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# Spinal Cord Injury: A Comprehensive Treatment Approach to Occupational Therapy Treatment

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Spinal Cord Injury: A comprehensive treatment approach to  
occupational therapy treatment

by

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Scholarly Project

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## CHAPTER ONE

### INTRODUCTION

According to Trombly and Radomski (2002), “spinal cord injury (SCI) affects 10,000 people per year in the United States” (p.966). There are approximately 220,000 people living in the U.S. with SCI (Palmer, Kriegsman, Palmer, 2000), and SCI most typically occurs in young males. According the Occupational Therapy Practice Guidelines for Adults with Spinal Cord Injury, the average age of injury is between 16-30 years of age (Dohli, 2001). A ratio of four injured males per one female has persisted over the past many decades. (Trombly & Radomski, 2002). Trombly and Radomski (2002) reported that “The National Spinal Cord Injury Statistical Center tracked data from 1973-1997 and found the causes of SCI to be: 43% from motor vehicle accidents, 22% from falls or being hit by an object, 19% from violence, 11% as a result of a sports injury. Another 5% are caused by nontraumatic SCI, such as spinal stenosis, infection, ischemia, and myelitis” (p. 966).

Although SCI is a devastating event, which may leave an individual with feelings of hopelessness, with holistic rehabilitation treatment he or she may increase quality of life and establish fulfilling life routines. Occupational therapy (OT) treatment addresses physical and psychosocial needs, as well as social and environmental barriers. This background allows for treatment of the whole person, their roles, and their interaction with the environment. Because of the specialties in these areas, an occupational therapist is an integral part of a SCI rehabilitation team.

While much research has been carried out in the area of treatment of SCI, we were unable to find a comprehensive rehab protocol from an OT perspective. In today’s

medical model, priority is often given to providing basic medical care and physical rehabilitation, without providing the necessary care to prepare clients to deal with emotional and social adjustments. It is the purpose of this scholarly project to construct a protocol, which will address a more broad range of client needs and provide a more holistic approach during rehabilitation. This protocol will provide education and other learning opportunities in the form of both group and individual sessions, in many areas including: activities of daily living (ADL's), environmental modification, community re-entry, employment, return to the educational environment, leisure and social participation, family and caregiver education, sexuality, and depression/suicide prevention

## CHAPTER TWO

### REVIEW OF LITERATURE

#### Introduction

Spinal cord injury causes a disruption in the motor and sensory pathways at the site of the lesion. Immediately following injury, there is a period of spinal shock which is characterized by areflexia, the absence of reflexes, below the level of injury. Spinal shock varies in duration and can last anywhere from hours to weeks. As the spinal shock subsides, reflexes below the level of injury may return and become hyperactive; however, at the level of injury, areflexia may remain due to interruption of the reflex arc (Trombly & Radomski, 2002). “As time after injury increases, the recovery rate declines. Most motor and sensory return occurs in the first six months post onset, and the rate of recovery is minimal after that” (Trombly & Radomski, 2002, p. 968).

Traumatic injury may result in lesions of the spinal cord, leading to a variety of impairments in function. The National Spinal Cord Injury Statistical Center tracked data from 1973-1997 and found the causes of spinal cord injury (SCI) to be: 43% from motor vehicle accidents, 22% from falls or being hit by an object, 19% from violence, 11% as a result of a sports injury. Another 5% have non-traumatic causes, such as spinal stenosis, infection, ischemia, and myelitis (Trombly & Radomski, 2002, p. 966)

#### Classifications

In addition, SCI can be classified as complete or incomplete. The American Spinal Cord Association (ASIA) impairment scale states that a complete injury is “no motor or sensory function is preserved in the sacral segments S4-S5” (American spinal cord injury association, 2000).

The ASIA (2000) defines an incomplete injury in three ways:

- 1) Sensory but not motor function is preserved below the neurological level and extends through the sacral segments S4-S5.
- 2) Motor function is preserved below the neurological level, and the majority of key muscles below the neurological level have a muscle grade less than three.
- 3) Motor function is preserved below the neurological level, and the majority of key muscles below the neurological level have a muscle grade greater than or equal to 3. (p. 2)

Spinal cord injury may result in tetraplegia or paraplegia and refer to damage to the neural elements within the vertebral canal. Tetraplegia has replaced the term quadriplegia and results in functional impairment of the arms, trunk, legs, and pelvic organs. It is defined as impairment in motor and/or sensory function in the cervical segments of the spinal cord. Paraplegia refers to motor and sensory impairment at the thoracic, lumbar, and sacral segments of the spinal cord. Paraplegia results in sparing of arm function and, depending on the level of the lesion, impairment in the trunk, legs, and pelvic organs. (Trombly & Radomski, 2002, p.967)

### Syndromes

In addition, there are also various injuries and syndromes that can cause disruption to the spinal cord. Reed (2001, pp. 539-541) describes the following syndromes; anterior cord syndrome, brown-sequard syndrome, cauda equina, central cord syndrome, conus medullaris, posterior cord syndrome, and mixed syndrome.

#### *Anterior Cord Syndrome*

“Anterior cord syndrome results from a flexion injury, in which bone or cartilage causes damage to the anterior spinal artery or anterior aspect of the spinal cord. This causes paralysis of motor functions and the sensation of pain and temperature are lost” (Reed, 2001, p.541).

### *Brown-sequard syndrome*

Brown-sequard syndrome occurs when one side of the spinal cord is damaged. The result is motor paralysis and loss of proprioception below the level of injury on the same side as the injury, and loss of pain, temperature, and touch sensation, on the opposite side of the injury.

### *Cuada Equina Syndrome*

Cauda equina involves injury to the peripheral nerves at the caudal aspect of the spinal cord. Sensory deficits vary greatly based on the specific nerves injured.

### *Central Cord Syndrome*

Central cord syndrome is the destruction of cellular tissue in the center of the spinal cord. This syndrome more commonly affects the upper extremities, as nerves that supply the upper extremities are more centrally located.

### *Conus Medullaris Syndrome*

“Conus medullaris occurs to the sacral and lumbar nerve roots, which results in areflexic bladder, bowel, and lower limbs”

### *Posterior Cord Syndrome*

Posterior cord syndrome results from damage to the posterior spinal artery and/or the posterior aspect of the spinal cord. Since injury occurs to the posterior portion of the spinal cord, motor tracts and pain and temperature remain intact. However, there is a loss of proprioception, two-point discrimination, stereognosis, deep pressure, and vibratory sensation.



### *Mixed Syndrome*

The combination of two or more of the above listed syndromes results in what is termed mixed syndrome.

### Areas of Intervention

#### *Health Maintenance and Management*

Individuals with SCI experience a high number of hospital readmissions following rehabilitation, with incidence rates ranging from 19%-57% (Pershouse, Cox, & Dorsett, 2000, p 23). These high rates of hospital readmission result in stress on relationships, leisure, and vocational activities. In addition, the cost of hospitalization can be a large burden.

Pershouse, Cox, and Dorsett(2000), studied the influence of community based rehabilitation on hospital readmissions. The researchers reviewed the medical records of 166 individuals consecutively discharged from the spinal cord injury unit between December 1, 1991 and January 31, 1995. Specific exclusion criteria were developed for this study to ensure that the participants were eligible for the community-based programs; ventilator dependent clients were also excluded from the study. Sixty-eight clients were selected to be potential subjects for the study. Each subject who responded affirmatively was asked the name of the facility and to sign a waiver to be used for the researchers to gain additional information, such as dates and specific reasons for the hospitalization. Each hospitalization record was reviewed by a spinal rehabilitation specialist who completed a two-step classification. First each episode of readmission was classified as to whether it was linked to a secondary condition that was casually related to SCI (i.e if the

patient, because of the SCI, was at a greater risk of developing the specific condition). If the hospitalization was due to a secondary condition, the specialist was asked to consider whether or not it was preventable with compliance or problem solving strategies.

The 68 participants were compared to 34 clients who did not participate in the community-based treatment programs. There was no significant difference for level of injury or bowel/bladder management. However, the nonparticipant group did have a younger mean age, shorter length of stay for initial rehabilitation, and scored slightly higher on the functional independence measure (FIM) overall. Twenty-one of the participants were readmitted at least one time during the first two years post discharge from initial rehabilitation. There were 60 total hospital readmissions. The overall average length of stay was 10 days, for secondary complications it was 11 days, for potentially preventable conditions it was 41 days, and for those conditions specifically related to SCI, such as removal of spinal instrumentation, length of stay was 8 days. Most of the re-hospitalizations that occurred were admissions to medical and surgical wards. Some of the common reasons for hospitalization were pain, removal of spinal instrumentation, post surgical complications, and urinary tract infections. The majority of hospitalizations were caused by conditions secondary to SCI and many were potentially preventable. By identifying the most common conditions to occur following SCI, health professional will be able to educate clients in health maintenance issues and hopefully reduce the risk of readmission to hospitals. (Pershouse, Cox, & Dorsett, 2000)

#### *Autonomic Dysreflexia*

As one can see from the above-mentioned study, education regarding health risks is an important portion of a client's rehabilitation. A primary health concern is

autonomic dysreflexia. This can occur in anyone who has sustained an injury at or above the T6 level. It is related to disconnections between the body below the injury and the control mechanisms for blood pressure and heart function (Spinal Cord Resource Center, 2003). It causes the blood pressure to rise to potentially life-threatening levels. It can be caused by anything that normally causes pain, such as a urine retention, constipation, urinary tract infection, or pressure sores. Symptoms may include severe headache, blurred vision, sweating, and flushing of the skin. One of the first things to do to relieve this condition is sit up, since this will naturally decrease the blood pressure, catheters, bowels, and skin should be checked immediately. The primary risk of autonomic dysreflexia is stroke, which is a potentially life threatening condition and symptoms should be attended to immediately. (Trombly & Radomski, 2002 & Spinal Cord Resource Center, 2003)

#### *Deep Vein Thrombosis*

Another potential complication of SCI is deep vein thrombosis (DVT). DVT is a blood clot that may develop in damaged blood vessels or in places where the blood flow stops or slows down. DVT in the lower leg is common during the early stages of recovery, but DVT does not become a great concern until it is in the upper thigh. In this position, there is a higher risk the clot becoming dislodged and entering the vascular tree and eventually the lungs. Often medications, such as Coumadin and Heparin are used to reduce blood viscosity and improve flow. In addition, ace wrapping the lower leg and/or wearing Ted hose, pressure stockings, is often recommended. Also due to the sedentary life style that may follow spinal cord injury, these individuals are at a higher risk for cardiovascular disease. Careful monitoring of cardiopulmonary function and participation

in exercise programs can decrease this risk. (Spinal Cord Resource Center, 2003 & Hammell, 1995).

### Neuropathic Pain

Naturopathic/spinal cord pain is a significant problem in some clients who have sustained SCI. Damage to the spine and soft tissue surrounding the spine can cause aching at the site of injury. This type of pain is often described as a quick, sharp pain and occasionally the client will describe pain that radiates from the level of the lesion. To treat this pain, nerve block procedures are often used following the injury. (Spinal Cord Resource Center, 2003).

### Respiratory Complications

Respiratory complications are predominant following SCI, with one of the most common complications being pneumonia. If the injury involves the upper thorax, the normal breathing pattern is disrupted and changed. Normally, the diaphragm does most of the work during quiet breathing and the intercostals muscles are used for deep breathing and coughing. The diaphragm takes over these functions when the intercostals and abdominal muscles are affected by SCI. The result of this change is poor coughing and deep breathing, therefore increasing the risk of pneumonia. Preventative measures are important in reducing this risk and include percussion and drainage using gravity assist, assisted coughing, abdominal binders to increase the resistance against which the diaphragm works, and getting the client out of bed as soon as possible following injury. (Spinal cord resource center, 2003, & Sunrise Medical, 2001)

### *Skin Breakdown/Pressure Sores*

As will be discussed further throughout the literature review, skin break down is a complication for many clients. According to the results of a study done on the long term predictors of pressure ulcers, out of 118 participants 31 % reported having had a pressure ulcer in the past year; 24% reported having had surgery for a pressure ulcer in their lifetime. A follow up study was done three years later, with 100 of the original participants. At this time 32% of the participants had at least a stage two pressure ulcer upon examination. (Garber, Rintala, Hart, Fuhrer, 2000, p. 468)

After SCI there is a change in sensation, muscle tone, and blood supply, and this in turn decreases skin integrity. Pressure sores occur as a result of excessive pressure or sheering forces and generally occur over bony prominences. Because of the high risk of skin breakdown, it is important that the patient understands how to safely transfer themselves to prevent sheering forces from damaging the skin (Sunrise Medical, 2001). In addition, regularly checking the skin should be incorporated into the client's daily routine to prevent pressure ulcers from developing. Long handled mirrors may be used to aid individuals to complete this task independently.

