

Chapter 2

ADDITIONAL CONSIDERATIONS: CULTURAL AND RELIGIOUS PRACTICES, SEXUALITY AND LANGUAGE PREFERENCES, CO-OCCURRING DISABILITIES AND SECONDARY CONDITIONS

CULTURAL, RELIGIOUS, SEXUALITY & LANGUAGE DIFFERENCES

Professionals need to understand cultural and religious differences in approaching injury or illness. Staff needs to be aware of sociocultural differences and personal resources (or lack thereof). Sexual differences may arise in care giving. In addition, individuals whose primary language is not English, or who are hearing impaired, may need an interpreter to fully be educated and to understand the concepts being taught.

CO-OCCURRING DISABILITIES

When someone has a spinal cord injury this does not preclude that they have a co-existing disability. Some examples may include a substance abuse issue, a mental health problem, another physical disability, a visual or hearing disability or a learning disability. For rehabilitation to progress these issues must also be identified and treated appropriately.

A good example could be the approach and treatment for someone who has an addiction. Certain medications might need to be avoided as much as possible. Other issues may require medication and psychotherapeutic intervention. Some individuals and families might benefit from support groups and one-on-one interventions, whereas other individuals may prefer contact with someone they perceive as “more like themselves.”

PREVENTION AND CARE OF SCI SECONDARY CONDITIONS

You will need to be aware of potential health and medical issues. In

addition, one must be educated and knowledgeable about daily preventive measures and early signs and symptoms. This will assist you to remain healthy and prevent additional medical care. The more common potential medical issues are discussed below. Furthermore, one may also obtain a medical identification bracelet, necklace and/or medallion engraved with pertinent medical information. This will ensure that if one requires care for a medical emergency that the medical team will be educated on possible conditions and/or precautions. One can contact local hospitals, the **American Red Cross or American Medical Identifications, Inc.**, PO Box 925617, Houston, Texas 77292, 7136957358 for ID information. Some facilities give out wallet size cards with the symptoms of autonomic dysreflexia and what should be done.

SKIN CARE

Skin care is extremely important for a person with a spinal cord injury. A person with normal sensation receives messages from the skin telling him/her to change position when there has been increased pressure on an area of skin for too long. In the presence of a spinal cord injury there may be impaired or absent sensation, blood flow and muscle bulk.

Hence, the person may not get enough or any of warning signs and messages of excessive pressure on the skin. This leaves the skin susceptible to pressure sores (ulcers) and/or breakdown. Both of which are common and serious complications of spinal cord injury. A pressure sore (ulcer) may be the result of prolonged pressure over a bony area. For example, skin can become pinched between an underlying bone and the surface below. The pinching prevents adequate amounts of blood flow and oxygen from reaching the skin and the underlying tissue.

This causes the skin and tissue cells to die from inadequate nutrition, blood flow and oxygen. Hence, a pressure ulcer is created. Skin breakdown can also occur from excess moisture, such as sweat, urine or feces (stool). Friction or excessively tight clothing or braces may also lead to skin problems. In addition, "breakdown" can occur from trauma or from excessive heat or cold.

A person with decreased sensation must learn to change position frequently enough to prevent development of a pressure sore. Failure to properly

manage one's skin can lead to serious complications. Pressure ulcers are grades or staged to classify the degree of tissue damage observed. The following staging applies to pressure ulcers/sore only (and not to other types of skin breakdown) and is according to US Agency for Health Care Policy and Research guidelines.

- Stage I: Non-blanchable erythema (redness) of intact skin. In individuals with darker skin, discoloration of the skin, warmth, edema or hardness may also be indicators.
- Stage II: Partial thickness skin loss involving epidermis, dermis, or both. The ulcer is superficial and appears as an abrasion, blister, or shallow crater.
- Stage III: Full thickness skin loss involving damage to or necrosis of subcutaneous tissue that may extend down to, but not through, underlying fascia. The ulcer appears as a deep crater with or without undermining of adjacent tissue.
- Stage IV: Full thickness skin loss with extensive destruction, tissue necrosis (death), or damage to muscle, bone or supporting structures. Undermining and sinus tracts also may be associated with Stage IV pressure ulcers.

