



SCI: MOVING FORWARD

A RESPONSE TO COVID-19

Attendant Care in the time of COVID-19

MAY 19, 2020

PRESENTED BY:



North American
Spinal Cord Injury
— Consortium —

Agenda

1. Introduction to NASCIC & SCI: Moving Forward
2. Audience Poll
3. Providing Care to Persons Living with SCI (Teren Clarke)
4. Caregiver Advocacy and Options (Jenn Wolfe)
5. Q&A



North American
Spinal Cord Injury
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About NASCIC

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.

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/>

SCI: Moving Forward

Upcoming Webinar Topics

- Addressing specific concerns in the SCI Hispanic Community
- SCI-specific Health Concerns & Risks amid COVID-19 crisis
- Emergency and Disaster Planning – Supply Shortages
- Isolation and Mental Wellness during COVID-19
- SCI Nutrition 101
- Resiliency
- Self Advocacy and System Change
- Getting back to our new normal



Audience Poll

QUESTION 1:

HAVE YOU EXPERIENCED ISSUES WITH ATTENDANT CARE SINCE THE COVID-19 PANDEMIC HIT NORTH AMERICA?

QUESTION 2:

OF THESE WEBINAR TOPICS, WHAT DO YOU CONSIDER TO BE THE MOST IMPORTANT TO THE SCI COMMUNITY RIGHT NOW?

1. SCI-SPECIFIC HEALTH CONCERNS & RISKS AMID COVID-19 CRISIS
2. EMERGENCY AND DISASTER PLANNING – SUPPLY SHORTAGES
3. ISOLATION AND MENTAL WELLNESS DURING COVID-19
4. SCI NUTRITION 101
5. RESILIENCY
6. SELF ADVOCACY AND SYSTEM CHANGE
7. GETTING BACK TO OUR NEW NORMAL

Providing Care to Persons living with SCI



PRESENTED BY TERENCE CLARKE BN, MM (MGMT.)

FORMER CEO FOR SPINAL CORD INJURY ALBERTA (2005-2019)

PAST CHAIR FOR THE SCI CANADA EXECUTIVE DIRECTOR COUNCIL (2014-2016)

CURRENT MEMBER OF THE STRATEGIC CLINICAL NETWORK – NEURO, REHAB AND VISION

CURRENT MEMBER OF THE EXECUTIVE COMMITTEE FOR NASCIC

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COVID 19 Impact to Care Provided in the Home

- Persons with SCI who have lived successfully in the community face many new challenges as a result of the current pandemic
- Hired care providers may be fearful of contracting COVID 19 or of being a symptomatic carrier and passing it on to the recipient of their care services
- Hired care providers may suddenly require self isolation and therefore not show up
- Hired care providers may not fully understand how to use personal protective equipment (PPE) effectively or may experience a shortfall in equipment

What Can You Do to be Prepared?

- Assume that a disruption to your care providers routines will happen during this pandemic and that you may need to rely on persons with little to no prior experience.
- Create a backup plan – you are still in charge of your routines and care
- Create a list of your network of supports: family, friends, students, unemployed friends and identify 2-3 individuals who agree to provide back up care if required
- Create a list of organizations and individuals with expertise around SCI
- Familiarize yourself with training resources to help your back up care providers deliver safe services to you
- Document (post on your fridge) your care plan and personal care directives should you become ill and have difficulty communicating
- Document/post/fridge the contact list for key members of your family and health services team

Preparing Your Back Up Care Providers

- If you receive agency care, enquire about their contingency plans related to dealing with the pandemic but note that many agencies have been overwhelmed by the demand for in home support/care during the pandemic
- Discuss your care routines with your back up care providers
- Visit YouTube videos and other online training resources to assist the inexperienced care provider to visualize their role in taking direction from you and providing personal care and support in activities of daily living
- Familiarize yourself with COVID 19 resources specific to living with SCI (available from many govt and non-government agencies in your state or province)

Training Resources Available Online

Example: Spinal Cord Injury Alberta developed an online care provider training resource that can be a resource to you and your back up care providers

Background context for the program:

- More than 5000 individuals live with SCI in the province of Alberta (pop 4.41 million) located above Montana
- Life satisfaction is reported highest among community dwellers who utilize the self-managed care option of home care (health services program of the provincial govt.)
- Self Managed Care is available to persons with SCI whom live at home and wish to be more involved in their community through employment, education or volunteerism but face a barrier when receiving direct service from home care because they cannot control the scheduling of the care they require.