The cost of medical treatment for pressure sores can be great; one source estimated this cost to be between \$10,000-\$50,000 per admission (Spinal Cord Resource Center, 2003). In addition to the cost of hospitalization, there is also a loss of productivity. This risk of developing this skin breakdown can be combated through pressure relief, either through manual chair push-ups, pressure-relieving wheel chair cushions, or tilt in space chairs.

### Osteoporosis

Osteoporosis is another complication faced by clients with SCI. When clients with SCI are not using their legs for weight bearing, calcium and phosphorus are lost and bones become weakened and brittle. Maintaining bone mass can be done through having the client do weight bearing in standing. Support can be provided by using a variety of standing frames and by using braces for parallel bar walking if appropriate. At this time, there is no way to reverse osteoporosis and once the bone breaks it takes longer to heal. (Spinal Cord Resource Center, 2003).

### Heterotrophic Ossification

Heterotrophic ossification occurs when the body lays down bone outside of the normal skeletal structure. Typically, this occurs at larger joints such as the knee and hip and causes risk for joint stiffening and potential fusion. Preventing this condition includes range of motion programs and functional activities that include movement of the joint.

### Spasticity

After SCI nerves below the level of injury become disconnected from the brain; the responses from these nerves become exaggerated, which develop into spastic patterns. Bladder infections and pressure sores can also cause spasticity; thus serving as a “warning” that something is wrong. Another benefit is that it does maintain muscle and bone size and assists with maintaining circulation in the legs. Range of motion programs are also helpful in the management of spasticity. In addition, medication is often used in the treatment of spasticity, three main medications used include; Baclofen, Valium, and Dantrium. (Trombly & Radomski, 2002)

### Activities of Daily Living

Activities of daily living (ADL's), such as bathing, dressing, eating etc., are a large part of what makes us who we are. When individuals who have suffered a SCI are dependent on others to aid them with these ADL's, there is often a negative impact on their self-worth and self-esteem. ADL's are part of everyone's daily routine, and are often taken for granted. However when an individual can no longer wash themselves or care for their bowel and bladder needs, they often feel as though they are a burden to their loved ones who take on the responsibility of assisting them. This is why it is crucial to address each patient's needs in the areas of ADL's to allow them to be as independent as possible.

### Bathing and Grooming

Bathing and hygiene/grooming tasks can often be the most daunting, due to the amount of time they may take. In addition, these tasks are usually done privately. Requiring assistance of another may not only decrease self-worth; it can also lead to embarrassment. Being independent in bathing and hygiene/grooming in one's home environment usually means having an adapted environment, as well as proper adaptive aids. There are a variety of aids available to assist with independence in these tasks. It is important to remember that each patient is unique and that what works for one individual may not work for another (Hill, 1986). Therefore, practicing with different types of equipment to determine what will work best should be encouraged. Level of independence is also dependent upon the level of the spinal injury. For example, individuals who have a C5 or lower injury should be able to bathe their upper extremities independently with the use of proper bathing aids. Individuals with an injury at the level

of C6 or below should be independent in bathing their trunk, and individuals with injuries at C8 or below may have the muscle strength to be submersed in the bathtub (Hill, 1986). These levels serve only as a guide for what patients should be able to achieve. Each individual is unique, therefore they may not always be able to achieve what is expected for their level of injury, or they may supersede the expected return of function. Regardless of the level of injury, patients should be allowed to do as much of these tasks as they can independently, in order to increase their feelings of self-worth. However, complete independence is not always a realistic goal. For example, clients with an injury above C5 will require a personal care attendant 24 hours per day and part of the rehab education should include selecting and educating a care attendant.

#### *Bowel and Bladder Care*

Bowel and bladder management is yet another important aspect of hygiene. This area is primarily addressed by the physician and nursing staff; however occupational therapists often assist the patient in performing bowel/bladder management techniques with adaptive equipment (Hill, J. 1986). Occupational therapists also play an important role in strengthening the patient's musculature to allow increased independence in bowel/bladder management. For example, OT intervention may include working on sitting endurance, in order to allow a patient to sit at a 90-degree angle for an extended period of time; to be independent in self-catheterization. The bladder muscle is innervated at the levels of S2-S4 and with a complete spinal injury above these levels bladder control is lost. Individuals with an incomplete spinal injury above these levels may retain partial voluntary control over bladder contraction. There is often insufficient emptying of the bladder, which may cause autonomic dysreflexia. Occupational therapists should watch



for signs of autonomic dysreflexia (Hill, 1986). These signs will be further discussed within this review of literature.

### *Dressing and Feeding*

Independent dressing and feeding are also important factors to be considered. There are a variety of adaptive devices available to aid individuals to carry out these ADL's successfully. Therapists should educate patients on the proper use of equipment and demonstrate techniques. Patients should also be allowed to practice dressing/ self-feeding with the equipment. Often patients will get frustrated at their struggle to use the equipment successfully; therefore, a process of trial and error to determine what works best is common. When working on ADL based goals it is important to collaborate with the client to gain insight into their priorities. Gange and Hoppes (2003) found that patients treated with a goal focused therapy approach had less frustration and gained greater improvements in their ability to dress their upper body. This type of approach should be considered when upper extremity dressing is the primary area of concern.

### *Sexuality*

Sexuality is probably the most private of all of the ADL areas and therefore is the least often addressed in therapy. However, sexual dysfunction has a negative impact on an individual's self-concept, and self-worth. It is common for individuals who suffer from sexual dysfunction, secondary to a SCI, to have feelings of depression, anxiety, and often become preoccupied with feelings regarding their sexual loss. (Sumerville & McKenna, 1998)

Summerville and McKennan (1998) reviewed several past studies that had been done on sexuality education in rehabilitation. The findings in one study done by

Charlifue, S., Gerhart, K., Mentor, R., Whiteneck, G., & Manely, M. 1992, indicated that individuals with SCI's felt sexuality counseling was a very important part of the rehabilitation process. The authors of the same study interviewed a sample of 31 women, and found that only 14 women reported that they had received information on sexuality during their hospitalization. The participants also reported that they felt the information that they had received was incomplete and did not provide practical examples of how to modify sexual techniques. (Charlifue, S. et. al., 1992)

According to Summerville & McKenna, 1998, a study done by Zwerner, in 1982, found that out of 68 women surveyed after having a SCI, fewer than 50% of them reported receiving any information on sexuality during their rehabilitation. Eighty-five percent of these women reported that they felt this type of information would have been beneficial. Summerville & McKenna, 1998, reviewed a third study by Tepper in 1992, in which the data revealed that men were almost twice as likely than women to receive information on sexual concerns during the rehabilitation process. It was suggested that this may be because following a SCI, women are usually still fertile and conception and delivery of a child is possible. However, men often lose their ability to maintain an erection or ejaculate, therefore causing them to be impotent. Regardless of the reasoning, the results found that women's sexuality following SCI's is often overlooked. Men and women were also found to rate the importance of sexual activity differently. Men rated sexual activity fifth out of twelve basic life domains, (physical, financial, appearance, etc.). Whereas, women rated sexual activity tenth out of the same twelve domains. (Sumerville, McKenna, 1998)

The results of a final reviewed study by Novak & Mitchell, 1988, found that 55% of occupational therapists felt sexuality education was a high priority, and 64% of occupational therapy department heads also felt that sexuality should be a top priority addressed during rehabilitation. However only 48 % of the occupational therapists surveyed were providing sexual education to their patients. Occupational therapists reported feeling undereducated in this area and that was why they were not providing sexual education material for their patients. (Sumerville, McKenna, 1998)

Based on previous research and literature, Sumerville & McKenna, 1998, concluded that sexuality is not adequately addressed during the rehabilitation process. It is clear that therapists need to take initiative to educate themselves in the area of sexual education so that they may become comfortable discussing the sensitive issue of sexuality with patients. Discussing sexuality will establish rapport and meet the patient's needs. However, therapists must also recognize when this issue falls outside of the treatment realm of occupational therapy, and be able to refer the client to a more qualified professional.

### *Parenting*

In addition to sexuality concerns, individuals with SCI's may have concerns regarding conception. As previously stated women are usually able to conceive following a SCI, however men may not be able to impregnate their partner following injury. There are several assistive reproductive technologies (ART's) which therapists should be aware of to allow them to provide education on ART's to those patients who wish to become parents. It is common for patients to hesitate or fear being a parent after their injury. Therapists need to reassure patients that "babies accept what is there without learned

biases or fears—they do not judge care methods as right or wrong” (Stiens, Krishblum, , Groath, Mckinley, & Glitter, 2002 p. s77). Results found by Steins, et. al, have also shown that children with fathers who have a SCI have positive attitudes toward their fathers, had positive responses to requests from their fathers, and grew up to be well adjusted adults. These adults also reported that they did not feel they were stigmatized as a child, due to having a father with a disability. Patients often have the misperception that having a disability means they will not be a good parent. Therapists need to address these psychological aspects in addition to the physical aspects of conception. (Stiens, et.al., 2002) In 1995 Hammell reviewed a study by Beck and Hohmann that examined the relationships between fathers with SCI and the adjustment patterns in children. The researchers found that these children were well adjusted, emotionally stable, and had normal sex identities. In addition, they found that health patterns, body image, recreational interests, interpersonal relationships, and family relationships remained unaffected by the father’s disability. (Hammell, 1995, p. 295) Results such as these can be pointed out to couples that are struggling with these issues to instill hope and confidence in the couple. Clients who already have children should be encouraged to continue developing relationships with their children.

#### *Community Mobility/Re-integration*

Community mobility is one of the largest parts of being independent. Individuals with SCI’s often are dependent on others for transportation and assist them with buying groceries, going to the bank, using the Laundromat, going to the mall, etc. Being dependent on others in such a way can cause one to feel like a burden and to have increased feelings of worthlessness or depression. In response to the guilt of burdening

others, individuals will often not call family or friends for assistance when they need it. In their study Carlson and Myklebust (2002), found that limited mobility had adverse affects on social life. The research data indicated 71% percent of individuals with disabilities got together with friends or neighbors; but that only 61% of individuals with disabilities, that required the use of wheelchairs for mobility, visited friends or neighbors. Sixty-eight percent of wheelchair users reported that they did not attend church, 72% reported no longer attending sporting events or going to movies, and 49% no longer ate out at restaurants, due to the difficulty accessing these places. (Carlson & Myklebust, 2002) This is why it is important to allow individuals to be as independent at maneuvering in the environment outside of their home as possible.

There are a variety of mobility devices that can assist individuals in being independent within the community. Patients should be assessed to determine what their needs are and what types of equipment will work best for them. For example, does the patient have the strength to propel a manual wheelchair, or do they require a power wheelchair for mobility. As previously mentioned, positioning needs to be taken into consideration when fitting an individual for a wheelchair. Patients should also be made aware of assistant services available in the community. For example, is there an accessible transportation system available in their community. In addition, for client with an injury below the level of C4-5, driving is possible with a specially equipped vehicle an training. (Trombly & Radomski, 2002)

### *Leisure*

Leisure plays a large role in maintaining a healthy life style, as well as defining who we are. However, returning to leisure activities following a SCI is often not

addressed during rehabilitation. Historically it was assumed that individuals with disabilities did not have the physical capabilities to participate in many athletic types of leisure. It was thought that individuals with disabilities should just change their leisure interests to activities they were capable of participating in. For years disabled individuals conformed to these standards of society, and lost much of the enjoyment they received out of leisure activities. However, gradually as adaptive equipment has lessened the physical barriers for individuals with disabilities, they are returning to their prior leisure interests. Individuals with disabilities have begun a whole new movement towards adapted leisure activities, particularly in the area of sports. (Stiens, et. al. 2002)

Many sports activities have been adapted for individuals with disabilities to meet their mobility limitations; some have even been modified to allow mutual competition between able bodied individuals and individuals with disabilities. In a study done with individuals who had a SCI and were active in sports, Stiens, et.al. (2002), found that these individuals had decreased breathlessness, increased cardiac dimensions, and a higher maximal work rate. Participation in sports was also found to improve strength, endurance, coordination, and task performance. Research results indicated that wheelchair users who participate in sports have fewer physician visits per year, fewer rehospitalizations, pressure ulcers, and medical conditions over time “Sports build self-esteem, foster a positive body image, and frequently result in improved overall physical health” (Stiens, et. al. 2002, p. s75).