Pressure sores may produce serious illness as a result of infection that may spread in the bone and bloodstream and become life threatening.

Prevention: A person with a spinal cord injury should be able to prevent skin breakdown if he/she takes the following precautions:

1. Inspect the skin daily, especially over bony prominences, morning and night. Keep off any red areas observed and contact your medical team.
2. Relieve skin pressure often. Frequent position change (both while lying and sitting) must become a way of life. It is recommended to perform a weight shift every half hour when sitting and every two hours in bed.
3. Maintain proper hygiene and good nutrition.

NUTRITION

Basic nutritional needs for the individual with spinal cord injury do not differ much from the needs of an uninjured person. A healthy diet helps to assure adequate intakes of essential nutrients including proteins, carbohydrates, fats,

vitamins, minerals and water. Special attention should be placed on daily intakes of fiber. This assists with both bowel mobility and waste elimination. Adequate fluid intake is needed to flush the urinary tract helping to guard against stones. It is recommended to intake two to three quarts of water daily. Optimum body weight should also be maintained. This will promote good health, optimal cardiac conditions, ease of transfers and prevention of skin breakdown.

BLADDER MANAGEMENT

Spinal cord injury can affect any part of the urination process. This depends on the location and extent of nerve damage. Loss of voluntary control of the bladder or sphincter secondary to spinal cord damage may result in a neurogenic bladder. The bladder's spinal reflex arc remains intact; however the bladder does not work properly. A normal bladder will store urine at low pressures.

This will ensure the ureters can transport appropriate amounts of urine without damaging the kidneys. Furthermore, a normal bladder is able to empty completely when needed. Neurogenic bladders make it difficult to manage the bladder's storage capabilities. Hence, intermittent catheterization is utilized to ensure healthy bladder management. Sometimes, there is a failure to store the urine resulting in reflex incontinence. A "nonreflex" bladder is when there is nerve damage to the reflex arc. This damage results in urinary retention and overflow incontinence. The bladder may be managed using several different techniques.

Empty the bladder at regular intervals. Medications may also be given to prevent the bladder from contracting, further improving its ability to store. If the bladder empties reflexively, some individuals may initiate this emptying by tapping on the lower abdomen over the bladder in an attempt to elicit a reflex. Men may also choose to use a condom catheter to collect their urine.

Chronic indwelling catheters (Foley or suprapubic) constitute another option to manage the bladder, although may place the individual at a higher risk for infections, stones, kidney damage, and bladder cancer.

It is important that the bladder empty completely. Any urine remaining in the bladder after incomplete emptying is called "residual urine". Bacteria grow more easily in stale residual urine and can result in a urinary tract infection.

Urinary tract infections need to be immediately treated. Bladder stones may be produced and can travel up the ureters and cause a serious kidney infection.

Signs of urinary tract infection

- Unusual cloudiness or change in urine color
- Strong urine odor
- Blood or bloody mucous in the urine
- Chills and/or fever
- Increase in muscle spasms
- Urinary incontinence or leakage or urine around an indwelling catheter

Report any of these signs of infection to your doctor. It may be necessary to send a urine specimen for culture and sensitivity. If you are voiding without a catheter, make sure that you make a conscious effort to empty your bladder every 2-3 hours, to decrease the chances to infection caused by incomplete emptying. Be sure to drink sufficient fluids daily (2-3 quarts usually recommended), with attention to maintaining reasonable catheter volumes (not to exceed 400 cc). Although intermittent catheterization is usually the recommended method of bladder management after spinal cord injury, know yourself and the program that has been developed for you. Maintaining good kidney function is extremely important to your overall health. Routine follow-up with an urologist is strongly recommended.

BOWEL MANAGEMENT

A spinal cord injury can also affect the body's ability to control the bowel. It is imperative that one learns how to manage a bowel program that will successfully work for you. It may take time but it is vitally important to your health and general sense of wellbeing. In addition, a successful bowel program can be a major factor for individuals striving to return back to school, work or social activities.

The bowel is part of the digestive tract. The bowel is under both automatic and voluntary control. With a spinal cord injury, the body's voluntary control over elimination can be lost. A bowel program's primary goal is regularity or a

controlled pattern of elimination. Medications and other aids may be used to achieve this. Bowel control depends on the level of your injury. The type of bowel program you will utilize depends on the type of bowel you have. A reflex bowel usually occurs with injuries above T12 and a nonreflex bowel usually with injuries at T12 or below.

