M4G 3V9 Canada
Phone: 416-587-3422 ext. 6264
Fax: 416-422-5216
www.scipilot.com

This site provides assistive technology support based on the first hand experiences of those who use it.

- Well Spouse Association
Mainstay, PO BOX 30093
Elkins Park, PA 19027
www.wellspouse.org

This site provides caregivers, who are spouses to those they care for, with opportunities to be a part of support groups.

- USA Tech Guide
United Spinal Association
75-20 Astoria Boulevard
Jackson Heights, NY 11370
Phone: 718-803-3782
Fax: 718-803-0414
www.usatechguide.org

This site provides information on wheelchairs and other types of assistive technology. It includes reviews by people who are currently using the technology and resources to help you locate different types of assistive technology.

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CHAPTER V

SUMMARY

The *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* is designed to assist occupational therapists in meeting the needs of caregivers of individuals with spinal cord injuries. Although numerous websites and guides are available to individuals with a SCI and their families, there is not a guide specific to treating the occupational and psychosocial needs of the caregiver from an occupational therapy (OT) perspective. It is hoped that the *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* will begin to bridge the gap faced by occupational therapists in treating the needs of the caregiver.

Current literature suggests that individuals with spinal cord injury are transitioning into the community earlier with the majority of care being provided by informal caregivers (Boschen, Tonack, & Gargaro, 2005). The literature supports the need for training and follow-up education of the caregiver subsequent to the rehabilitation phase (Boschen et al., 2005; Elliot, Kurylo, & Lindsey, 1998; Grey, Horowitz, O'Sullivan, Kharasch Behr, & Abreu, 2007; Manns & May, 2007; Moghimi, 2007). From the literature review, the needs of the caregiver were identified which include: emotional, physical, knowledge, support systems, and accessing healthcare professional assistance. These needs were the focus of the *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* utilizing Malcolm Knowles Adult Learning Theory of Androgogy. Based

on the caregiver's needs and the adult learning perspective, the product was specifically designed with education and strategies on caring for yourself, medical management, adaptation, and a resource list.

Proposed Implementation

The *Occupational Therapy Caregiver's Guide to Spinal Cord Injury* could be distributed to rehabilitation facilities that treat individuals with spinal cord injury and home health agencies that provide care to these individuals. Skilled OT's would then present the information to caregiver's of individuals with spinal cord injury when the client and caregiver are participating in rehabilitation or prior to discharge from rehab for a more successful transition home. It is recommended that the guide be distributed at a rehabilitation facility that also provides follow-up care during community reintegration.

Recommendations

Further research needs to be conducted on the role of occupational therapy services aimed at serving the unique needs of caregivers of people with SCI. Laliberte-Rudman et al., (2006) examined the loss of certain occupations following a SCI for both the client and the caregiver and it was found that studies need to address the reason for the reengagement in some occupations and the loss of others. Meade, Taylor, Kreutzer, Marwitz, and Thomas (2004), suggested, "Future studies can also examine how injury, socioeconomic status, ethnicity, employment status, and other factors relate to family needs".

It is also vital that future studies prove the need for preventative services for the caregiver and how those services will affect the wellbeing of the person with the SCI and the amount of money spent on services for both parties. Richards and Shewchuk, (1996)

stated, “If we are able to link the physical well being of the caregiver to health outcomes of the person with SCI, there will be obvious policy implications for these finding and therefore a stronger argument for increased provision of home care services”.

An outcome based survey, such as the one that accompanies the guide, should be used to measure the effectiveness of the product after a six month trial period. If the caregiver shows significant improvements in their ability to care for themselves and/or the needs of their loved one, the guide should be distributed on a wider basis.

Conclusion

The guide is not intended to be the only resource/intervention used to assist OT’s in meeting the needs of caregivers. Occupational therapists should also utilize their own skill and clinical reasoning when providing services to caregivers and care recipients since every situation will be unique. If necessary, the guide can be adapted to more effectively meet the needs of individual facilities and community providers. The authors hope that the *Occupational Therapy Caregiver’s Guide to Spinal Cord Injury* will be a helpful tool for occupational therapists when providing services to caregivers of individuals with SCI in order to improve the quality of life of the caregiver and the care recipient.

APPENDIX
Occupational Therapy Caregiver's Guide to Spinal Cord Injury
Outcomes Measure

Rate your satisfaction with this product
1-very dissatisfied 2-dissatisfied 3-neutral 4-satisfied 5-very satisfied

Questions	1	2	3	4	5	Comments
How satisfied were you with your ability to prepare for your loved ones return home?						
How satisfied are you with your ability to continue participating in occupations you enjoyed prior to your loved ones injury?						
How satisfied are you with the information provided about respite care?						
How satisfied are you with your ability to care for your own emotional and physical well-being?						
How satisfied are you with the information provided about problem solving?						
How satisfied are you with the information provided explaining the medical terms, complications, and care guidelines?						
How satisfied are you with your ability to assist your loved one with self-care after using the guide?						
How satisfied are you with your ability to modify your home after reading the guide?						
How satisfied are you with your ability to move your loved one through the community after using the guide?						
How satisfied are you with your ability to help your loved one with using assistive technology?						
How satisfied are you with the resource list that is provided at the end of the guide?						
How satisfied are you with the guide overall?						
How satisfied are you with your collaboration with your occupational therapist using the guide as a tool?						

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