Stiens, et. al. (2002), also reported that although there are many benefits to participating in sports for individuals with disabilities, there are also risks. Percentage of injury to wheelchair users during sporting activity has been reported to range from 26%

to 97%, depending on type of injury. Overuse syndrome was the most common type of injury to wheelchair users who were active in sports. This study reported an estimated 52% of wheelchair sports injuries are overuse injuries, and approximately 16% of injuries are traumatic (Steins, et.al. 2002, pp. s75-s76). Wheelchair users primarily use their upper body for weight bearing and propulsion, and therefore are at highest risk for shoulder overuse/impingement syndromes.

Another risk of participating in sports is its affects on thermoregulation. Individuals with SCI's are at higher risk of thermal imbalance than able-bodied individuals. Therapists should educate patients on taking precaution to prevent core temperature changes. During participation in sports this means dressing cool, drinking plenty of water, and paying attention to the physical symptoms of being overheated, such as dizziness and increased fatigue. Patients should also be instructed to prevent core temperature changes from occurring due to extreme weather changes, by dressing in layers.

Participation in sports may also lead to autonomic dysreflexia . Some wheelchair athletes will intentionally initiate autonomic dysreflexia, in order to improve their performance. This is most commonly done by clamping off the bladder catheter, and is referred to as “boosting”. Therapists need to be aware of this, and provide education to patients regarding the hazards of boosting such as, seizure, cerebral hemorrhage, retinal hemorrhage, and even death. (Stiens, et. al. 2002)

### *Independent Living*

According to Palmer, Kriegsman, and Palmer (2000), the disruption to normal everyday habits and routines can be challenging enough, even without the continuous

changes in environments. Moving from hospital to rehabilitation center and rehabilitation center to home, are major transitions for someone following SCI. Once a person is nearing the end of his or her stay at a rehabilitation center, they may be so eager to get home and back to friends and family or they may experience just the opposite—fear of what it will be like to go on with life without the support of the professional rehabilitation team. When a client is planning to return home there are many areas to consider before making the transition. Discharge planning should be done throughout the client's stay at the rehabilitation center to help ensure a smooth transition. While at the rehabilitation center ADL's should be simulated in an environment as close to possible as the home, thus allowing the client to see challenges he or she will have and problem solve strategies to increase independence. This time will also allow the client to try out adaptive equipment and decide what to obtain for use at home. Once the client is home, actual structural changes to the home will become clear. During the rehab process it is important to provide this information, so that remodeling, such as widening doorways, can be underway before the client returns home. When clients return home they often become easily frustrated and compare themselves to others, again questioning "why me". Also, they may feel anxious not having the amount of help they are used to available. To help smooth the transition, a rehabilitation program must be comprehensive, including both the physical and emotional aspect of returning home.

Other considerations to increase independent living include electronic aids for daily living (EADL's). EADL's allow a disabled individual to interact with and gain control over their environment. EADL's range from being a simple switch, to being a complex computerized system. There are a variety of EADL's available for individuals



with disabilities. Most electronic devices can be activated using an EADL. Therefore, EADL's allow individuals with SCI to control the appliances and manipulate objects in their home environment, such as turning on and off the radio, television, using the computer, and turning the pages of a book. (Trombly & Radomski, 2002)

### *Employment*

While working with clients with SCI it is important to remember that they have desires similar to the rest of the population, one example of this is to work and the ability to be productive. Some research suggests that the transition back to work may take longer for someone with quadrapelgia than someone with paraplegia to return to employment (Hammell, 1995). However, many people with quadriplegia do return to work after modifications to their workspace or job description. Recent surveys suggest that 70% of modifications to workspaces cost \$500 or less (Spinal Cord Resource Center, 2003). The Americans with Disabilities Act (ADA) advocates for changes such as these and the inclusion of people with SCI in the workforce. Education was the factor that was shown to influence re-employment most strongly. Moreover, people who increased their level of education post SCI were more likely to gain employment when compared to those who remained at the same educational level. (Hammell, 1995)

Often following SCI clients are overwhelmed by all of the changes they have made to their routines and have decreased self-concept and self worth. Because of these feelings looking into vocational pursuits may be overwhelming causing them to focus on barriers to gaining employment. This concept was further explored in a study by Fielder, Indermuehle, Drabe, and Laud (2002). The researchers intended to identify barriers to employment in individuals who have sustained a spinal cord injury. The sample consisted

of 123 individuals who were randomly selected from a hospital rehabilitation log; of the 123 who were contacted 97 agreed to participate and met inclusion criteria. The inclusion criteria included: more than one year post injury, between 15-65 years of age at the time of administration. The sample was comprised of 19% complete tetraplegia, 20% incomplete tetraplegia, 35% complete paraplegia, and 26% incomplete paraplegia. Eighty-two percent of the study was made of males and 18% of females. The mean age in this study was 38.8 years. Fifty-one percent of the participants reported being involved in vocational rehab at some time and 41% had severe disabilities to make an attendant for care necessary. Fifty-one percent of participants reported annual income of \$10,000 or less, which is considered below the poverty line (pp.74-75).

Fieldler, et. al. (2002) utilized the “Employment barriers” survey to further explore over 200 items regarding sociodemographics, disability related information, pre and post injury employment history, motivation, awareness of assistance programs, and perceived barriers to employment. A vocational counselor met with each participant either in his or her home or following an outpatient visit to the rehab center. Interviews took from 45 minutes to three hours to complete, but most typically took 90 minutes. This time frame also included the service component, which gave the interviewer time to go over referral sources and opportunities for future job placement.

The results of this study displayed distinct classes of employment including: employed (33%), unemployed and looking for work (26%), and unemployed and not looking for work (32%), and other, which included students (9%). The researchers also looked into the types of jobs participants held previous to their injury as compared to the jobs they are currently holding. 25% reported a shift from unskilled or skilled positions to

a professional position and 13% noted a shift to an office or sales position. With those who were employed, 90% did not report a change in job satisfaction pre and post injury. Also, 86% of participants who perceived their preinjury job as transitional now report their post injury job as career building (pp.76-79).

The researchers noted that there was decreased awareness of available programs, with only a low percentage of participants reporting knowledge of these programs. When asked to report barriers to employment the top two concerns among the employed included lack of transportation and lack of social security benefits, while those who were unemployed ranked lack of transportation as their number one concern and lack of social security benefits much lower on the list. The perception of work place accommodation as a barrier was also much different, with only 9% of the employed participants reporting this, while 39% of unemployed participants reported this as a concern. When looking at helpful factors to gaining employment, the largest differences occurred when looking at family and friends and coworkers as helpful factors. Those who were employed reported these as helpful much more frequently. (Fielder, et.al., 2002, p. 76-79) All of these factors should be kept in mind when working with clients who have sustained a spinal cord injury. By knowing which areas are perceived as helpful and which are perceived as barriers to employment, healthcare workers will better understand areas to focus on when looking into job procurement.

### *Psychological Aspects*

From these various types of SCI, it is evident that each client will face unique challenges based on their level/type of injury. Because the majority of injuries have a traumatic onset and cause critical impairments, in the beginning much of the focus of

treatment is on medical stabilization. Initially clients may experience shock and denial of the severity of their injury. Many times clients hope that the injury is temporary, but eventually he or she may realize that the injury is permanent. This may lead to depression, and feelings of hopelessness, or even suicidal behavior. With time, clients begin to form a new self-image. During this process of searching, clients are testing out new behaviors and may appear angry and aggressive. The anger and aggression expressed is often a client's way of covering the pain and loss they feel. Successful adjustment results in confident self-image, goal setting, decision making, and problem solving, thus allowing the client to take an active role in their recovery. As the client progresses through stages of adjustment it is important that the treatment focus also advances appropriately. (Palmer, Kriegsman, Palmer, 2000 & Hammell, 1995)

#### *Depression Following SCI*

For the person who has recently experienced and survived a traumatic SCI, they face the challenge of going on living with impairments. Everything in their life has been drastically altered, even the way they do the simplest tasks. Initially a SCI is looked at as crisis and denial, the client has survived the traumatic event and at this point attention is directed toward medical intervention. However, not all of the attention should be focused on the medical aspects of the injury. The focus needs to be divided between the medical and psychological crisis. This stage is often accompanied by denial. However, denial must not be confused with hope. It is all right for a client to be hopeful for recovery, it may provide motivation, but it is equally as important not to allow this hope to turn into denial and rejection of reality. It is common for clients to move through all stages of

grief related to SCI but to keep in mind that each client is an individual and will do so at their own pace. (Palmer, Kriegsman, Palmer, 2000 & Hammell, 1995)

It has been suggested that if some level of depression is not seen acutely that the client may be in denial of his or her functional loss and the social implications of this loss (Palmer, Kriegsman, Palmer, 2000). Some of the hallmark signs of depression include: feeling sad, markedly diminished interest or pleasure in all, or almost all activities, significant weight change, insomnia, fatigue, feelings of worthlessness and hopelessness, recurrent thoughts of death/suicide, and diminished ability to concentrate (Kaplan & Sadock, 1996, p.164). The diagnostic and Statistical Manual of Mental Disorders, ed. 4 (DSM-IV), further classifies depression into specific categories.

Although it is not universal, many SCI clients experience varying levels of depression, sadness, or grief. This was supported in the materials gathered for this literature review. A study done by Kennedy and Evans (2001), was designed to look at the correlation between individuals who had recently suffered a SCI's and post-traumatic stress symptomology. In this study various instruments were utilized to collect data; one was the Beck Depression Inventory (BDI). In this study 92% of the group classified as "high distress" met the cut-off for the depression (Kennedy & Evans, 2001). A different study by Krause, Kemp, & Cocker (2000) displays differing results. Krause, et.al. (2000) used the Older Adult Health and Mood Questionnaire (OAHMQ) to measure depressive symptoms. The average QAHMQ score was 6.8, with 52% of participants scoring in the nondepressed range, 24% of participants scoring in the range of clinically significant symptoms, and 24% of participants scoring in the probable major depression range. The highest portion of depressive cases fell within either the least years post injury or the

most years post injury. (Krause, et.al. 2000). Results from these two studies indicate that depression, sadness, and grief are experienced at varying times and levels following this traumatic event.

There are many possible reasons someone may experience depression after SCI: a person may experience feelings of hopelessness until basic ADL's are relearned, may become depressed when the reality of his/her disability is accepted, may experience feelings of hopelessness and wish to die, he or she may experience difficulty in finding new friends and interacting in group situations (Reed, K., 2001). Another possible reason that depression can follow SCI is that the person may have a lack of appropriate coping methods. This was displayed in a study that was set up to examine the modes of coping and adjustment in people with SCI. The 66 subjects who participated were split into 3 clusters and cluster analysis was done to identify those at risk for psychosocial morbidity. The Beck Depression Inventory (BDI), Satisfaction with Life Situation (SWLS), the Katz Adjustment Scale, Relative Form (KASR), Dyadic Adjustment Scale (DAS), Functional Independence Measure (FIM) were used to examine the modes of coping and adjustment of those with SCI. The group that was identified as being at risk for developing psychological difficulties displayed lower levels on internal locus of control, coping skills, and social supports. Other areas of difficulty included a care-giving burden, social role dissatisfaction, and high levels of depression. (Chan, Lee, Lieh-Mak, 2000).

In addition, some of the current research has suggested that depression following SCI may be correlated with situational factors. One such study consisted of a sample of 104 patients who were admitted to a national rehabilitation center for traumatic SCI from 1990-1994. Participants were interviewed while they were in rehabilitation and sent

questionnaires after discharge. The FIM, Beck Depression Inventory (BDI), State Anxiety Inventory (SAI), and the Social Support Questionnaire (which measures quantity and levels of satisfaction) were administered. There was a significant increase noted in depression and anxiety scores between 24 and 48 weeks post injury; these scores decreased following discharge. This may suggest that the longer the hospital stay, the more depressed and anxious patients may become. This may indicate that this is a critical time for interventions that target reducing anxiety and depression be implemented. (Kennedy & Rogers, 2000). In another study, the Depression Adjective Checklist (DACL) was used to assess the mood of the patients. The patients' mean DACL scores did not vary significantly over weeks of stay. However, a decrease in DACL scores was seen as the patients approached discharge, which indicated a better mood. This may suggest that depression is not a universal stage, but rather that the patient's level of depression is strongly related to situational factors; in this case, preparation for discharge. (Cushman & Dijkers, 1991).

