



SCI: MOVING FORWARD

A RESPONSE TO COVID-19



North American
Spinal Cord Injury
— Consortium —

Positive Learnings from COVID-19

SCI: Moving Forward is made possible by:



About NASCIC



North American
Spinal Cord Injury
— Consortium —

The North American Spinal Cord Injury Consortium (NASCIC) has the mission to bring about unified achievements in research, care, cure, and policy by supporting collaborative efforts across the spinal cord injury community.

www.nasciconsortium.org

About SCI: Moving Forward

- Webinar series in response to the COVID-19 pandemic and how it is affecting the SCI population
- Website to house archived webinars and additional resources

<http://www.nasciconsortium.org/scimovingforward.com/>

Takeaways

WHAT WE'VE LEARNED FROM SCI: MOVING FORWARD



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EPISODE 1:

VIRTUAL CARE
AND ASSISTANCE

Takeaways – Virtual Care and Assistance

- Many SCI service organizations in Canada and the US have adapted their programs, training and supports to online platforms
 - United Spinal Association chapters are offering online peer-support and put their Train the Mentor program online
 - Spinal Cord Injury Ontario launched their online platform VIP for SCI which connects those living with SCI to all their networks – family doctor, peer support, friends & family, employment services, rehab services etc.
- Online education platforms such as Cortree and SCI Alberta's Online Learning are now offering free or discounted courses i.e. Working as a home care provider
- Telemedicine is readily available for the SCI community

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TELEMEDICINE

In the wake of COVID-19 Provincial governments in Canada made telemedicine billable, with the hope that this will remain in place after COVID-19

Medicare in the US has allowed expanded telehealth services and loosened many restrictions, private insurance companies have followed suit as well





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EPISODE 2:

ATTENDANT CARE
IN THE TIME OF
COVID-19

Takeaways – Attendant Care

- Make sure you have a back-up plan if your caregiver becomes ill (back-up attendant, friend/family member)
- Make sure your caregiver properly uses and disposes of PPE when in contact with you
- Have an open dialogue with your caregiver about who they are coming in contact with i.e. other patients, friends, family etc.
- Provide your caregivers with detailed instructions on your care needs and on your wishes regarding extreme measures (my health passport)

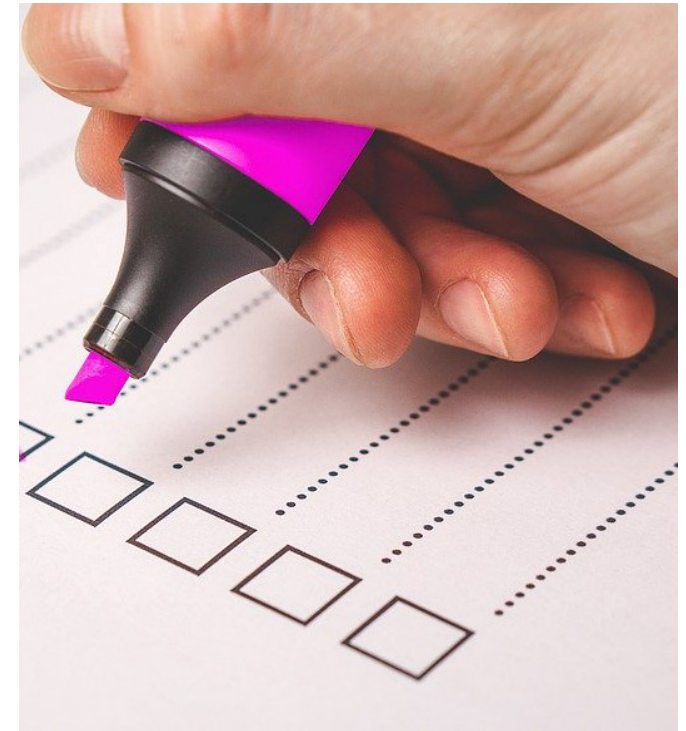
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PREPARATION