Most persons with spinal cord injuries are very successful in regulating their bowel through training. A successful program will enable you to have bowel movements on a convenient schedule. Factors that promote successful bowel management include: regularity and timing, physical activity, position, diet and fluid intake, and medications. It is highly recommended that bowel movements never be more than 3 days apart to avoid complications. Sufficient fiber and fluid intake is extremely important. If you continue to experience zero or poor results on an every-other-day schedule, change to an everyday program temporarily until good results are achieved. Your rehabilitation medical team will work with you to find a routine that is best for you. It is important that your program fits your own schedule and meets your own needs.

Modifications to the bowel program require education, gradual changes and patience. If change is necessary, change only one element at a time and allow at least 37 days to evaluate results. A successful bowel management program should enable you to: have a bowel movement at a regularly scheduled time (usually every 24 or 48) and to avoid bowel accidents (incontinence) between planned bowel routines. Remember, only you can make your program work well by following the recommendations and procedures learned in rehab and adjusting them to your particular situation. Although difficult at first, with adaptation and patience, regulation is possible.

AUTONOMIC DYSREFLEXIA

Autonomic dysreflexia (AD), also known as hyper-reflexia, is a potentially dangerous complication of spinal cord injury. The body is unable to adequately control increasing blood pressure. Individuals with SCI at T6 level or above are at a greater risk for this complication. With prompt recognition and immediate intervention, AD can usually be resolved. It is, however, considered a MEDICAL EMERGENCY since, if untreated, the blood pressure can rise to dangerous levels and can lead to stroke or possible death.

AD is more likely to occur when lying down. The symptoms of AD often become less acute with time. A person with spinal cord injury at or above T6 may never experience AD, but he/she must be acutely aware of its symptoms and necessary intervention in case it should occur. Family, and anyone involved with assisting the person with care, should also be aware of this condition.

Common Causes of Dysreflexia

- Bladder distention; plugged or kinked catheter; overfull leg bag or failure to catheterize on time.
- Stimulation of the rectum (digital stimulation or rectal exam); distention of the rectum by hard stool (constipation or impaction).
- Painful stimuli of the skin (heat, cold, direct blows, pressure sore, ingrown toenail, tight or restrictive clothing).
- Contractions or spasms of the uterus, especially just before and during the first day of menstrual period.

Signs/Symptoms:

- A sudden, severe pounding headache (of unique nature).
 - Extremely high blood pressure (200/300/150 mm Hg).
 - A fast-pounding pulse, followed by a slow, irregular pulse.
 - Sweating and flushing above the level of injury (particularly on the face and forehead).
 - Chills, without fever.
 - Paling below level of injury.
 - Goose bumps.
 - Nasal stuffiness.
 - Nausea.
 - Blurred vision.
 - Feeling of anxiety.
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TREATMENT OF AUTONOMIC DYSREFLEXIA

- Sit the person up, or raise head of bed if lying down. Take their blood pressure.
- Catheterize to ensure urinary drainage. Check their leg bag for fullness; check catheter tubing for kinks. Irrigate indwelling catheter if not draining; change catheter if necessary.

- If performing digital stimulation, stop. If the bowel is distended, disimpact after inserting anesthetic jelly or ointment per rectum.
- Loosen restrictive clothing and/or appliances. Remove all vascular support.
- Assess for any other possible sources of painful stimuli or irritation.
- If menstrual cramp, help person to sitting position.
- Monitor blood pressure every 23 minute throughout episode.
- If these measures fail, or if blood pressure continues to rise, call 911 or immediately take the person to the hospital (ER) to be evaluated and treated by a physician. Remember, not all emergency medical personnel are aware of this condition. Person should be kept in sitting position during transport and between procedures.

RESPIRATORY MANAGEMENT

As mentioned in Chapter 1, some individuals have a long term need for a ventilator, a phrenic pacer or a bi-pap machine. Careful monitoring including medical care, nursing care, respiratory care and training of a care giver will be necessary. It is good to notify someone in the Electric Company of your needs should there be a loss of power. Go to an Emergency Room if you are concerned your battery will wear out. Be careful to get tracheostomy changes on time and watch for respiratory infections.