Depression can have devastating effects on an individual with SCI. Depression can play a large role in the higher utilization of healthcare services and can be associated with suboptimal functional gains, increased complications such as pressure ulcers and urinary tract infections. Compromised immune function, increased hospital stays, increased medical expenses, decreased social integration, compromised intimate relationships, and strained caregiver support may also result. (Spinal Cord Medicine, 1998). A study was done by Benony, Lionel, Bungener, Chahraoui, Fernay and Auvin (2002) to examine depression, subjective perception of quality of life, and social support in clients with spinal cord injuries as compared to controls. Multiple instruments were

used to measure these items. The study consisted of 33 subjects in the experimental group and 33 subjects in the control group. The subjects in the control group were matched according to age, sex, socioeconomic status, and educational standards. The data suggested that subjects in the experimental group showed higher levels of emotional distress, perceptive distortion, unsophisticated and immature processing of information, and situation-related stress. Patients with SCI showed greater preoccupation with their bodies. Subjects with SCI indicated a higher level of support when compared with the controls. They reported receiving more support from people in general and friends. Subjects with SCI reported having a satisfactory subjective quality of life. Satisfaction in the area of ideal physical state vs. real physical state was the lowest, although the importance attached to it was the highest. A high degree of satisfaction with relationships with medical staff/caregivers and inner self was high. The SCI group reported dissatisfaction with their sexual life, personal relationships, leisure activities, and holidays. By identifying these areas appropriate intervention and support systems can be implemented.

Although the combination of SCI and depression can have global effects, the survival rate following SCI has increased. Therefore, the focus of treatment has shifted towards living with and adjusting to the disability. Although the above research shows that the level, onset, and severity of depression may vary from person to person, it also points out that there is a period when assistance with psychological adjustment may be helpful.

While depression is viewed as a normal event following a SCI, it should not be left untreated. Through the use of education and groups focused on coping skills,



assertiveness, communication, suicide, and symptoms of depression vs. “feeling down”, depression can be lessened, and the client will have a better understanding of skills used to cope with depression.

### *Suicide Following SCI*

Coping with the loss of function following a SCI is often overwhelming, and there are some individuals who struggle to see what their purpose in life is post-injury. “For a sizable number of persons with SCI’s, times of self-neglect, substance abuse, and divorce follow and, for the most troubled, suicide seems the only way out...” (Carlson & Myklebust, 2002 p. 31). According to Hammell (1995), suicide has been reported to account for 4-21% of all deaths among individuals with SCI. Research has determined suicide to be the leading cause of death for individuals with complete paraplegia, and the second leading cause for individuals with incomplete paraplegia. However results of research done on individuals who had a diagnosis of quadriplegia did not show these individuals to be at as high a risk for suicide as individuals with paraplegia were. (Hammell, 1995) “It has been speculated that because less physical (and therefore social) support is provided to persons with paraplegia than those with quadriplegia, the burden of coping is greater” (Hammell, 1995 p. 311).

A study by Hartkopp, Bronnum, Seidenschnur, & Sorensen (1998), also support these findings. Although not statistically significant, these researchers found that suicide mortality tended to be higher for individuals who had made almost a complete physical recovery. The researchers hypothesized that this may be due to the social expectation that the patient should not grieve because of their profound physical recovery. These individuals are compared to individuals with more severe SCI’s, and because their

deficits are much less, the loss often goes unrecognized by relatives, other patients, staff, and society in general. The researchers felt this may lead to increased depression and eventually to suicide, therefore explaining the higher mortality rate of these individuals. The researchers also found that individuals who had previously attempted suicide or who had a psychiatric condition in addition to the SCI were more likely to attempt and commit suicide.

The study by Hartkopp, et.al. (1998), provides valuable information to healthcare providers regarding which patients are most at risk for attempting suicide. Therefore high risk patients and their families need education regarding the grieving process and the importance of a strong support system. In addition, healthcare providers need to pay special attention to individuals who have a previous psychiatric diagnosis or have previously attempted suicide. It is important that the needs of all patients are met, however special care should be taken with these high risk populations to prevent the tragedy of suicide.

#### Current Research in SCI treatment

SCI treatment has come a long way since World War II. At that point in time SCI clients were considered fatal and if the person did not die as a direct result of the injury, he or she would certainly die soon after due to complications, such as infections or respiratory problems. For SCI sufferers this is not the case today, with the discovery of antibiotics, increased knowledge of preventative measures, and increased technology options people are able to adapt to their disability and live productive lives. Although clients who have experienced SCI are able to go on living, they do so with many physical limitations.

One area scientists are continuing to explore is spinal cord regeneration. For years scientists have focused on this perplexing question and have found no definite answers, but will continue with research of central nervous system regeneration. Further areas currently being explored include replacement of nerve cells, regeneration of damaged axons, and remyelination of axons. Recently scientists have learned that some adult CNS cells can be stimulated to divide and develop into new nerve cells. This new research has brought about some new possibilities for cell line development without using fetal tissue donation. Another technique scientists are exploring is genetically altering cells so they produce large amounts of growth factors and then to introduce these into the injury site. However, this type of research is in the very early stages and there is still much testing to be done. A further approach involves the use of a drug called 4-aminopyridine (4-AP), which is thought to help demyelinated nerves conduct signals. This type of treatment is intended to help improve function following injuries that have extensively damaged myelin sheaths, but do not disrupt nerve conduction. This research is also in its very early stages. (National Spinal Cord Injury Association Resource Center, n.d.)

In addition, there is much research going on in terms of drug treatment. Although drug treatment is not a cure for chronic SCI, it may help lessen the severity of some acute injuries. Research has shown that not all damage following SCI occurs at onset, but rather it is progressive. For this reason, researchers are hopeful that drug therapies will lessen the limitations due to the injuries. (National Spinal Cord Injury Association Resource Center, n.d.)

Research has also been done in the area of functional electrical stimulation (FES). FES is the use of external electrodes to stimulate paralyzed nerves to increase function in limbs. Three main applications of FES include FES for exercise, upper extremity function, and lower extremity function.

Although there is currently no cure for SCI, it is easy to see that treatment has come a long way since World War II. In the future researchers will continue to make advances in treatment and cure research. Nevertheless, therapists must continue provide quality and holistic treatment to clients to assist them in living a fulfilling life with a SCI.

## CHAPTER 3

### METHODOLOGY

Because SCI dramatically alters a client's life roles, routines, and habits a holistic approach to rehabilitation is necessary. Not only does a SCI leave a client with physical deficits, but also with many psychosocial needs. It is when these areas are left unaddressed and/or proper education has not been provided that clients experience feelings of worthlessness and hopelessness. This protocol is intended to provide therapists with a guide of areas to be addressed along with suggestions for therapeutic mediums to address each area.

Throughout this scholarly project, a comprehensive literature review has been compiled. Articles and information were gathered from various medical and allied health journals and books, as well as from organizations and associations such as the American Institute of Spinal Cord Injury and the National Spinal Cord Injury Association. In addition, the researchers gathered information from currently available educational protocols compiled by health care professionals. By gathering information from these sources a broad perspective of treatment was gained. This literature review provides the basis for the protocol presented in chapter four.

The protocol is presented as a resource to guide the rehabilitation process. The protocol covers many areas that the writers consider critical to establishing a holistic rehabilitation protocol. Areas to be covered include: health maintenance and management, sexuality, community re-integration, leisure, independent living, employment, education, depression, suicide, and coping skills.

## CHAPTER 4

### PRODUCT

#### Introduction

According to Trombly and Radomski (2002), “spinal cord injury (SCI) affects 10,000 people per year in the United States” (p.966). There are approximately 220,000 people living in the U.S. with SCI (Palmer, Kriegsman, Palmer, 2000), and SCI most typically occurs in young males. According the Occupational Therapy Practice Guidelines for Adults with Spinal Cord Injury, the average age of injury is between 16-30 years of age (Dohli, 2001). A ratio of four injured males per one female has persisted over the past many decades. (Trombly & Radomski, 2002). Trombly and Radomski (2002) reported that “The National Spinal Cord Injury Statistical Center tracked data from 1973-1997 and found the causes of SCI to be: 43% from motor vehicle accidents, 22% from falls or being hit by an object, 19% from violence, 11% as a result of a sports injury. Another 5% are caused by nontraumatic SCI, such as spinal stenosis, infection, ischemia, and myelitis” (p. 966).

Although SCI is a devastating event, which may leave an individual with feelings of hopelessness, with holistic rehabilitation treatment he or she may increase quality of life and establish fulfilling life routines. Occupational therapy (OT) treatment addresses physical and psychosocial needs, as well as social and environmental barriers. This background allows for treatment of the whole person, their roles, and their interaction with the environment. Because of the specialties in these areas, an occupational therapist is an integral part of a SCI rehabilitation team.

While much research has been carried out in the area of treatment of SCI, we were unable to find a comprehensive rehab protocol from an OT perspective. In today's medical model, priority is often given to providing basic medical care and physical rehabilitation, without providing the necessary care to prepare clients to deal with emotional and social adjustments. The purpose of this protocol is to address a more broad range of client needs and provide a more holistic approach during rehabilitation

This protocol is intended for use as a guide for occupational therapy treatment with clients who have sustained SCI. This protocol contains information to assist therapists in providing intervention and education in the following areas: health maintenance and management, leisure, education/employment, independent living/home modification, sexuality, and depression/suicide prevention. The protocol provides suggested treatment activities, educational resources, and additional resources for further information.









## Health Maintenance and Management

Individuals with SCI experience a high number of hospital readmissions following rehabilitation, with incidence rates ranging from 19%-57% (Pershouse, Cox, & Dorsett, 2000, p.23). These high rates of hospital readmission result in stress on relationships, leisure, and vocational activities. In addition, the cost of hospitalization can be a large burden. Maintaining good physical health is fundamental to full participation across all aspects of life.

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## **Autonomic Dysreflexia**

A primary health concern is autonomic dysreflexia. This can occur in anyone who has sustained an injury at or above the T6 level. Autonomic dysreflexia is related to disconnections between the body below the injury and the control mechanisms for blood pressure and heart function (Spinal Cord Resource Center, 2003). It causes the blood pressure to rise to potentially life-threatening levels. The primary risk of autonomic dysreflexia is stroke, which is a potentially life threatening condition and symptoms should be attended to immediately. (Trombly & Radomski, 2002, Spinal Cord Resource Center, 2003)

### **Causes:**

- Anything that normally causes pain
- Bladder (most common)
  - Urinary tract infection
  - Retaining urine
  - Blocked Catheter
  - Overfilled catheter collection bag
- Bowel
  - Constipation
  - Bowel obstruction
  - Hemorrhoids
  - Infection or irritation
- Skin related disorders
  - Direct pressure below injury

- Pressure sores
- Ingrown nails
- Burns
- Tight or restrictive clothing
- Sexual Activity
  - Over stimulation during sexual activity
  - Menstrual Cramps
  - Labor and Delivery of children
- Heterotrophic ossification
- Acute abdominal conditions
  - Gastric ulcers
  - Colitis
  - Peritonitis
- Fractures

**Symptoms:**

- Severe headache
- Blurred vision
- Sweating
- Flushing of the skin
- High blood pressure (above 140/90)
- Red face or red blotched on skin
- Nasal stuffiness
- Nausea

- Slowed pulse
- Goosebumps
- Cold, clammy skin below injury

**What to do if you experience any of these symptoms:**

- Sit up-this will naturally decrease blood pressure
- Check catheters, bowels, and skin immediately

**Prevention of Autonomic Dysreflexia:**

- Frequent pressure relief
- Use sunscreen and limit sun exposure during peak sun times to avoid sun burn
- Maintain a good bowel and bladder program
- Maintain a well-balanced diet
- Compliance with medications

(National Spinal Cord Injury Association, 2003; Lima & Schust 1998).

### **Deep Vein Thrombosis**

Another potential complication of SCI is deep vein thrombosis (DVT). DVT is a blood clot that may develop in damaged blood vessels or in places where the blood flow stops or slows down. DVT in the lower leg is common during the early stages of recovery, but DVT does not become a great concern until it is in the upper thigh. In this position, there is a high risk of the clot becoming dislodged and entering the vascular tree and eventually the lungs. Often medications, such as coumadin and heparin are used to reduce blood viscosity and improve flow. (Spinal Cord Resource Center, 2003).

#### **Recommendations to decrease the risk of DVT:**

- Ace wrapping the lower leg
- Wearing Ted hose/compression garments
- Participation in exercise programs
- Positioning limbs to prevent swelling
- Drinking plenty of water to avoid dehydration

### **Neuropathic Pain**

Naturopathic/spinal cord pain is a significant problem in some clients who have sustained SCI. Damage to the spine and soft tissue surrounding the spine can cause aching at the site of injury. This type of pain is often described as a quick, sharp pain and occasionally the client will describe pain that radiates from the level of the lesion. If this type of pain occurs consult with the physician, as nerve block procedures are often used as treatment following the injury. (Spinal Cord Resource Center, 2003).