The pandemic has forced the SCI community to become better prepared and for those living with SCI to have conversations with family, friends and caregivers about difficult topics i.e. end of life plans

UTILIZING RESOURCES

In certain US states, Occupational Therapy students that were unable to continue with their placements due to COVID-19, were approached to train as PSW's to help fulfill shortages





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EPISODE 4:

SCI-SPECIFIC HEALTH
CONCERNS & RISKS AMID
COVID-19 CRISIS

Takeaways – SCI Specific Health Concerns Amid COVID-19

- Persons with SCI are not known to be at a higher risk of contracting COVID-19
- If you have respiratory compromise, you may become sicker if you contract COVID-19
- There are additional precautions recommended for people with SCI
 - The proper use/disposal of PPE (for self and care giver)
 - Hand washing procedure
 - Wheelchair cleaning
- There are special considerations if you contract COVID-19
 - Respiratory equipment needed
 - Making special considerations to have a care provider/advocate to be in the hospital with you
 - Decisions regarding extreme measures

COVID-19 SCI Urology Guide

2020

know the facts

Although there is a lot to learn about COVID-19, it does not appear that urine contains significant amounts of the virus.

get extra supplies

Shipping times and in-store supplies are variable. Ensure you have at least 30 days extra supplies for your bladder management.



bladder botox

If you use botox injections for bladder management it may still be possible to receive your regular treatment. If you aren't able to get it, consider talking to your doctor about oral alternatives to temporarily help prevent bladder problem.

monitor your symptoms

Certain COVID-19 symptoms, like fever and fatigue overlap with Urinary Tract Infection (UTI) symptoms. It is important that you discuss your symptoms with your doctor. If you are concerned about a serious change in your health, go to your local emergency/ urgent care hospital to be assessed.



ask for help

Some people need frequent assistance from support workers for their bladder management. If you are concerned about the risk of this, or are unable to access your usual support workers, please discuss your concerns with your healthcare team.

go virtual

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GREAT RESOURCES

Since the pandemic there have been a lot of great resources created to help assist the SCI population stay safe and healthy including:

- Handwashing Guide
- Wheelchair and Assistive Technology Users: Precautions for COVID-19
- Navigation COVID-19 SCI Urology Guide



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COVID-19/CORONAVIRUS



EPISODE 5:

ISOLATION &
MENTAL WELLNESS
DURING COVID-19

Takeaways – Isolation and Mental Wellness

- Take the time for self care - in all its forms - physical and mental.
- Times of crisis are the perfect time to look at ourselves and our society and try to make improvements. Practicing mindfulness and compassion is a great option.
- These are challenging times for everyone, but for people with SCI especially. There are some aspects about our current situation that we have no control over. One area where we do have significant influence is the way we think about what's going on. Cognitive distortions are thinking traps can skew our perceptions and make us feel worse. CBT offers simple tools and techniques that can help us to question these “traps,” and think more wisely during these times of challenge.



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SLOWING DOWN

This is a time for us all to slow down and take the time to reflect. Our society is fast paced and now we have the opportunity to stop and take some much needed time for ourselves.

ONLINE RESOURCES

Weekly online mindfulness and yoga series through SCI&U



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EPIISODE 6:

SCI NUTRITION 101:
HEALTH & WELLNESS
DURING COVID-19



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EPIISODE 7:

SCI ADAPTED
EXERCISE
RESOURCES

Takeaways – SCI Nutrition and Adapted Exercise

- A healthy diet helps support the immune system, reduces inflammation, reduces stress, increases energy
- GET OUTSIDE!
 - we need our daily dose of vitamin D to support our immune system
 - studies shows that supplementing with vitamin D can reduce the rate of respiratory infections by more than 50%
- GET SLEEP!
 - Sleep is essential to overall health
 - Repairs & Restores our body
 - Decreased sleep causes increased inflammation
- Get moving - Any movement is better than no movement
- Exercise has biological, environmental, psychological and sociological benefits
- There is still a lot you can do to get exercise from home with no access to equipment
 - use stockings as resistance bands
 - soup cans for weights
 - Rolled towels as supports
- Many adaptive gyms are offering online training – Walk-it-Off

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BOOSTING THE IMMUNE SYSTEM

The information on the importance of nutrition and exercise for those living with an SCI is not new but it has given the SCI community a chance to reintroduce themselves to living a healthy lifestyle. Having a balanced diet and getting exercise is more relevant today, since the SCI population is vulnerable and maintaining a healthy immune system is the best defense against COVID-19.