PAIN

Pain may also be a common problem following spinal cord injury. The most frequent source of discomfort is known as neurogenic pain. At the level of spinal injury, the local structures and nerve roots that are between the normal cord and the injured cord may create an area of irritation. This irritation may be generalized pain throughout the body or it may be localized to the particular root(s). This pain may burn or be sharp, dull, itching, or nauseating. It differs from individual to individual. With time, the symptoms decrease and the individual may be able to tolerate the pain.

A more insidious type of pain may be a consequence of an incomplete injury. This is secondary to the sparing of many sensory fibers. These fibers can cause severe pain when irritated. Such pain is much more difficult to control. It requires very careful assessment and extremely prudent management to ensure

adequate and timely control of the pain. The primary physician will evaluate you and ensure all possible treatments are assessed. In addition, a pain specialist may be consulted to assist with best determining if any other medication or procedure could be helpful in relieving the symptoms. Various methods to treat severe pain include: electrical stimulation; psychotropic medication; surgical procedures to abate certain parts of the central nervous system; and electrical implants to the spinal cord.

SPASTICITY

Spasticity is also very common in persons with spinal cord injury. Spasticity is voluntary muscle movement and/or muscle stiffness that occurs as a result of the injury. Prior to the spinal cord injury, the brain and spinal cord were able to communicate and keep the spinal reflexes under control. Spasticity of the muscles occurs when the nerve pathways are interrupted in the brain or spinal cord. The reflex causing spasticity may be increased by any stimulus that would have generated nerve signals of pain or discomfort. With a spinal cord injury, the signals from the spinal cord are prevented from reaching and communicating properly with the brain. Urinary tract infections, bed sores, constipation, and ingrown toenails can significantly increase spasticity.

Spasticity is not necessarily “bad”. For example, some people are able to use the stiffness in their legs for transfers. Without this stiffness, their muscles would be too loose and unable to be used to support the person’s body weight. However, many other people need to control their spasms because the spasms are very painful or they are so severe that they interfere with transfers, mobility, self-care, and safety. Spasms may also increase the risk of skin breakdown.

Furthermore, spasticity may also lead to contractures (permanent decreases in extremity range of motion). This can significantly limit sitting, transfers, functional mobility and activities of daily living. Spasticity can greatly threaten one’s independence, function, and quality of life hence it is important to recognize what it is and how to treat it.

A careful discussion should be held between the patient and his/her doctor as to the best way to treat spasticity. The medical evaluation may include a thorough history and physical examination. The medical team will also ensure that there are not any infections in the body, that your skin is intact and that

one have a successful bowel program.

The treatment of spasticity starts with good general care. Prevention of skin breakdown, early treatment of urinary tract infections, successful bowel programs, and the prevention of contractures all help minimize spasticity. A daily stretching program is a very important part of the prevention and treatment of spasticity and should be part of a home exercise program. Passive or active movement of the legs and/or arms (Range of Motion) may give relief for several hours. Sometimes a physician and therapist may be successful in using modalities such as icing, electrical stimulation, or casting and/or splinting to treat spasticity.

There are also a number of oral medications that can be used. Examples of these include: Lioresal (Baclofen), Clonidine (Catapress), Diazepam (Valium), and Dantrolene (Dantrium). Tizanidine (zanaflex) has also been shown to be very effective. If additional treatment of spasticity is still necessary, a doctor may recommend a nerve block or motor point block. This can only be used if the spasticity is in a localized area.