## **Respiratory Complications**

Respiratory complications are predominant following SCI. One of the most common complications being pneumonia. If the injury involves the upper thorax, the normal breathing pattern is disrupted and changed. Normally, the diaphragm does most of the work during quiet breathing and the intercostals muscles are used for deep breathing and coughing. The diaphragm takes over these functions when the intercostals and abdominal muscles are affected by SCI. The result of this change is poor coughing and deep breathing, therefore increasing the risk of pneumonia. (Spinal Cord Resource Center, 2003; Sunrise Medical, 2001)

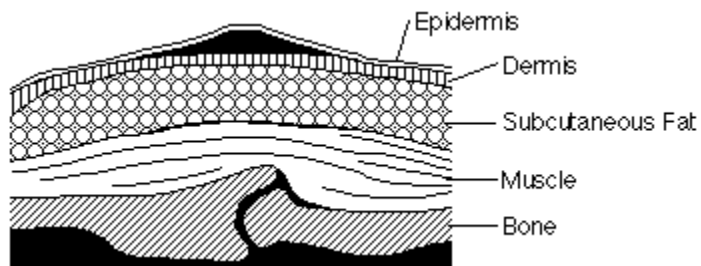
### **Preventative measures include:**

- Percussion and drainage using gravity assist
- Assisted coughing
- Abdominal binders to increase the resistance against which the diaphragm works
- Assisting the client out of bed as soon as possible following injury

## **Skin Breakdown/Pressure Sores**

Skin break down is a complication for many clients. After SCI, there is a change in sensation, muscle tone, and blood supply, and in turn decreases skin integrity. Pressure sores occur as a result of excessive pressure or shearing forces, generally over bony prominences. There are four stages of pressure sores.



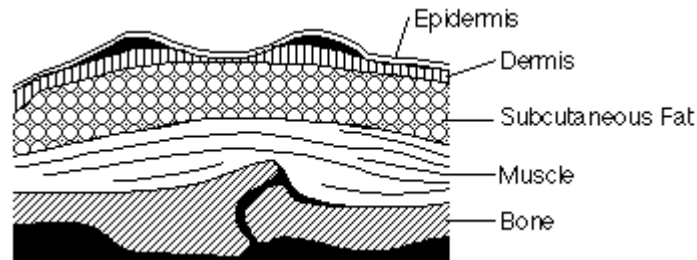
**Stage One:**

(Taken From SCI-Info-Pages, 2003).

- This stage is classified by a reddened area on the skin that does not fade within 30 minutes after pressure has been relieved from the area.

**What to do if you recognize this:**

- Change position so the pressure is relieved from the area
- Wash the area with warm water and mild soap, pat area dry rather than rubbing the area to dry
- Consult a dietician or healthcare provider regarding a balanced diet
- Check the surface the area was supported by when the pressure sore was noticed, such as mattresses, wheelchair cushions.
- Evaluate transfer methods and transfer surfaces
- If the area continues to remain reddened for several days or continues to reoccur, consult a physician.

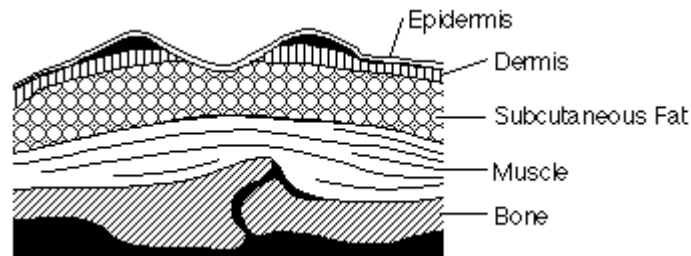
**Stage Two:**

(Taken From SCI-Info-Pages, 2003).

- This stage is classified by a break in the skin surface, appearing as a shallow open area. During this stage there may be drainage from the sore.

**What to do if you recognize this:**

- Change position so the pressure is relieved from the area
- Wash the area with warm water and mild soap, pat area dry rather than rubbing the area to dry
- Consult a dietician or healthcare provider regarding a balanced diet
- Check the surface the area was supported by when the pressure sore was noticed, such as mattresses, wheelchair cushions.
- Consult a healthcare provider for treatment, which may include
  - Wound cleansing
  - Application of wound dressings
  - Inspection for signs that the wound may be infected

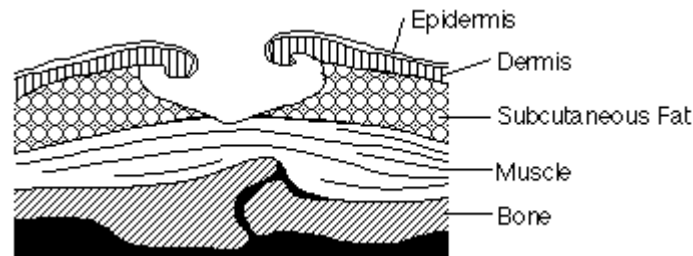
**Stage Three:**

(Taken From SCI-Info-Pages, 2003).

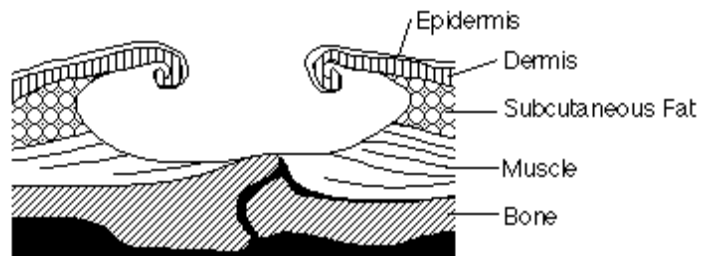
- This stage is classified by a break through the skin and other protective skin tissues.

**What to do if you recognize this:**

- Change position so the pressure is relieved from the area
- Wash the area with warm water and mild soap, pat area dry rather than rubbing the area to dry
- Consult a dietician or healthcare provider regarding a balanced diet
- Check the surface the area was supported by when the pressure sore was noticed, such as mattresses, wheelchair cushions.
- Consult a healthcare provider for treatment, which may include
  - Wound cleansing
  - Application of wound dressings
  - Inspection for signs that the wound may be infected
  - Antibiotics may prescribed to assist with preventing infections
  - Prescription of a pressure relieving mattress and/or wheelchair cushion

**Stage Four:**

(Taken from SCI-Info-Pages, 2003).



(Taken From SCI-Info-Pages, 2003).

- This stage is classified by breakdown of muscle tissue, which if left untreated may extend down to the bone.

**What to do if you recognize this:**

- Consult your health care provider immediately for treatment options, which often include:
  - Surgery

**Complications of pressure sores:**

- Autonomic dysreflexia
- Prolonged bed rest
- Amputations
- Spreading of infection to other areas of the body
- If left untreated, pressure sores may be life threatening

**Reapplying pressure to a previously damaged area :**

Pressure should only be reapplied after the wound is fully healed and the skin has returned to normal coloration. However, if scarring occurs, skin may be a slightly different shade. Initially, pressure should be reapplied in short intervals, for example ten to fifteen minutes at a time. If the skin appears red after removing the pressure and it does not fade within fifteen minutes, damage has occurred. At this point you will need to wait at least one hour before reapplying pressure to the area. After applying pressure for three trials of fifteen minutes, with no indication of damage, the interval duration can be increased to thirty minutes at a time. Following three successful trials of thirty minutes each, the interval time may be increased by thirty minutes per day. By increasing the interval duration as tolerated, the skin is allowed to rebuild its tolerance for pressure. In addition to following this protocol, skin integrity needs to be evaluated frequently.

**Prevention:**

- Position changes every two hours
- Avoid lying directly on bony prominences for extended periods of time
- Do not sit in one static position for longer than sixty minutes
- Do pressure relief often
  - For every fifteen to thirty minutes that one position is maintained, do one minute of pressure relief
    - This may include: turning on to the other side of the body, bending forward while sitting, wheelchair push ups, or tilting the wheelchair back sixty-five degrees

- Minimize shear forces when transferring
  - Example: do not slide across the transfer surfaces
- Utilize equipment to reduce pressure
  - Example: pressure relieving wheelchair cushions and mattresses

(Adapted from SCI-Info-Pages, 2003; Lima & Schust, 1998; Hill, 1986)

### **Maintaining Healthy Skin:**

- Eat a healthy diet
  - Consult a dietician for assistance with meal planning to ensure the proper amount of nutrients.
- Maintain good circulation. This may be done through:
  - Not smoking-the nicotine in cigarettes causes blood vessels to become smaller, which in turn prevents blood, oxygen, and nutrients from getting to the skin.
  - Perform regular range of motion programs to prevent edema from collecting in the tissues. When edema occurs, skin in that area becomes thin, fragile, and more prone to injury.
  - Be watchful for anemia, which is a decrease in red blood cells. If this occurs, less oxygen is delivered to the skin, which may cause skin cells to become unhealthy. Anemia should be evaluated and treated by a physician.

- Vascular disease is caused by the blood vessels narrowing. This narrowing may be caused by diabetes, smoking, high blood pressure or high cholesterol.
- Keep skin clean and dry—wash thoroughly, rinse, and dry
- Avoid harsh soaps and alcohol-based products that may be drying to the skin
- Keep finger and toe nails clipped.

(Lima & Schust, 1998)

### **Osteoporosis**

Osteoporosis is faced by clients with SCI. When clients with SCI are not using their legs for weight bearing, calcium and phosphorus are lost and bones become weakened and brittle. At this time there is no way to reverse osteoporosis and once the bone breaks it takes longer to heal. (Spinal Cord Resource Center, 2003).

#### **Techniques to maintain bone mass:**

- Bearing weight through his or her legs if able
- Using a standing frame
- Using braces for parallel bar walking

### **Joint Complications**

Heterotrophic ossification occurs when the body lays down bone outside of the normal skeletal structure. Typically, this occurs at larger joints such as the knee and hip and causes risk for joint stiffening and potential fusion. (Spinal Cord Resource Center, 2003).

**Preventing of heterotrophic ossification:**

- Individual range of motion programs
- Functional activities that include movement of the joint.

**Spasticity**

Spasticity is another complication following SCI . After SCI nerves below the level of injury become disconnected from the brain; the responses from these nerves become exaggerated, which develop into spastic patterns. Bladder infections and pressure sores can also cause spasticity; thus serving as a “warning” that something is wrong. Another benefit is that it does maintain muscle and bone size and assists with maintaining circulation in the legs. (Trombly & Radomski, 2002)

**Common treatment of Spasticity:**

- Medications are commonly used and include: Baclofen, Valium, and Dantrium
- Individual range of motion programs

**Bowel and Bladder**

Bowel and bladder management is yet another important aspect of maintaining overall health. The bladder muscle is innervated at the levels of S2-S4 and with a complete spinal injury above these levels bladder control is lost. Individuals with an incomplete spinal injury above these levels may retain partial voluntary control over bladder contraction. In addition, bowel control is often affected by SCI. This area is primarily addressed by the physician and nursing staff; however occupational therapists also play a role in bowel/bladder management techniques (Hill, J. 1986).

**Treatment:**

- Work with healthcare team to establish an individual bowel and bladder program



### **Depression Following SCI**

For the person who has recently experienced and survived a traumatic SCI, they face the challenge of going on living with impairments. Everything in their life has been drastically altered, even the way they do the simplest tasks. It has been suggested that if some level of depression is not seen acutely that the client may be in denial of his or her functional loss and the social implications of this loss (Palmer, Kriegsman, Palmer, 2000). Thus being depressed is not an abnormal event.

Some of the hallmark signs of depression include: feeling sad, markedly diminished interest or pleasure in all, or almost all activities, significant weight change, fatigue, feelings of worthlessness and hopelessness, and diminished ability to concentrate (Kaplan & Sadock, 1996, p.164).

Depression can have devastating effects on an individual with SCI. Depression can play a large role in the higher utilization of healthcare services and can be associated with suboptimal functional gains, increased complications such as pressure ulcers and urinary tract infections. Compromised immune function, increased hospital stays, increased medical expenses, decreased social integration, compromised intimate relationships, and strained caregiver support may also result. (Spinal Cord Medicine, 1998).

While depression is viewed as a normal event following a SCI, it should not be left untreated. Through the use of education and groups focused on coping skills, assertiveness, communication, suicide, and symptoms of depression vs. “feeling down”, depression can be lessened, and the client will have a better understanding of skills used to cope with depression.

