

SUMMER 2021

Welcome to the Summer 2021 edition of MRSCICS Matters, the newsletter of the Midwest Regional Spinal Cord Injury Care System (MRSCICS) at Shirley Ryan AbilityLab, formerly the Rehabilitation Institute of Chicago (RIC). You are receiving this newsletter because you are enrolled in the National Spinal Cord Injury Model Systems Database. The Database studies long-term outcomes after traumatic spinal cord injury (SCI). Thanks to participants like you, the study has been active for over 50 years!

You enrolled in this study while you stayed at SRALab (or RIC) for inpatient SCI rehabilitation. We contact people for follow-up surveys one year after injury, and then every 5 years after (5, 10, 15, 20...45 years post-injury) to collect information about your physical health, mental health, and daily life. This newsletter comes out twice per year so that we can stay in touch and share useful information about living with an SCI. Thank you for being a part of the SCI Model System!

INSIDE:

Adaptive Sports

Adaptive Cycling for people of all ability levels!

Mental Health

Depression and opioid addiction: Learn the signs, symptoms and treatments.

SCI Resources List

Find supportive organizations near you, and share any that we missed!

Covid-19 Update

What is the Delta variant?

The Delta variant is a newer version of the virus that caused the Covid-19 pandemic. As viruses reproduce, they change quickly. Some of these changes make the virus stronger. When a new version of the virus is "better" at infecting people than an old version, the new version takes over by reproducing and spreading faster. The Delta variant is one example of the Covid-19 virus becoming stronger.



Wear a mask

Just when you thought it was safe to throw your old masks away... The CDC recommends everyone start wearing masks again indoors. Even if you're vaccinated, you may still be able to spread the virus to others.

Get vaccinated

The vaccine is safe for people with SCI, and it is the best way to stop the spread of Covid-19. Find answers to frequently asked questions about the vaccine here:

<https://www.cdc.gov/coronavirus/2019-ncov/vaccines/faq.html#Safety>

Adaptive Sports: Anyone Can Try

Are you looking for a new hobby? Working on your mental or physical health? Bored of staying at home? Getting outside for some fresh air and exercise is a great way to enjoy the last few weeks of summer. We caught up with the adaptive sports team at Shirley Ryan AbilityLab to learn how cycling works for people with SCI.

A spinal cord injury (SCI) does not have to keep you from being active. Adaptive sports and recreation are good for your health and well-being. Cycling is one of the most adaptable sports. You can cycle with a team, by yourself, and with friends of all ability levels!

How can bikes be adapted for people with SCI? Do you need to have a certain level of upper body function or balance?

Bikes can be adapted to people of all abilities and functional levels. There is no minimal amount of upper body function or balance that a person needs. Inclusion is a crucial part of adaptive sports. With the help of different assistive devices, anybody can cycle.

People commonly think individuals that are quadriplegic cannot cycle – this is not true. We have a variety of grips, straps, gear shifters and brakes that we place in different locations on the cycle to adapt. **Grip devices** allow for the cyclist to get a better hold on the handles to push the bike forward. We have multiple people with high-level SCI that participate in our cycling program using these quadriplegic grips. There are also adaptations for elbow brakes and brakes that can be compressed by moving your head.

Bluetooth shifting allows a cyclist without upper extremity control to shift gears through another person using a remote control. For people with balance issues, all cycles at SRAlab are low to the ground with three wheels, making them much more stable and less likely to tip over. This makes the cycle as accessible as possible to meet each person's unique needs.



Do you hear any common concerns or misconceptions from people before they get involved in adaptive cycling?

People usually worry most about are how they are going to transfer into and out of the cycle. It can look hard at first, but with the expertise of our staff and volunteers, we are able to adjust the individual's position as needed where they will feel comfortable enough to ride. A common hesitation we receive is, "I'm not strong enough to propel the bike". With the look of how a handcycle works, this can be a common misconception. But, as mentioned earlier, different grip devices help with the power it takes to propel a bike.

Another common misconception that comes up frequently is that the cycles cannot go on bike paths. This is false. Adaptive cycles can go anywhere, so you can ride with family members who have their own bicycle. There are also adaptive mountain bikes for people looking to ride more advanced trails with inclines and obstacles.

Adaptive Sports: Anyone Can Try

What would you tell someone with an SCI who is hesitant, nervous, or self-conscious about getting involved in adaptive sports or fitness?

We would tell them to come join our program or a program like ours! We have a good group of volunteers and very qualified staff to not only adapt the cycle for them, but also build their skills. Even if it just starts out as visiting our programs to observe, this can be very beneficial.

Adaptive sports programs provide more than just a recreational experience. They have a significantly positive impact on physical, social, and mental well-being. These programs give people a chance to meet others with similar ability levels and interests. Seeing others succeed can be very inspirational.

What are some key things to look for when you're choosing a cycling program?

The number one key thing to look for in a program is the type of equipment provided. What type of adaptations are available? When is the equipment available? Can I get my own equipment later on?

