

Functional Changes

Are you slowing down, having more pain or noticing new weakness? Do you need more help or find that you are unable to do things that were once routine for you? Are these just the signs of normal aging or is something else going on? These are the types of questions currently being researched at the Rehabilitation Research and Training Center on Aging with a Spinal Cord Injury (RRTC). These changes in function may be preventable, and by incorporating new strategies, the effect on daily life may be reduced. Investigations continue to identify the common cause of changes in function and how best to treat and prevent them. So "stay tuned" for future updates on the subject.

People with long-term SCI report new problems with pain, fatigue and weakness. These problems have negative effects on function. Working a full day, pushing long distances, socializing, participating in recreation, transferring, bathing and performing routine chores become more difficult and sometimes impossible for people to keep doing. Changes in function sometimes result in the need for help with activities that once were performed independently. Some people have assumed that the aches and pains and the slowing down are just a normal part of growing older; others are shocked and surprised by these changes. Whether expected or not, the important issues are to determine the causes, treat the problems, identify how to best prevent loss of function, and plan for changes that are unavoidable.

Who is having a problem?

People experiencing these problems are not really that old – they are in their mid-forties or have had a spinal cord injury for about 20 years. The level and completeness of the spinal cord injury does not seem to make a difference in who experiences problems.

What is the problem?

Fatigue

In a recent study conducted by the RRTC on Aging with SCI, 61% of the people having changes in function identified fatigue as a major problem. The lack of energy, or lowered energy level surprised many previously active and energetic individuals. Getting tired much faster than in the past or feeling that once simple things now require a maximum effort are commonly reported. A single cause for fatigue has not been clearly identified; instead it may be a result of many different factors. Underlying medical problems such as anemia, thyroid deficiency, diabetes, depression, respiratory problems or heart disease may cause fatigue. Certain medications such as muscle relaxants, pain medication, sedatives, and others can

contribute to fatigue. Low fitness levels or becoming "out of shape" may result in too little energy reserves to meet the physical demands of daily life.

The important thing to realize is that fatigue may be caused by a number of factors. It is essential to talk with your physician and health care team and take the fatigue seriously. A thorough medical evaluation will help identify potential causes of the fatigue and direct treatment toward these problems. In some cases a medical cause for the fatigue is not found. If so, it is helpful to assess what other factors may contribute to fatigue and find a way to manage it. Examples of these might include increased stress, changes in the environment requiring more of an energy demand, depression, alcohol or drug use, and changes in diet and exercise. Health care providers can assist you with the following activities to manage fatigue:

- Recommend pacing techniques for energy conservation,

- Assess your need for new or different assistive devices or technology that may relieve some physical demands,

- Analyze your daily activities and work with you to make things more efficient,

- Provide instruction for safe physical activities/exercise to increase your stamina.

Pain

Many people with SCI live with chronic pain and develop ways to cope with it on a daily basis. The pain SCI survivors are experiencing with age is different from the chronic neurologic pain associated with the original SCI. This new pain, often occurring in joints or muscles of the shoulders, wrists, elbows, neck or back, seems to result from injury to the joints, muscles or nerves or "abnormal wear and tear" on the body. The demands on the shoulders and arms of a person pushing a wheelchair are very different from what they were originally designed to do. For example, consider the number of transfers per day, how far and over what surfaces a person pushes his or her chair, the number of times the hand or wrist contacts the wheel when pushing, how often a person reaches for something overhead, or has to look upwards during conversations. The accumulation of these activities, day after day, results in abnormal strain on muscles and joints. Certain muscles become stronger while other muscles are not used as much. The result is muscle imbalances around joints that can cause injury. Injury to the muscles or tendons of the shoulder, such as a rotator cuff tear, impingement syndrome, or tendonitis/bursitis are common problems. Repetitive wheelchair pushing, using an open hand method to transfer or using crutches or canes to walk may result in damage to the nerves at the wrist, causing problems similar to carpal tunnel syndrome. Neck and back pain result from poor posture in the chair. scoliosis. the abnormal stress from being seated for

prolonged time periods and inappropriate seating or positioning equipment.

Most importantly, do not ignore pain hoping that it will go away. Seek treatment. Often treatment is more effective if started early before the problem becomes chronic. A thorough evaluation of the type, location, and cause of pain is essential for an accurate diagnosis. Tell your health care provider what activities cause the pain, what the functional demands on your arms are, and even demonstrate how you perform activities. Depending upon the diagnosis, treatment options should be possible. These options may range from conservative to extensive, and the impact of these options on your daily function should be discussed. The following are some examples of options that may be explored; many of these are accomplished with the assistance of a health care provider:

- Modify how activities are performed,

- Therapy to treat the pain and to improve muscle function,

- Identify new equipment and technology needs,

- Identify personal assistance needs,

- Evaluate current medications and determine need for changes or additions,

- Identify need for surgical options.

Weakness

People who are long past the acute phase of SCI have reported new muscle weakness. Persons with complete injuries as well as individuals with incomplete injuries have reported losing muscle strength. The weakness usually begins gradually and develops subtly. The weakness may not be severe but the effect on function is usually noticeable. If weakness or functional decline occurs rapidly, it is imperative to seek out *immediate* medical attention to rule out a potentially reversible neurologic condition known as syringomyelia (fluid filled cyst in the spinal column). Other potential causes of weakness may result from injury to nerves (such as carpal tunnel syndrome, ulnar nerve entrapment, disc problems, or pinched nerves), changes in the stability of your spine, injury to your muscles, tendons, or joints, or medical conditions such as multiple sclerosis or other neurologic disorders. It is critical, in any case, to obtain a medical evaluation to identify the cause of the weakness and begin treatment in order to prevent further loss of function. In some cases, weakness is not reversible and additional assistive devices or bracing becomes essential to protect and preserve the remaining muscle function.

Overall Recommendations

Despite the fact that many people with SCI are experiencing these problems does not mean that it is normal. Take any changes in function seriously and have your

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health care provider take them seriously. You know what is normal for you. When changes occur, take action. Delaying treatment will usually not make the problem go away and in some cases you may miss the opportunity to effectively treat a problem. The following are some general guidelines to keep in mind:

Do not overly accept change.

Obtain a thorough evaluation of the problem.

Give the recommendations provided a good trial. Don't discard the recommendations before giving them a chance to work.

Discuss with your health care provider how the treatment options work for you, if the first attempts are not helpful, other options may exist.

Recognize how the choices you make now might affect your future function.