## **Suicide Following SCI**

Coping with the loss of function following a SCI is often overwhelming, and there are some individuals who struggle to see what their purpose in life is post-injury. “For a sizable number of persons with SCI’s, times of self-neglect, substance abuse, and divorce follow and, for the most troubled, suicide seems the only way out...” (Carlson & Myklebust, 2002 p. 31). According to Hammell (1995), suicide has been reported to account for 4-21% of all deaths among individuals with SCI. Research has determined suicide to be the leading cause of death for individuals with complete paraplegia, and the second leading cause for individuals with incomplete paraplegia. However results of research done on individuals who had a diagnosis of quadriplegia did not show these individuals to be at as high a risk for suicide as individuals with paraplegia were. (Hammell, 1995) “It has been speculated that because less physical (and therefore social) support is provided to persons with paraplegia than those with quadriplegia, the burden of coping is greater” (Hammell, 1995 p. 311).

Hartkopp, Bronnum, Seidenschnur, & Sorensen (1998), also support these findings. Although not statistically significant, these researchers found that suicide mortality tended to be higher for individuals who had made almost a complete physical recovery. The researchers hypothesized that this may be due to the social expectation that the patient should not grieve because of their profound physical recovery. These individuals are compared to individuals with more severe SCI’s, and because their deficits are much less, the loss often goes unrecognized by relatives, other patients, staff, and society in general. The researchers felt this may lead to increased depression and eventually to suicide, therefore explaining the higher mortality rate of these individuals.

The researchers also found that individuals who had previously attempted suicide or who had a psychiatric condition in addition the SCI were more likely to attempt and commit suicide.

The study by Hartkopp, et al. (1998) provides valuable information to healthcare providers regarding which patients are most at risk for attempting suicide. Therefore high risk patients and their families need education regarding the grieving process and the importance of a strong support system. In addition, healthcare providers need to pay special attention to individuals who have a previous psychiatric diagnosis or have previously attempted suicide. It is important that the needs of all patients are met, however special care should be taken with these high-risk populations to prevent the tragedy of suicide.

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**Common Symptoms of Depression:**

- Loss of interest in previously enjoyed activities
- Feeling sad
- Decreased libido
- Restlessness
- Feeling worthless or guilty
- Changes in appetite or weight gain/loss
- Suicidal thoughts/attempts
- Difficulty concentrating, remembering, or making decisions
- Trouble sleeping, or sleeping too much
- Loss of energy
- Headaches, or body aches and pains
- Digestive problems
- Sexual problems
- Feeling anxious
- Low self-esteem
- Withdrawal
- Fatigue
- Irritability/agitated
- Crying easily
- Extreme feelings of grief
- Inability to function
- Nausea
- Negative thoughts/attitude
- Boredom
- Fear
- Paranoia
- Easily frustrated
- Skin problems
- Eyes feel strained and tired
- Increased use of alcohol
- Craving unusual foods

If experiencing these symptoms contact your health care provider.

(Copelad,1992)

**Treatment for Depression:**

Treatment works gradually over time. Some individuals will notice changes after four weeks of taking medications, others may notice changes more quickly or slowly based on the type of treatment. Your healthcare provider can inform you about the types of treatment and help you to choose the treatment that is best for you. Common treatments for depression include:

- Antidepressants
- Psychotherapy
- Light therapy
- Electroconvulsive therapy
- Support Systems

(Lima & Schust, 1998)

### Alleviating Symptoms of Depression Worksheet: Activities to try

<i>Activities</i>	<i>I've tried</i>	<i>I would like to try</i>
<i>Exercise</i>		
Sports		
Taking a bath		
Gardening		
Reading		
Listening to music		
Doing a craft project		
Writing in a journal		
Shopping		
Cleaning		
Meditation		
Spending time with children		
Watching a funny movie		
Watching a favorite TV show		
Helping others		
Talking with a physician/therapist		
Attending support groups		
Spending time with friends		
Caring for a pet		
Others:		

**Using Relaxation to Improve Mood:**

Utilizing effective relaxation techniques can decrease stress, and depression, relaxation has also been found influence health and improve mood. The following are a few suggestions for learning and practicing relaxation:

- Take a meditation course
- Purchase an instructional video
- Listen to audio relaxation tapes
- Find a quiet place that makes you feel calm
- Focus on your breathing and let go of all your worries/concerns
- Practice deep breathing exercising
- Take a quick nap

(Copeland,1992)

**Breathing Exercise Worksheet**

Proper breathing relaxes both the body and the mind. Practicing breathing exercises regularly can create a sense of overall well being.

Lie on the floor with knees bent, arms at your sides, palms up, and with your eyes closed. Breathe through your nose and focus on your breathing pattern. Place your hands on the part of your torso/abdomen that most noticeably rises and falls as you breathe. You want to make your abdomen rise and fall more so than your chest. Practice moving your breathe into your abdomen, and taking long, slow, breaths. Do this for several minutes before getting up. Get up slowly to prevent from becoming lightheaded. To increase the effectiveness of this exercise practice doing this exercise once or twice a week for several weeks. (Copeland, 1992)

*How did you feel before doing the breathing exercise?*

How do you feel after doing this exercise?

Did this exercise increase your mood?

Did this exercise relieve any of your depressed symptoms?

How do you feel after doing this exercise daily for two weeks?



**Building a strong support system:**

Everyone needs support from family, friends, peers, etc. especially following a traumatic injury. Support groups provide a great way to get the support clients need and allow them to relate to others who have had similar experiences.

How to start a support or discussion group:

Step one:

- Identify the people you want in your support group. Choose individuals who have a shared interest or need for support.
- You can start a group by yourself if you do not know anyone who has a shared interest or problem. However starting a group with two or three people is less work for you and often your “partners” can be supportive before the actually group gets started.
- Decide who can attend the group, ie only individuals with SCI, or individuals with all types of disabilities. Also will the group be only for individuals with disabilities, or will it also be open to their family members?

Step two:

- Decide how often, where the group will meet, and what the emphasis of the meetings will be. Choose one central location for meetings to be held.
- Your group should meet at least once a month, otherwise there is a risk that it may loose momentum and not be successful.
- Decide how to let people know about your group

- Decide what kind of group you will have, ie will it be a peer support group, a discussion group, or a professionally led group?

Step Three:

- Begin advertising your group. Use local newspapers, radio, and television ads to let the community know about the group.
- Hand out or hang up flyers announcing your group.
- Keep your flyers simple with basic information about the group and meeting location, date and time.

Step Four:

- Have a plan to follow at the meeting
- Let those in attendance know how the meeting will be run
- Ask participants what they would like to discuss or learn about for the next meeting
- Plan time for people to visit and get to know each other before or after the meeting
- Do not feel discouraged if the first meeting does not go as planned

(Adapted from the National Spinal Cord Injury Association, 2003)

**Identifying your supports:**

List five people who you can trust, feel comfortable talking with, who treat you with love and respect, who play with you-sing, tell jokes, etc., who are not judgemental, and who can help you and ask you for your help. If you can not list five people, list activities you could do in order to increase your supports, such as attending a support group.

- 1. \_\_\_\_\_
- 2. \_\_\_\_\_
- 3. \_\_\_\_\_
- 4. \_\_\_\_\_
- 5. \_\_\_\_\_

List three places you can go for support, such as church, or support groups.

- 1. \_\_\_\_\_
- 2. \_\_\_\_\_
- 3. \_\_\_\_\_

List five activities/ coping techniques you can use to help you feel less depressed.

- 1. \_\_\_\_\_
- 2. \_\_\_\_\_
- 3. \_\_\_\_\_
- 4. \_\_\_\_\_
- 5. \_\_\_\_\_

From the names, places, and coping techniques you listed above, fill in the situation blanks and what you can do/who you can call for support for each situation.

1. If I am feeling suicidal I can \_\_\_\_\_
2. If I am anxious I can \_\_\_\_\_
3. If I am feeling frustrated I can \_\_\_\_\_
4. If I need to be alone I can \_\_\_\_\_
5. If I need people to be around me I can \_\_\_\_\_



**Suicide Prevention Tips:**

- Regulate the amount of medications in the household
- Remove all firearms from the home
- Be cautious about driving
- Express your emotions
- Get support
- Give yourself positive affirmations
- Think of the things you are grateful for
- Think of the pain you would cause your loved ones if they were to lose you

(Copeland, 1992)

## Independent Living

According to Palmer, Kriegsman, and Palmer (2000), the disruption to normal everyday habits and routines can be challenging enough, even without the continuous changes in environments. Moving from hospital to rehabilitation center and rehabilitation center to home, are major transitions for someone following SCI. When a client is planning to return home there are many areas to consider before making the transition. Discharge planning should be done throughout the client's stay at the rehabilitation center to help ensure a smooth transition. Once the client is home, actual structural changes to the home will become clear. During the rehab process it is important to provide this information, so that remodeling, such as widening doorways, can be underway before the client returns home. When clients return home they often become easily frustrated and compare themselves to others, again questioning "why me". Also, they may feel anxious not having the amount of help they are used to available. To help smooth the transition, a rehabilitation program must be comprehensive, including both the physical and emotional aspect of returning home. (Palmer, Kriegsman, Palmer, 2000)

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## **Modifications for Wheelchair Mobility:**

### **Outside of the Home:**

- Park close to the entrance of the home
- Make sure the sidewalk is wide enough for the wheelchair
- Clear any landscaping that may interfere with entrance into the home
- If living in an apartment building, reserve a handicapped parking spot
- If there are steps to get into the home a ramp will need to be built

### **Ramp Instructions:**

- Ramps should be constructed out of a durable material that provides good traction or a non skid surface, such as adhesive nonskid strips or sand mixed with paint
- Ramps need to be 1foot long for every inch of ascending height, and at least 36 inches wide
- If the door at the top of the ramp opens out there needs to be a 5x5 ft area for maneuverability. There should be at least 1ft of extension on both sides of the door
- If the door opens in a 3x5 ft area is needed for maneuverability
- If wood is used to build the ramp it should be treated to resist rotting, and constructed to allow for drainage of water
- Ramps should not be carpeted, because carpet holds water and decreases the surface traction



- Ramps should have curbs on both sides to prevent the wheelchair from slipping over the edge. Curbs should be at least 2 inches high
- On long, steep ramps, a rest platform should be constructed at every 10 foot interval. Platforms should allow a 5x5 ft area for turning
- Ramps should have a handrail on at least one side. The rail should be 32 inches high
- There should be at least five feet of clearance at the bottom of the ramp
- In addition the ramps there are also stairwell glides and elevators that can be installed to increase the accessibility into and within the home.

### **Within the Home:**

#### **Doors and Doorways:**

- Doors should be at least 32 inches wide and allow a 5 ft space for turning on both sides of the door
- Kick plates can be installed on doors to prevent damage from wheelchair footrests
- Use matwells to create level surfaces over the doorway threshold
- Change door knobs to easy to open handles such as pulls and latches. Handles should be placed between 3-4 ft high on the door
- Door locks should only require one hand to be used to unlock them

- Raised thresholds, such as those with sliding doors should be avoided. Raised wooden thresholds may be shaved down so they are level. Sliding doors do work well for closets.

**Floors:**

- Floors should have hard surfaces for easy wheelchair mobility. Hard floors should also be nonskid. A dark colored flooring material will hide wheelchair tire tracks more easily.
- If carpet is used it should be a tightly woven carpet with little padding. The carpet should also be snugly attached to the floor to prevent damage from the wheelchair tires.

**Walls:**

- Clear plastic shields can be used to protect walls from wear or nicks, such as around corners
- Windows should open out and if possible horizontal sliding windows should be used
- Light switches should be placed at 3ft to 3ft 3 inches high., Two-way switches should be used on walls at the ends of hallways or staircases.
- Rocker switches for individuals who are unable to use, or have limited use of, their hands and fingers can replace flip switches, or switch extenders may be used. Switches may also be adapted to be operated by remote.

- Switches should be placed at the entryways of rooms, and there should not be more than two switches per wall plate. Lamps with pull chains can be added if further lighting is needed.
- Electrical outlets should be easily accessible at a height between 18-24 inches
- Thermostats should also be within reach

**Hallways:**

- Hallways should be 4ft wide if possible
- Wider doorways should be used if the hallway is narrow
- If possible turning room should be provided at each end of the hallway

**Appliances:**

- Dishwashers, washing machines, and dryers should be front loading
- Small appliances (toaster, microwave, etc.), should be kept within reach

**Bathroom Modifications:****Faucet controls:**

- Install easy to use handles, such as lever style handles on sink and shower faucets
- Hand held shower heads allow for more ease while bathing

**Counters and Sinks:**

- Counters should be 27 inches deep and securely mounted to the wall
- Counters should be within reach of the toilet

- Counters should provide space for the knees and feet to move under the counter.