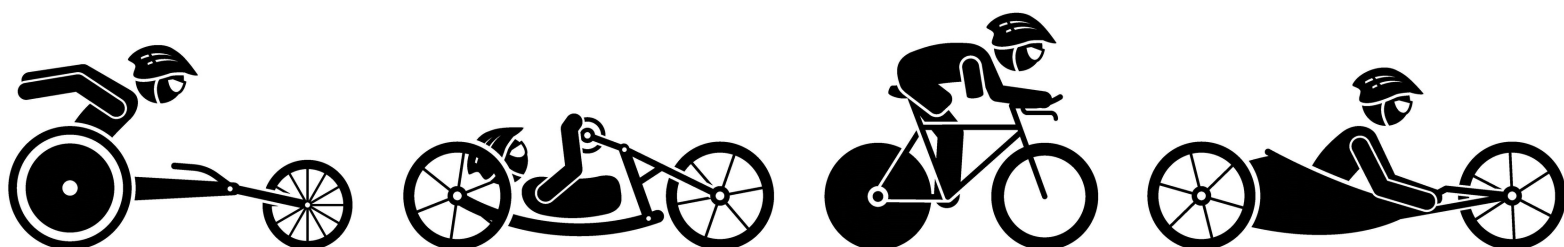
It's also important to consider the amount of staff or volunteer support: Will there be someone to ride with to help develop my skills? Who will help me transfer in and out of the bike?

Any final advice for someone who wants to get started?

Just try it! Until you actually get into a cycle and try to adapt to it, you won't be successful. You just have to get going, and then there will be endless opportunities to become stronger.

"Bikes can be adapted to people of all disabilities and functional levels. There is no minimal amount of upper body function or balance that a person needs. Inclusion is a crucial part of adaptive sports, so with the help of different assistive devices, anybody is able to cycle."

To learn more about the adaptive cycling program at SRAIab:
<https://www.sralab.org/article/adaptive-cycling-program>



Mental Health and Spinal Cord Injury: Depression

Mental health is important to our overall health and well-being. It affects how we think, feel and act. Depression and addiction are two of the most common mental health concerns experienced by people living with spinal cord injury (SCI). Rates of depression and addiction also went way up during the Covid-19 pandemic. People who felt healthy before may now be struggling with mental health. Knowing more about the symptoms and available treatments can help you keep yourself and your loved ones healthy.

What is depression?

Depression is not just feeling "sad," "blue," or "down in the dumps." It is a medical condition where your body makes too much or too little of certain chemicals, just like diabetes or high blood pressure. These chemicals are called neurotransmitters. When the neurotransmitters in your brain are out of balance, it can affect your mood, enjoyment, sleep, energy, appetite, and focus.

Although we don't know for sure what causes depression, we do know that stress and medical problems can change the balance of neurotransmitters. This is why living with a traumatic spinal cord injury (SCI) might make you more likely to experience mental health problems such as depression. Depression is not caused by personal weakness, laziness, or lack of willpower. It is normal to feel unhappy sometimes. But, if you are feeling unhappy almost daily for two weeks or more, you should talk to your doctor right away.

Depression is closely linked to your thoughts and feelings, but it also affects your physical health. Depression can make you feel tired, weak, or sick. It can be very hard to complete simple daily tasks.

Can you treat depression?

Symptoms of depression can almost always be treated with specific types of counseling or medications. A combination of both counseling and antidepressant medication has the best results. Regular exercise, especially when paired with counseling or medications, can also improve mood.

Many mental health professionals are qualified to treat depression. For example, psychiatrists have special training in medication for depression, and psychologists are trained to provide counseling for depression. Other physicians, such as primary care physicians, neurologists, and nurse practitioners can often get treatment started and help you find mental health professionals as needed.



Symptoms of Depression

Depression looks different for everyone. The picture below lists some of the most common signs and symptoms of depression. Everyone experiences these feelings sometimes, but if you notice changes lasting two weeks or more, it might be time to get help.

Guilt

Feeling like you are disappointing yourself or your loved ones.

Hopelessness

Feeling like things will not get better, you cannot find anything to look forward to.

Worthlessness

Feeling like you do not matter or do not deserve to be happy.

Insomnia

Not being able to sleep. Sleeping too little or too much are both symptoms.

Aches and Pains

Your body feels sore, weak, or tired for no reason.

Anger

Feeling mad or irritable over things that normally would not bother you as much.

Isolation

Losing connections with friends or family, skipping social events, feeling like people do not want to spend time with you.

Suicidal Thoughts

Feeling like you would be better off dead, wishing you did not wake up, thinking of ways to harm yourself.

Weight Changes

Gaining or losing weight without trying to. Feeling very hungry, or not having an appetite.

Fatigue

Feeling physically tired, like your body and mind are exhausted.

Concentration

You cannot focus, even on simple tasks like reading. You can't pay attention at work or school.

Dependence

Using alcohol or drugs to cope with your feelings or escape your daily life.