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EPISODE 8:

SCI ADVOCACY
DURING COVID-19
AND BEYOND

Takeaways – SCI Advocacy during COVID-19 and Beyond

- If the system isn't providing what you need in terms of care, get involved in advocacy!
- The SCI community is getting louder and more organized as a result of the injustices the disability community has faced during the pandemic
- Many SCI organizations are challenging their local, state/provincial, and federal governments to take action
 - Support Important Provisions of the HEROES Act – United Spinal Association
<https://unitedspinal.org/advocacy-action/?vvsrsrc=%2fcampaigns%2f74337%2frespond>
 - Include-Me.ca <https://www.include-me.ca/include-me-covid-19/blog/2020/04/recommendations-government-canada-relating-covid-and-people>



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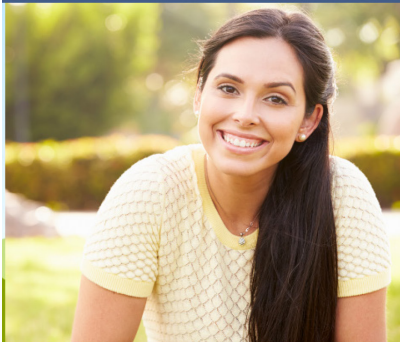
SPIRIT OF COOPERATION

Many SCI organizations across North America are banding together for the first time to share information and make the voice of the SCI community louder.

We are all in this together!



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EPISODE 3:

COVID-19 AND THE
LATINX COMMUNITY



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EPISODE 9:

SCI LATINX COMMUNITY AND
COVID-19: A CONTINUED
CONVERSATION

Takeaways – SCI Latinx Community

- Recognition of cultural diversity in regards to medical issues, treatment and advocacy initiatives
- Peer support for the SCI Latinx community is crucial for gaining trust
- There have been many organizations that are working to get assistance to those who are undocumented and afraid to seek help for fear of deportation – Access Living in Chicago, IL

Positive Learning

ONE PERSON CAN MAKE A DIFFERENCE

During this time of crisis it is the work of the local and frontline organizations that is so important to the Latinx community.

Robert Medel, Clinical Program Coordinator at the Santa Clara Health & Hospital System expressed during his presentation that he is willing to be of assistance to anyone who needs it, no matter where they live or their status. It's about making this community feel safe so they can get the help they need.



Summary of Positive Learnings

- Awakening of the SCI community – disability community not initially recognized during this pandemic
- Sheer nature of this series shows that North America has the ability to work together in improving the lives of people living with SCI
- SCI: Moving Forward has introduced us to new individuals from the SCI community, which is a direct result of the pandemic
- Sharing of new and existing resources
- The SCI community has taken virtual connections to new heights
 - VIP for SCI
 - Telemedicine
 - online learning
- Frequent and better access to all resources for the SCI community

Thank you to our Guests Speakers and Panelists

- Dr. Stuart Howe
- Bill Fertig
- Teren Clarke
- Jenn Wolff
- Joanne Smith
- Dr. Marc Ross
- Reveca Torres
- Ligia Zuniga
- Robert Medel
- Maya Altman
- Sara Munoz

- Vicky Perez
- Michelle Garcia
- Dr. Chester Ho
- Matthew Rodreick
- Kent Keyser
- Peter Athanasopoulos
- Rebecca Wheeler



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You can watch all 10 episodes and access COVID-19 resources for the SCI community on our SCI: Moving Forward website

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