**Toilets:**

- Toilet height should be raised to 20 inches. A raised toilet seat can be used to increase the height of the toilet.
- The area around the toilet should allow space for transferring.
- The toilet area should have grab bars in place for safety during transfers. Grab bars should be placed at a height for the individual's ability and needs.
- Toilet paper and the sink should be within reach from the toilet.
- The flushing handle on the toilet should be easily manipulated

**Medicine Cabinets and Mirrors:**

- The bottom edge of the cabinet or mirror should be 36 inches high.
- The shelves of the cabinet should provide space for single row storage.
- Full length mirrors are recommended

**Bath Tubs:**

- Grab bars should be in place for safety during transfers. Grab bars should be placed at a height for the individual's ability and needs.
- A bath seat or bench should be used for safety.
- A non-skid bath mat should be used for safety.

- Shelves or compartments for shampoo, soap, etc. should be placed within easy reach.

**Showers:**

- Showers should be roll in when possible
- A shower bench and non skid floor mat should be used for safety
- Grab bars should be in place for safety during transfers. Grab bars should be placed at a height for the individual's ability and needs.
- The shower area should provide adequate space for transfers
- Shelves or compartments for shampoo, soap, etc. should be placed within easy reach.
- Temperature control handles should also be within reach.
- A long handled sponge, washcloth mitt, or other adaptive equipment may also be beneficial to make bathing easier.

**Towel Racks:**

- Towel racks should be no more than 40 inches high
- Towel racks should be able to stand 250 pounds of pressure

**Kitchen Modifications:****Counters:**

- Counters should be 30-33 inches high
- Any pullout or work counters should be 30 inches high

**Sinks:**

- Sinks should be 6 inches deep
- Sinks should have a rear drain
- There should be space for knees under the sink
- Lever style faucets, or easy to use handles should be installed
- If possible sinks should have a garbage disposal

**Refrigerators:**

- A one door refrigerator with a freezer on bottom works best for wheelchair users
- Refrigerators should be self-defrosting

**Ovens:**

- Ovens should have side hung or drop doors, with the door being strong enough to support the weight of food
- There should be room for the feet under the oven
- The oven shelves should be easily accessible

**Stove Tops:**

- Burners should be in a single row
- The stove should have a hood for ventilation
- Stove controls should be located in front
- The stove should have a lip or drain along its front edge

**Cabinets and Shelves:**

- Cabinets should have easy pull handles
- Cabinets should provide floor clearance for wheelchair footrests
- Shelves should allow commonly used food and products to be placed within reach

**Table:**

- Round tables with a pedestal base work best to provide room for wheelchairs
- Table and chair heights should be adjusted as needed.
- A lap tray may be used on the wheelchair to assist with kitchen tasks and carrying food from the counter/stove, to the table.

(Adapted from Lima & Schust, 1998; Adaptive Environments Center, 2002).

**Electronic aids for daily living:**

In addition to these home modifications, there are a variety of electronic aids that may be used to increase independent living. One resource for therapists in this area is Cook and Hussy:

Cook, A., Hussy, S. (2002). Assistive technologies: Principles and practice. (ed. 2). St. Louis, Mo: Mosby, Inc.

**Additional resources include:**

[www.abilityhum.com/ecu/](http://www.abilityhum.com/ecu/)

[www.makoa.org/ecu.htm](http://www.makoa.org/ecu.htm)

**Assistance for Independent Living:**

For some individuals, even with home modifications, a personal care attendant may be needed. Often care attendants can be found through home health agencies, or hospitals. Contact information for home health agencies is easily found in the yellow pages of the phone book. Before hiring an assistant the client must determine what areas they need assistance in, the level of assistance needed, and the amount of time an assistant will be needed; the preferred gender of the assistant; the wage the assistant will be paid, and whether or not the assistant position will involve driving. After these factors are determined a job description can be drawn up to seek an assistant caregiver. The job description should include all of the above listed factors. If the client is uncomfortable posting specific care needs, a general job description with a contact number for more information can be posted. Interviewing possible attendants is a very important aspect to finding a care attendant that best suits the client's needs and personality. When interviewing possible attendants the client should be specific about the job duties, including all personal cares, as well as homemaking tasks. (Lima & Schust (Eds.), 1998)

**Independence in Driving:**

Community mobility is one of the largest parts of being independent. Individuals with SCI's often are dependent on others for transportation and assist them with buying groceries, going to the bank, using the Laundromat, going to the mall, etc. Being dependent on others in such a way can cause one to feel like a burden and to have increased feelings of worthlessness or depression. Some individuals may not be able to return to driving. However there are public transportation systems available for these individuals. Other individuals may be able to return to work. Therapists should refer



clients to a certified driving evaluation program to determine if they are safe to drive.

There is a variety of adaptive equipment available for vehicles, which can aid individuals in becoming independent in driving.

**Resources:**

This site contains information on adaptive equipment, driving aids, and home care supplies: [www.fscip.org/organization.htm](http://www.fscip.org/organization.htm)

This site has personal success stories of independent living and links to adaptive equipment: [www.scipilot.com](http://www.scipilot.com)

This site provides suggestions for home modifications:

[www.aota.org/featured/area6/links/link02ca.asp](http://www.aota.org/featured/area6/links/link02ca.asp)

This site provides information on adapted gas and brake pedals:

[www.acesams.com/aids/aids.html](http://www.acesams.com/aids/aids.html)

This site provides information to therapists for starting a driving rehabilitation program:

[www.drivr.com/rehab.html](http://www.drivr.com/rehab.html)

The following two sites provide information on elevators and stair glides:

[www.realpagessites.com/mobilityfreedomvans/page4.html](http://www.realpagessites.com/mobilityfreedomvans/page4.html)

[www.acmehe.com](http://www.acmehe.com)

This site provides information on bathroom modification and pictures of modifications:

[www.homemods.org/library/drhome/bathrooms.html](http://www.homemods.org/library/drhome/bathrooms.html)

This site provides information on adaptive equipment as well as funding, and some adaptive leisure activities:

[www.wheelchairnet.org/wcn/homemod/html#anchor11054460](http://www.wheelchairnet.org/wcn/homemod/html#anchor11054460)

Adaptive Environments Center, (2002) Consumer's Guide to Home Adaptation

### **Return to Employment and/or the educational setting**

While working with clients with SCI it is important to remember that they have desires similar to the rest of the population, one example of this is to work and have the ability to be productive. Prior to the passage of the Americans with Disabilities Act (ADA) of 1990 there were many discriminatory hiring practices, architectural barriers, and transportation difficulties. With the enforcement of the ADA many of these obstacles to employment have lessened. The ADA advocates for changes such as these and for the inclusion of people with SCI in the workforce. However, even with reasonable accommodations some individuals may be unable to return to their previous job. At this point additional education or career training are additional options to explore. (Hammell, 1995)

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**Americans with Disabilities Act Facts:**

- Employers are required to provide reasonable accommodation to allow a potential employee to be considered for the job
- Reasonable accommodation may also be required to enable you to perform a job, gain access to the workplace, and enjoy the "benefits and privileges" of employment available to employees without disabilities
- An employer cannot refuse to consider you because you require a reasonable accommodation to compete for or perform a job
- An employer does not have to provide a specific accommodation if it would cause undue hardship, meaning if it would require major, unfeasible expenses or great difficulty
- Examples of reasonable accommodations include:
  - Ensuring that recruitment, interviews, tests, and other components of the application process are held in accessible locations
  - Providing or modifying equipment or devices
  - Adjusting or modifying application policies and procedures
- How to ask for a reasonable accommodation:
  - The request must be made orally or in writing by the individual with the disability or a family member, friend, health care professional, ect.
- The employer cannot ask about the applicant's disability or if they will require a reasonable accommodation during the interview process. However, if the employer knows the applicant has a disability, they may ask whether he or she

will have difficulty performing specific tasks of the job. At this point the employer may inquire about a reasonable accommodation.

- The employer must provide the essential functions of the job.
- An employer cannot refuse to hire you because you will be unable to perform minor duties that are considered non-essential functions of the job.
- An employer cannot refuse to hire you based on speculation of risk or generalization of your disability.
- For more information on these issues you may visit <http://www.eeoc.gov>

(Understanding disabilities creating opportunities, 2003 & Prabst-Hunt, 2002)

**Sample Accommodation Request Letter:**

Date of Letter

Your name

Your address

Employer's name

Employer's address

Dear (e.g. Supervisor, Manager, Human Resources, Personnel):

Content to consider in body of letter:

- Identify yourself as a person with a disability
- State that you are requesting accommodations under the ADA (or the Rehabilitation Act of 1973 if you are a federal employee)
- Identify your specific problematic job tasks
- Identify your accommodation ideas
- Request your employer's accommodation ideas
- Refer to attached medical documentation if appropriate
- Ask that your employer respond to your request in a reasonable amount of time

Sincerely,

Your signature

Your printed name

cc: to appropriate individuals

- Provide an attachment of medical information to your letter to help establish that you are a person with a disability and to document the need for accommodation.

(Taken from Job accommodation network, 2003)

**Resources for accessing employment:**

- Works with companies, government, and non-profit agencies to employ people with disabilities: <http://www.jobaccess.org/>
- <http://www.officetec.com/disabled2work/>
- Provides information about ADA, job accommodations, and employing people with disabilities: <http://www.jan.wvu.edu/>
- Ticket to hire matches employers with Employment Networks and State Vocational Rehabilitation Agencies that are working with SSA beneficiaries with disabilities looking to return to work. <http://www.earnworks.com/tth.asp>
- Career Inventory tests that may be helpful when returning to work:  
<http://www.careerkey.org/english/>  
[http://www.careerexplorer.net/features/career\\_assessscore.asp](http://www.careerexplorer.net/features/career_assessscore.asp)
- Vocational Rehabilitation Programs in your area

**Steps to talking about your disability to receive accommodations:**

- Step 1: Explain you are eligible to receive services.
- Step 2: Describe how your disability affects the task you are requesting accommodation for.
- Step 3: Explain how this accommodation will allow you to compensate for the deficit.

**Resources for returning to the educational environment:**

- Disability Support Services can be found on all college campuses. This service is set up to coordinate and provide reasonable accommodations, promote an inclusive campus environment, and encourage student independence. Reasonable accommodations are afforded to eligible students and are individualized to address specific functional limitations resulting from a disability. It is your responsibility to make the request for accommodations in a post-secondary setting.
- Your rights and responsibilities when accessing post secondary education with a disability: <http://www.ed.gov/about/offices/list/ocr/transition.html>.
- If the client is unable to return to school in his or her home community, guidelines for independent living and personal care attendants are provided in the independent living section.



## Leisure

Leisure plays a major role in maintaining a healthy life style, as well as defining who we are. However, returning to leisure activities following a SCI is often not addressed during rehabilitation. Historically it was assumed that individuals with disabilities did not have the physical capabilities to participate in many athletic types of leisure. It was thought that individuals with disabilities should change their leisure interests to activities that they were capable of participating in. For years individuals with disabilities conformed to these standards of society, and lost much of the enjoyment they received out of leisure activities. However, adaptive equipment has lessened the physical barriers for individuals with disabilities, thus allowing them to return to their previous leisure interests. Individuals with disabilities have begun a whole new movement towards adapted leisure activities. Leisure activities encompass everything from reading a book or playing cards to biking or mountain climbing, and everything in between. (Stiens, Krishblum, Groath, McKinley, Glitter, 2002)

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### **Physical Fitness Suggestions for SCI Levels:**

**C4 and above:** Encourage daily scheduling and decision making, provide education on electronic aids for daily living, provide education on proper breathing techniques, instruct patient and caregivers in range of motion activities, focus on utilizing "mental fitness activities", such as reading, watching TV, planning projects, and spending time with friends and family.

**C5:** Work towards increasing endurance for pushing a manual wheelchair (beginning with hard, flat surfaces for short distances), focus on deltoid and bicep strengthening, utilize an arm bike to increase strength and endurance, promote proper posture during activities, be careful not to cause overuse injuries to weak musculature, and a standing frame may be utilized during activity to decrease spasticity.

**C6:** Provide activities that increase strength of rotator cuff muscles to promote proper posture and decrease risk of shoulder impingement syndromes, encourage wheel chair runs and use of equipment to strengthen upper extremities, promote flexibility exercises, and use a standing frame regularly.

**C7-T1:** Focus on activities that strengthen trunk and upper extremity muscles, promote wheelchair runs for increased distance and over more difficult terrain, and continue to focus on upper body strengthening.