Online Training Context (continued)

- Home care workers provided through the direct service option work for Home Care or a private contracted agency and as such take their direction from the agency
- Self managed care option allows the person with SCI to use the home care allocated dollars/hours to hire their care providers giving them control over timing and tasks
- A challenge to the self-managed care program is the availability and experience of workers particularly in smaller communities and rural or remote areas of the province.
- Turn over of care providers created a training burden on the person with SCI
- Members of SCI Alberta requested that a training curriculum be made available online and which respected the philosophy of the independent living movement
- The curriculum development was guided by a committee of persons with lived experience including SCI, NMD, CP and MS.
- The curriculum was tested with in person training sessions led by the committee members and then an IT company with expertise in adult online learning tools was contracted to convert the material to an interactive and easy to use online training experience

What Courses are Available on the Online Campus? Which ones are Fundamental to Care Provision?

Skin Care and Pressure Ulcer Prevention

LGBT+ Diversity and Inclusion Training for Workplaces

Medical Terminology

Respect and Inclusion in the Workplace

Canadian Indigenous Culture Training - Truth and Reconciliation Edition

Infection Control and Prevention Basics for Healthcare Workplaces

Diversity and Inclusion Training for Volunteers

Bloodborne Pathogens

WHMIS 2015 (GHS)

Fire Safety

Feeding Eating Swallowing

General Safety

Peer Mentor Volunteer Training

Mental Health

Obtaining and Maintaining Employment

Personal Care

Respiratory Care

Basic Anatomy

Working as a Home Care Provider

Medication Assistance

Working Safely Alone

Volunteer Safety Orientation

Care Provider Training Courses

- Of the 22 online courses 12 are specific to the original Care Provider Training
- 4 of the courses are specific to the Alberta context for Care Provision
- 8 of the courses have generic application to persons who live with physical disability and want more control over the hiring and training of their care providers and may be of benefit to persons anywhere in North America (We apologize that translation beyond English is not available)

Care Provider Training (continued)

Courses with application beyond Alberta include:

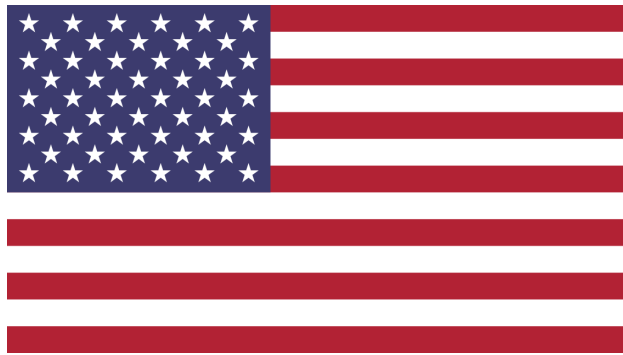
- Skin Care and Pressure Ulcer Prevention
- Feeding Eating and Swallowing
- General Safety
- Mental Health
- Personal Care
- Respiratory Care
- Basic Anatomy
- Medication assistance

To go straight to the course, please click on the following link.

<http://scialberta.online-compliance.com>

Summary

- Plan and document your contingency plans for care
- Train your back up care providers and be prepared to implement your contingency
- Familiarize your self with the emerging science specific to COVID 19 and spinal cord injury
- Review the webinars that have been developed with you in mind
- Stay home and stay healthy and follow the recommendations of the medical and scientific experts in your community!



Caregiver Advocacy and Options – In the Time of COVID-19

PRESENTED BY JENN WOLFF

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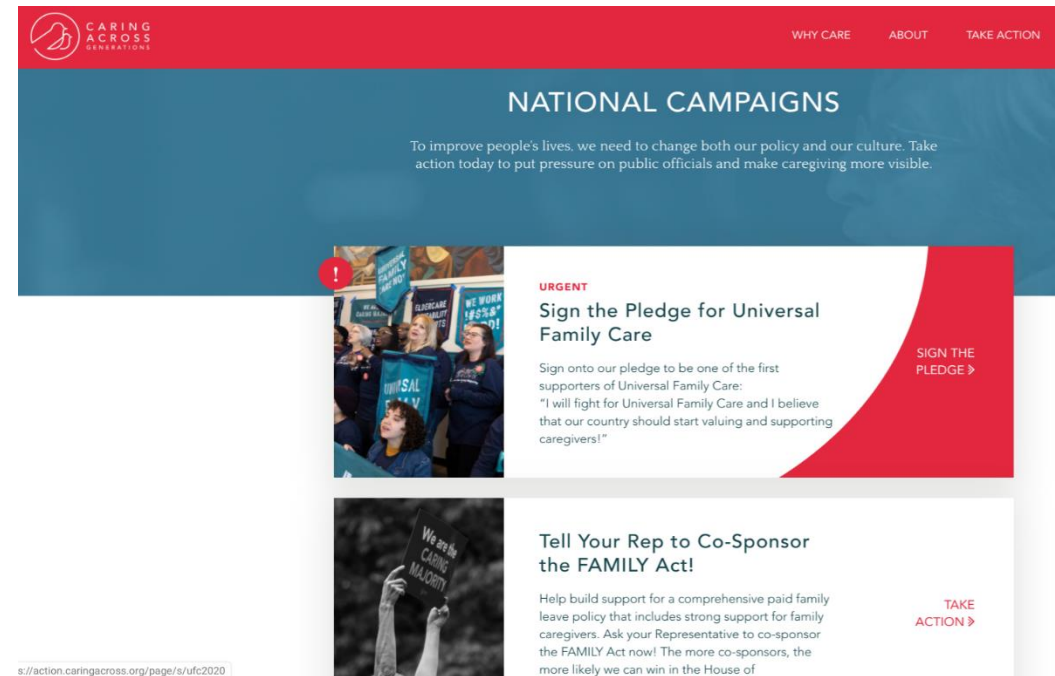
Advocacy for Improved Care Policies (US)