National Suicide Prevention Lifeline: 1-800-273-8255

Lifeline Chat: <https://suicidepreventionlifeline.org/chat/>

I'm Alive Chat: <https://www.imalive.org/>

Crisis Text Line: <https://www.crisistextline.org/>

◦ Text the word "HOME" or "Hello" to 741741

Mental Health and Spinal Cord Injury: Opioids

Anyone can become addicted to opioids. Some people with SCI have pain, and opioid medications are prescribed to treat pain. These medications can be safe and effective for people with SCI. They also carry risks. Learning about opioid addiction could save your life!

What are opioids?

Opioids are a group of drugs that come from **opium** in poppy plants. While some opioids are made from the plant directly (like morphine), others are created in a lab (like fentanyl). Opioids are prescribed as medication to relieve pain. But, opioids can also make people feel very relaxed or “high” which is why they are often misused for non-medical reasons.

Opioids are addictive. Overdoses and death are more common when people use opioids for non-medical reasons. However, as more and more people have been prescribed opioids for the treatment of severe pain, there has been an increase in overdose deaths reported in persons who are prescribed opioids for pain as well.

What are some common opioids?

Prescription medications:

- **Morphine**
- **Codeine**
- **Fentanyl**
- **Hydrocodone** (AKA Vicodin, Norco, Lorcet)
- **Oxycodone** (AKA Percocet, OxyContin)
- **Hydromorphone** (AKA Dilaudid, Palladone)
- **Tramadol**
- **Methadone**

Plus, illegal drugs like **heroin**

What should you know about opioids?

- Many people get used to opioids over time and need higher doses to get the same effect. This is called **tolerance**.
- Even if prescribed by a doctor, using any opioids puts you at higher risk of addiction, accidental overdose and death.
- Risk of overdose or death is higher with higher doses of opioids. But, accidental overdose and death can still occur with lower doses.
- There are effective treatments for opioid use disorders.

What are some treatment options?

Naloxone (AKA Narcan) is an emergency medication used to treat people who overdose on opioids.

Methadone is an opioid that is actually used to treat opioid addiction by slowly lowering the dose over time. This gives your body time to adjust to getting less opioids each day.

Counseling with a mental health professional to treat the emotions that led to addiction and find other outlets.

Sometimes, an inpatient (overnight) treatment program might be the best option to combine medication and counseling in a safe setting.

List of Resources for People Living with SCI

Are you involved in a community organization, local club, discussion group on social media, disability advocacy group, or something similar? The MRSCICS team is creating a list of resources to help connect people living with SCI to helpful organizations.

Model Systems Knowledge Translation Center (MSKTC) for SCI: msktc.org/sci

- **SCI Factsheets:** <https://msktc.org/sci/factsheets>

United Spinal Association: unitedspinal.org

- **SCI Resource Center:** spinalcord.org

Americans with Disabilities Act (ADA) National Network: <https://adata.org/>

- **Find your local ADA branch here:** <https://adata.org/find-your-region>

National Center on Health, Physical Activity and Disability: <https://www.nchpad.org/>

Administration for Community Living (ACL): <https://acl.gov/>

Employment Resources for People with Disabilities:

<https://www.sralab.org/research/labs/Disability-Employment/projects/employment-resource-guide-people-physical-disabilities>

FacingDisability.com

- **Voices of Experience video series:** <https://facingdisability.com/voices-of-experience-videos>
- **"You Are Not Alone - Dealing with Spinal Cord Injury" Facebook group:**
<https://www.facebook.com/groups/FacingDisability/>

Christopher & Dana Reeve Foundation: <https://www.christopherreeve.org/>

Equip for Equality: <https://www.equipforequality.org/>

Through the Looking Glass: www.lookingglass.org

Crime Victims' Compensation Program: <http://victimsofcrime.org>

SPINALpedia: <https://spinalpedia.com/>

HelpHOPELive: <https://helphopelive.org/>

Kelly Brush Foundation: <https://kellybrushfoundation.org/>

Challenged Athletes Foundation: <https://www.challengedathletes.org/>

Triumph Foundation: <https://triumph-foundation.org/>

We want to hear from you!

Contact Jennifer Burns at 312.238.2826 or jburns03@sralab.org with comments, questions, or suggestions.

Follow us on Facebook : <https://www.facebook.com/RehabOutcomes>

Are you an adult with a physical disability experiencing chronic pain?

You may be eligible to participate in the Employment-related Telephone Intervention for Pain (E-TIPS) study, which involves 8 treatment sessions via phone and four online surveys over 9 months.

Contact Angelika Kudla for more information: **312.238.8167** or akudla@sralab.org

Are you an adult providing hands-on care to someone living with a physical disability?

We are recruiting care partners to participate in a virtual focus group about standardized assessments used in rehabilitation. You will be asked to participate in a 60-minute discussion over WebEx video.

Contact Niveda Tennety for more information: **312.238.3042** or ntennety@sralab.org



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