REHABILITATION AFTER A RARE NEURO-IMMUNE DISORDER

The Transverse Myelitis Association

advocating for those with adem, nmosd, on and tm (including afm)

activity and rehabilitation are key to living optimally with a rare neuro-immune diagnosis Rehabilitation should be started soon after someone with a rare neuro-immune disorder is medically cleared for activity, whether one has regained some muscle strength or has shown no short-term recovery. Starting a rehabilitation program early can help mitigate some of the bone loss and muscle atrophy that occurs in the areas affected by paralysis.

endogenous stem cells in the nervous system can be activated[1] It is possible for the nervous system to repair itself many years after a demyelinating event or a non-traumatic spinal cord injury from a rare neuro-immune disorder. Our nervous system has endogenous stem cells, which are stem cells that originate from our bodies. These stem cells can repair damage in the spinal cord and brain. The stem cells in the spinal cord can only repair the damaged connections, if those connections are active, which can be accomplished through a rigorous rehabilitation program. This process is very slow, so even if immediate progress is not seen, continuing rehabilitation can re-activate connections.

activity-based restorative therapy has been shown to be successful The goal of activity-based restorative therapy (ABRT) is to activate the neurological levels above and below the injury. ABRT includes patterned activity, such as locomotor training and functional electrical stimulation (FES), non-patterned activity, such as strengthening and task-specific training, and sensory stimulation. Studies on ABRT have shown positive results, including increased muscle strength, improved walking speed, endurance, and symmetry, and improved standing balance.[2]

a rehabilitation program should include various types of activity and target multiple muscle groups Rare neuro-immune disorders may affect multiple muscles and functions of the body. A rehabilitation program should involve activation of multiple muscles and various types of activity (e.g., FES, weight training, cardio etc.), unless there is a medical contraindication. A rehabilitation program should always include functional goals that are important to the person enrolled in the program including walking, going up stairs, driving, etc.

all rehabilitation programs are alike The truth is, a good rehabilitation program should be custom designed by physicians and therapists for individuals with rare neuro-immune disorders based on level of disability and the goals individuals have for their recovery. A rehabilitation program should allow for periods of rest, accommodate for falls, changes in health, and management of neuropathic pain and fatigue symptoms after a rare neuro-immune diagnosis. Individuals diagnosed with rare neuro-immune disorders should work with their therapists and physiatrists to customize a program for them – one that they will be able to do on their own with support of family or friends.

it can be too late to start a rehabilitation program In fact, it is never too late to start a rehabilitation program. The repair process in the spinal cord can continue throughout life if an active and aggressive rehabilitation program is maintained. An individual can start a rehabilitation program even years after diagnosis. While it was initially thought that recovery only occurs within the first two years, this is no longer thought to be the case. It was also initially thought that a third of people with the diagnosis of Transverse Myelitis (TM) recover fully, a third partially recover, and a third don't recover at all, but this data predates a number of more aggressive treatment protocols currently used and is likely invalid. Furthermore, regardless of when it is started, a rehabilitation program can improve cardiovascular health, help build muscles, decrease atrophy, and promote bone health.

neuropathic pain and fatigue will worsen with activity Fatigue can often be an issue for those with a rare neuro-immune disorder. Starting a new rehabilitation program slowly, and then escalating the activity program over time can help reduce issues with fatigue. Some people stop activity because of pain, but pain levels tend to improve the more active one becomes. Working closely with a physician to determine the best way to manage pain, whether it is orthopedic or neuropathic pain, can be beneficial for ensuring that an activity routine is maintained. Activity has been shown to decrease fatigue levels and improve mood and decrease stress levels. Fatigue can also be managed by recognizing the underlying causes, such as poor sleep, depression, medication side effects, and addressing stress levels.

activity can trigger a relapse While activity should not trigger a relapse, an increase in body temperature can cause recurrence of old symptoms but this is not harmful and should subside with a short rest. If this is the case, doing therapy indoors or using a cooling device can help prevent overheating. Activity may trigger a potentially dangerous condition called autonomic dysreflexia (AD). AD is not a relapse and should subside if a trigger for the AD is found.

glossary

activity-based restorative therapy (abrt) ABRT is a rehabilitation strategy that emphasizes activating the neurological levels located both above and below the injury level using different rehabilitation techniques.

autonomic dysreflexia (ad) AD occurs when the involuntary nervous system abnormally overreacts to stimulation. AD is a medical emergency that can occur in those with spinal cord damage at or above the T6 level. If one experiences AD during activity, stop the activity immediately and try to identify the trigger, which can often be related to the bladder or bowel needing to be emptied.

functional electrical stimulation (fes) FES is a rehabilitation strategy where electrodes placed on the skin on top of muscle send an electrical signal that activates both the muscle and the connected nerve, which then sends a signal into the spinal cord, and back to the muscle. It is important to connect this stimulation with a functional task to get the most benefit from the activity. Recovery from using FES may be slow, but tracking changes in muscle strength and sensation over months and years with a physician or trained therapist can quantify progress. An FES bike for both arms and leg muscles can be used from a seated position or in a wheelchair.

locomotor training Locomotor training is one type of rehabilitation that re-teaches walking. Individuals with rare neuro-immune disorders are placed on a treadmill, with the assistance of a harness if necessary, and trained therapists move their legs in a walking pattern.

neuropathic pain Neuropathic pain is a certain type of pain that occurs when there is damage to the spinal cord. It occurs because sensory input to the brain is interrupted and incomplete, so the brain fills the gap of the missing sensory signals with unpleasant sensations, such as burning and tingling.

non-patterned therapy Non-patterned therapy includes strengthening activities, such as lifting weights, and task specific training, which is when individuals are re-trained on how to do functional tasks.

patterned therapy Patterned therapy includes FES and locomotor training (see above).

rare neuro immune disorders Rare neuro-immune disorders are immune-mediated disorders that occur when a person experiences an inflammatory attack at some location in their central nervous system (brain, spinal cord, and/or optic nerves). The disorders include Acute Disseminated Encephalomyelitis, Neuromyelitis Optica Spectrum Disorder, Optic Neuritis, and Transverse Myelitis, including Acute Flaccid Myelitis.

references

(1) Sadowsky CL, McDonald JW. Activity based restorative therapies: concepts and applications in spinal cord injury-related neurorehabilitation. *Dev Disabil Res Rev.* 2009;15(2):112-6.

(2) Jones ML, Evans N, Tefertiller C et al. Activity-based therapy for recovery of walking in individuals with chronic spinal cord injury: results from a randomized clinical trial. *Arch Phys Med Rehabil.* 2014;95(12):2239-46.

(3) Sadowsky CL, Becker D, Bosques G et al. Rehabilitation in transverse myelitis. Continuum (Minneap Minn). 2011;17(4):816-30.

interested in participating in a research study?

Please visit https://myelitis.org/shaping-the-future/research/clinical-studies-trials for a list of active studies that are currently enrolling.

how to find a rehabilitation center or physiatrist near you?

Physical and Occupational Therapists who work in outpatient rehabilitation centers often specialize in treatment for individuals who have had spinal cord injuries, multiple sclerosis, transverse myelitis and other demyelinating disorders, thus making them an ideal resource for your recovery. You can find a list of physiatrists and medical professionals at https://myelitis.org/living-with-myelitis/resources/medical-professional-network

information & resources

Please visit http://myelitis.org/living-with-myelitis/resources/resource-library for a list of resources that are related to rehabilitation.