Caring Across Generations

www.caringacross.org

#CaringMajority

#Care4All



The screenshot shows the website's navigation bar with the logo and links for 'WHY CARE', 'ABOUT', and 'TAKE ACTION'. Below is a 'NATIONAL CAMPAIGNS' section with a mission statement: 'To improve people's lives, we need to change both our policy and our culture. Take action today to put pressure on public officials and make caregiving more visible.' Two campaign cards are visible: 'Sign the Pledge for Universal Family Care' (marked 'URGENT') and 'Tell Your Rep to Co-Sponsor the FAMILY Act!'. The first card includes a quote from a supporter and a 'SIGN THE PLEDGE >' button. The second card includes a 'TAKE ACTION >' button. A URL 's://action.caringacross.org/page/s/ufc2020' is visible at the bottom left of the page.

COVID-19 Advocacy (US)

Partnership for Inclusive Disaster Strategies

Disaster Hotline
(800) 626-4959
info@disasterstrategies.org

<http://www.disasterstrategies.org/>

Systems Advocacy Tools:

- ❖ 3/3/20 PIDS: **National Disability Rights Call To Action** [\[Link\]](#)
- ❖ 3/9/20 PIDS: **Letter to White House COVID-19 Task Force** [\[Link\]](#)
- ❖ 3/12/20 PIDS: **COVID-19 Recommendations** for Personal Assistance Services [\[English Link\]](#) [\[Spanish Link\]](#)
- ❖ 3/13/20 AAPD: **Template Letter** to send to Insurance Commissioner or others [\[Link\]](#)
- ❖ 3/16/20 DRCA: **Letter to Governor Newsom** [\[Link\]](#)
- ❖ 3/16/20 **CLS of Philadelphia**: **Letter to DHS - Steps to Protect Its Clients and the Community in the Face of COVID-19** [\[Link\]](#)
- ❖ 3/18/20 **NCD**: **Letter to Health and Human Services Office for Civil Rights** [\[Link\]](#)
- ❖ 3/18/20 **NAD**: **Letter to White House About Coronavirus Conferences** [\[Link\]](#)
- ❖ 3/20/20 **CCD**: **Letter to U.S. Dept of Health & Human Services & Office of Civil Rights RE: COVID-19 - Disabilities & Discrimination** [\[Link\]](#)



For Occupational Therapist and Students

TAP (Therapist Action Plan)

Facebook group to find OT volunteers
interested in emergency/disaster
management and filling caregiver positions

<https://www.facebook.com/groups/687248598715935/?ref=bookmarks>





**National Disability Covid-19
Healthcare Advocacy and Rapid
Response Support Hotline**

(800) 626-4959

info@disasterstrategies.org

WHO: This hotline is for anyone who identifies as a person with a disability or who has an access and functional need.

WHEN: 24 hours a day, 7 days a week

WHAT: Callers will be prompted to leave a message indicating their emergent need. Within 24 hours or less, they will be contacted by expert familiar with the strategies for meeting the immediate needs of people with disabilities in times of crisis and disaster.

ACCESS: Accessible and multilingual information is available; as is TTY and videophone for Deaf callers via email to: info@disasterstrategies.org for videophone.

Need healthcare advocacy or mutual aid, contact **Disability Underground** at **contact@disabilityunderground.org**

Those Needing Care During this Crisis

Join TAP Partners!

Facebook group for disability organizations/groups who have members needing a care attendant and to share resources and advocate for change.

https://www.facebook.com/groups/211677610128328/?ref=book_marks



Questions & Answers

Become a Member of NASCIC!

www.nasciconsortium.org/membership/

Principal member: A consumer-based organization may be a member of NASCIC. The organization must be a registered 501c3(USA), Registered Charity not-for-profit organization, or the equivalent in its jurisdiction that directly serves, represents, or advocates for the SCI community whether national, regional, or local.

Patron member: Any individual living with a spinal cord injury or directly representing a person living with a spinal cord injury, such as a caregiver or family member, with a main objective of representing themselves and not an organization.

Partner member: Any organization or individual with an interest or activities related to people living with SCI but do not meet the above membership categories.



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Today's Takeaways

1. If you are able, put together a contingency care plan now and don't wait until you are in crisis
2. If the system isn't providing what you need in terms of care, get involved in advocacy!