**T2-T6:** Focus on strengthening upper extremity muscles, emphasize strengthening to create a balance among upper body muscle groups, utilize equipment/activities which provide resistance for strengthening muscles (i.e. swimming and free weights), limit transfers during fitness and leisure activities to reduce strain on shoulders, when transferring remember to use skin protection measures.

**T7-T12:** Work to increase upper body strength, add abdominal and back strengthening activities, increase cardiovascular endurance through aerobic exercise.

**L1-S5:** Concentrate on flexibility of hip flexors, which will assist with upright ambulation, to prevent overuse and injury balance fitness workouts with functional activities, encourage use of the lower extremities as much as possible during activities such as swimming and cycling.

Sample activities to incorporate during treatment:

-wheelchair endurance runs

-arm-cycle ergometry

-hand cycling

-wheelchair aerobics

-wheelchair racing

-swimming

-rowing

-free weights/weight machines

-pulley system exercises

-theraband exercises

-medicine balls

(Spinal Cord Injury: Patient Education Manual, 1997).

**Semi-structured recreational assessment:**

Addressing recreational areas through a semi-structured interview will allow the therapist and client to determine a recreational program that is client centered and based on their abilities, needs, and goals. According to Point of care, Team based, Information system (1998), the following are areas to address during the interview:

- Strengths, interests, and values
- Previous leisure activities and expectations
- Available resources in your home and community
- Social needs and relationships
- Economic and other potential problem areas in your participation in recreational and leisure activities
- Life-style adjustments necessary for healthy leisure functioning.

**Life Balance Activity:**

This activity is intended to address life balance. This will assist the clients in planning their day in terms of ADL's, work, leisure, and relaxation. In addition, this activity will assist with the transition between a rehab facility/hospital and home. While at a rehab facility/hospital the client's day tends to be fairly structured, this activity will provide the client with a realistic plan of how to schedule their day.

**Sample Processing Questions:**

How do you feel your days will be different at home?

What concerns do you have about creating a balance in your life?

What areas do you think will be more time consuming than they were before your injury?

## Weekly Planner

Time	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
6:00 am							
7:00am							
8:00 am							
9:00 am							
10:00 am							
11:00 am							
12:00 pm							
1:00 pm							
2:00 pm							
3:00 pm							
4:00 pm							
5:00 pm							
6:00 pm							
7:00 pm							
8:00 pm							
9:00 pm							
10:00 pm							
11:00 pm							
12:00 am							

**Leisure worksheet:**

This activity will assist the client in identifying leisure interests and perceived barriers to leisure. The client will be provided with a list of leisure activities to serve as a prompt for identifying past areas of interest and possible activities to explore. During this activity the client will be provided with education and resources to address barriers. In addition, resources for pursuing new leisure interests should be provided by the therapist.

Leisure Worksheet

**Areas of leisure previous to SCI:**

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**Barriers to continuing past leisure interests:**

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**Steps to take to resume previous leisure activities:**

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**Possible leisure activities to explore:**

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**Steps to explore leisure interests:**

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### Sample leisure Checklist

This list is to assist you with identifying areas of leisure interest; you may add more of your own interests.

<input type="radio"/> Arts and Crafts	<input type="radio"/> Basketball
<input type="radio"/> Bird watching	<input type="radio"/> Volleyball
<input type="radio"/> Boating	<input type="radio"/> Tennis
<input type="radio"/> Bowling	<input type="radio"/> Skating
<input type="radio"/> Dancing	<input type="radio"/> Skiing
<input type="radio"/> Gambling	<input type="radio"/> Football
<input type="radio"/> Board games	<input type="radio"/> Track and Field
<input type="radio"/> Gardening	<input type="radio"/> Soccer
<input type="radio"/> Building models	<input type="radio"/> Softball/baseball
<input type="radio"/> Listening to music	<input type="radio"/> Badminton
<input type="radio"/> Camping	<input type="radio"/> Billiards
<input type="radio"/> Photography	<input type="radio"/> Playing cards
<input type="radio"/> Reading	<input type="radio"/> Swimming
<input type="radio"/> Cooking	<input type="radio"/> Weight lifting
<input type="radio"/> Attending sporting events	<input type="radio"/> Rock Climbing
<input type="radio"/> Watching TV	<input type="radio"/> Scuba Diving
<input type="radio"/> Going to movies	<input type="radio"/> Hunting
<input type="radio"/> Going to theater productions	<input type="radio"/> Fishing
<input type="radio"/> Prayer/meditation	<input type="radio"/> Biking
<input type="radio"/> Attending religious activities	<input type="radio"/> Riding horse
<input type="radio"/> Traveling	
<input type="radio"/> Playing musical instruments	
<input type="radio"/> Volunteering	
<input type="radio"/> Pet care	

**Resources:**

Finding a disability-friendly gym: [www.icanonline.net](http://www.icanonline.net)

Finding a certified fitness professional: [www.icanonline.net](http://www.icanonline.net)

Funding options to set up leisure recreation:

[http://www.califmall.com/SP\\_WC01.html#THE%20ASSOCIATION](http://www.califmall.com/SP_WC01.html#THE%20ASSOCIATION)

The National Center on Disability and Physical Activity web fact sheet provides information on a variety of physical activities for people with disabilities:

<http://www.ncpad.org/>

Directory of Sports Organizations for Athletes with Disabilities:

<http://www.aapmr.org/condtreat/athletes.htm>

Physical fitness: Vital for people with disabilities:

<http://www.mayoclinic.com/invoke.cfm?id=SM00042>

Information and links on various sports and fitness activities:

<http://www.disabilityinfo.gov>

**Where to look for leisure opportunities in your home community:**

Community disability association

College or University in your city

Local Fitness Centers

### Sexuality

Sexuality is probably the most private of all the ADL areas and therefore is the least often addressed in therapy. Sexuality is defined as many different things, including the way one dresses, feelings about one's body, and the way one relates—both physically and emotionally (SCI binder). Sexual dysfunction has a negative impact on an individual's self-concept, and self-worth. It is common for individuals who suffer from sexual dysfunction, secondary to a SCI, to have feelings of depression, anxiety, and often become preoccupied with feelings regarding their sexual loss (Sumerville & McKenna, 1998). These feelings may then have an impact on already established feelings and also on pursuing future intimate relationships. Clients should be reminded that having a physical disability does not rid him or her of sexual feelings, desire, and love.

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## **P-LI-SS-IT Model**

This model is suggested as an effective way to deliver sexuality education to individuals with spinal cord injury.

- **Permission:** This involves acknowledgement of the client's concern with sexuality and allow an atmosphere that allows clients to be comfortable discussing these concerns.
- **Limited information:** Sexuality information should be provided during the clients rehabilitation. The therapist should realize that he or she is not expected to be an expert in the area and may provide referral to other disciplines.
- **Specific Suggestions:** Providing specific suggestions to facilitate problem-solving skills. Other people, such as the client's partner and or other peers may be involved.
- **Intensive therapy:** This final step includes a professional sexuality counselor and is taken when the above three steps have not been effective.

(Sumerville & McKenna, 1998)

**Things to consider prior to sexuality activity:**

- ✓ Hypereflexia may occur with an injury above the T6 level. The symptom of this is a pounding headache. If this happens, stop sexual activity and sit up.
- ✓ Incontinence may occur
- ✓ Allow extra time to perform bladder care, remove clothing, and get into bed
- ✓ Since the same reflex that is triggered during sex also controls bladder activity, it may be a good idea to limit fluid intake a few hours prior to sexual intercourse
- ✓ Medication side effects
- ✓ Muscle spasms may interfere with positioning or movement during sex
- ✓ Autonomic dysreflexia may occur during sexual activity
- ✓ Catheter care
  - Intermittent catheter- catheterize just prior to sex
  - Indwelling catheter- place a condom over it to prevent irritation and use extra tubing so there is plenty of room.
  - Condom catheters- may either be removed or folded over with a regular condom placed over it

(Lima & Schust 1998).

### **Physical changes in male sexual function:**

#### ✓ Types of erections:

Psychogenic: the type of erection that is a result of fantasizing or watching something erotic

- This is the type of injury someone with T12 or below are most likely to achieve an erection this way.
- Reflexogenic: the type of erection achieved by touching the penis
  - A man with an injury at T12 or above is most likely to achieve this type of erection

### **Treatment options:**

#### ✓ Penile Implants

- Inflatable implants: A small pump is placed in the scrotum and is used to create an erection. This type of implant is the most expensive.
- Self-contained implants: This is placed in the penis and becomes firm when squeezed or bent.
- Semigrigid Implant: This is a bendable rod placed in the penis. With this method, the penis is constantly semierect

#### ✓ Non-surgical treatment

- Medications
- Self-injection of medication
- Sex aids
- Vacuum Devices

\*Consult your physician for more information regarding treatment.

(Lima & Schust 1998).

**Physical changes in female sexual function:**

- ✓ Menstruation may cease for a period of time following SCI, but typically resumes within 6 months.
- ✓ Females remain fertile following SCI
- ✓ If a female becomes pregnant, contact a physician immediately to ensure appropriate care during pregnancy.
- ✓ Many females do not experience orgasms the same as they did prior to injury, but report experiencing “phantom orgasm” (meaning females reported experiencing these feelings in other parts of the body).
- ✓ Birth Control options
  - Pills: This method works best to prevent pregnancy, but may also pose other health risks. In addition, the risk of getting a blood clot is higher while taking the pill. Watch for signs such as swelling, redness/hardness, pain, or a warm feeling to the leg.
  - Norplant: This is a time-released capsule that is placed under the skin and releases hormones. The side effects are similar to those of the pill.
  - Intrauterine Device: With this method there is a higher risk for infections in the uterus. If you use this method, watch for these signs: pain in the pubic area, cramps, fever, a change in vaginal discharge, changes in menstrual periods, increase in spasms. To use this type of birth control, the partner may need to check for proper placement and irritation that may not be felt due to absence of sensation.
  - Diaphragm/condom: this method causes the fewest problems and is effective 88% of the time.

✓ Vaginal Lubrication

- Psychogenic lubrication happens by thinking about sex and only happens in a female who has sustained an incomplete injury
- Reflexogenic lubrication occurs through touching of the pubic area and can happen if the injury is above the reflex area
- If your body does not produce enough natural lubrication, water soluble products, such as K-Y jelly may be used

(Lima & Schust 1998).



**Positioning:**

- Each couple will have to experiment to find out which positions work best for them, the following are suggestions for movement and positioning:
  - Female on back, male on top; pillows can be placed under woman's leg for support.
  - Partners on their sides, facing each other
  - Partners on their sides, male entering from rear
  - Female on back, holding legs up and back, male on top
  - Female on top, pulling with arms and hands around partners neck and shoulder
  - Female on stomach, partner entering from rear
  - Females on male's lap, using a rocking motion
  - Using a wheelchair- remove the arms from the chair and have one partner straddle over the other.

It is important to remember that a fulfilling relationship is not based only upon sexual performance. Sexuality involves much more than just sexual intercourse. Sexual activities should be enjoyable for both partners, so couples should feel free to use whichever fantasies, artificial devices, or other practices that are pleasurable.

(Point of care, Team based, Information system, 1998)

Sexuality is a private and individual subject and although the writers feel information must be provided during treatment, many individuals and their spouses will want to seek additional information independently. The following section includes resources that will be helpful when seeking this information.

**Resources:**

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## CHAPTER 5

### SUMMARY AND CONCLUSIONS

Each year, approximately 10,000 individuals per year are affected by a SCI. Due to this large number, there is clearly a need for occupational therapists to provide comprehensive rehabilitation services. With comprehensive treatment, these individuals will experience greater success and satisfaction when returning productive, daily living.

Throughout the research for this project, several areas of limitation in treatment following SCI were identified. These areas included: return to employment/education, leisure, health maintenance and management, independent living, depression/suicide prevention, and sexuality. Using the areas that were identified, the writers compiled a protocol to give occupational therapists a starting point when working with clients who have sustained a SCI.

This protocol is intended to be used as a guide to occupational therapy treatment. It includes information, educational materials, suggested treatment activities, and resources for further information in the above mentioned areas. Although this protocol provides occupational therapists with information to assist them in providing holistic treatment, it is not intended to be utilized independently as a treatment program.

We do feel this protocol provides an accurate representation of under addressed areas of SCI treatment. However, SCI is a traumatic event that requires the client to implement many changes into his or her lifestyle. Due to this, additional research on how to implement these changes with greater ease is an area to be continually explored. Also, as technology becomes more advanced, additional research on the implementation of these advances into the daily lives of clients living with SCI's will be needed.

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