In 1992, the FDA unanimously approved Intrathecal Baclofen for treatment of spasticity. In this system, a very small dose of Baclofen is provided directly to the cerebral spinal fluid. The cerebral spinal fluid is the liquid surrounding the brain and spinal cord. A pump must be implanted surgically under the skin of the abdomen. The medication runs through a long catheter to the intrathecal space in the lower back. A computer programmer uses radio waves to painlessly communicate with the pump to properly adjust the dose of Baclofen. It has been found that Baclofen's effect on spasticity is much improved when injected directly to the cerebral spinal fluid as compared to taking Baclofen orally. If appropriate for spasticity management, your medical doctor will recommend the pump and determine the right dosage. Hospitals in Connecticut with an active Intrathecal Baclofen Pump Program:

- Connecticut Children's Medical Center – Hartford, CT
- Gaylord Hospital – Wallingford, CT
- UConn Medical Center – Farmington, CT
- Hospital for Special Care – New Britain, CT

In rare cases, neurosurgical procedures are considered for severe cases of

spasticity that are not treatable with medications and/or Intrathecal Baclofen. Rhizotomies or the actual cutting of the spinal nerve roots may also be a successful treatment option.

EDEMA

Edema may also be another complication of a spinal cord injury. Edema is controlled by the ability to voluntarily contract and relax your muscles in your arms and legs. This muscle contraction acts like a pump that ensures all fluids in the extremities are pumped back and forth from the heart. In a spinal cord injury, the voluntary control over your muscles may be lost. Hence, your body may lose the ability to contract your muscles in a rhythmic, timely fashion. This can lead to the accumulation of fluid or edema in your extremities, particularly when the extremities are in a dependent position, i.e. sitting in a wheelchair. This swelling can result in increased sensitivity of the skin to pressure and may also lead to skin breakdown.

In addition, the legs may be more difficult to manage because of the increased weight of the fluid. It is extremely important to control the fluid that settles in the ankles as much as possible. This can be done by elevating the legs regularly to allow the swelling to go down. You can do this by using elevating leg rests or placing your legs on pillows. Support stockings may also be used to control edema. Care must be taken to make sure that point pressure from these stockings does not cause skin breakdown. Constriction from stockings at the knee must be avoided to prevent further swelling from occurring. Above the knee support stockings are usually recommended.

HETEROTOPIC OSSIFICATION

Heterotopic ossification (HO) is the abnormal growth of bone in soft tissue locations surrounding major joints, primarily hips, knees and shoulders. Due to paralysis and bone decalcification, calcium intake normally used for muscle movement and bone strengthening becomes excessive and collects in the joints. The increased calcium formation in the joints seriously limits the extremity from moving throughout the entire range of motion. Signs and symptoms may include swelling, redness around the joint or limb, fever, pain and reduced range of motion.

Heterotopic ossification may be diagnosed through x-ray findings, bone

scan, and/or elevated alkaline phosphatase. It is most often treated with bio phosphates, such as Didronel, which inhibit bone reabsorption and bone formation. Range of motion and weight bearing exercises may also be prescribed. Alternative treatment includes NSAID's (such as Motrin). Severe progression of heterotopic ossification may require surgical interventions, especially if severe loss of function and motion occurs. A well balanced diet is used to prevent heterotopic ossification. This diet should include adequate amounts of calcium and vitamin D.

DEEP VEIN THROMBOSIS (DVT)

After spinal cord injury, muscles may significantly lose their tone and the ability to contract. Hence, blood and fluids may pool in the extremities. When blood flow becomes impaired, a clot may form. This is called vein thrombosis or DVT.

If the blood clot breaks off and moves through your system, it can be dangerous. When the clot breaks off, it is called an embolus. If this clot reaches the lung, it is called a pulmonary embolus. A pulmonary embolus is an emergency and life threatening situation because the embolus prevents adequate oxygen from reaching cells throughout the body. Persons in bed for long periods of time are at an especially high risk for the occurrence of DVTs or pulmonary embolus. Signs and symptoms of DVT (50% of cases are without symptoms):

HEAT STROKE & SUNBURN

A spinal cord injury also effects temperature regulation. Due to a loss of sensation, the body can easily become overheated. The ability to sweat, allowing evaporation to cool the body, is not regulated smoothly in the areas below the lesion. Thus, overheating of the body, an extremely dangerous condition, can occur. In addition, persons with spinal cord injuries are more susceptible to being burned. This is because of impaired and/or absent sensation and some of the medications you are taking makes you more susceptible to the sun. The only way a human being can control his/her temperature effectively is to control their environment. The person with spinal cord injury must take special care to make sure their body does not get overheated and that the skin is well protected to prevent burns. **If extensive sunburn or overheating does occur, immediate medical attention must be sought.**