

March 2019

Winter Issue

PARATRACKS

Newsletter of Spinal Cord Injury (Manitoba) Inc.

CPA IS NOW SCI MANITOBA INC.

In This Issue:

***New SCI Manitoba
Website, Completely
Redesigned, pg. 3***



SERVICES TOOLS & RESOURCES NEWS COMMUNITY ABOUT MPF CONTACT



Also in this issue:

****Kristie Matheson Interview, pg. 12***

****Take Your Kid to Work Day, pg. 10***

****I Have Paraplegia, pg. 17***

****Investigation Report - Transit Plus, pg. 5***



ParaTracks is a publication of:

**Spinal Cord Injury
Manitoba Inc.**

825 Sherbrook Street
Winnipeg MB R3A 1M5

Tel: 204-786-4753

Fax: 204-786-1140

Toll-free: 1-800-720-4933

(within Manitoba only)

Email: info@scimanitoba.ca

Website: www.scimanitoba.ca

Supported by Manitoba
Paraplegia Foundation Inc.

ParaTracks is published three times per year. An online edition of ParaTracks is available on the SCI Manitoba Inc. website: www.scimanitoba.ca

Circulation: 950 copies
Estimated Readership: 2,000

Editor: Ron Burky
Layout: George Tataryn

Advertising Rates for
Photo-ready Copy are:

Full page: \$160

Half Page: \$87

Quarter Page: \$55

Business Card Size: \$33

Classified Ads are free to SCI Manitoba Members

Submissions, suggestions and comments are greatly appreciated—please email these to info@scimanitoba.ca or send by regular mail to SCI Manitoba at the address noted above.

Canada Post Publication
Agreement #40050723

Board of Directors

Art Braid *

Corrine Deegan *

Jeannette Gougeon

Lyall Hallick

Dan Joannis *

Norm Magnusson

Ron May

Audrey McIlraith *

Barbara Rapson

Leonard Steingarten—President *

Adam Terwin—Treasurer

Tim Toor

**spinal cord injury*

SCI Manitoba extends its sympathies to the families of the following loved ones who recently passed away:

Tina Niznowski

Ron Courchene

Dennis Stasziuk

Louise Hearn

Larry Kehler

Patricia Bonas

Krishna Ramnawaj

Donny Cunningham

WE NEED YOUR FEEDBACK

What would you like to see in future issues of ParaTracks ?

We try our best to publish articles and stories that are of interest to you, our members. To ensure we continue with this practice, we need your help. Without feedback from SCI Manitoba members, we can't always be sure that we're providing you with the information you require.

Please take a moment to provide us with your feedback. Was there an article that was of great interest to you? What did you like about this issue of ParaTracks? What didn't you like?

Please send your comments by email to Adrienne at info@scimanitoba.ca or give her a call at 204-786-4753 or 1-800-920-4933, ext. 222.

SCI Manitoba Inc. neither endorses nor guarantees any of the products or services advertised in ParaTracks. Readers are strongly urged to investigate the products and companies before purchase. Material printed in ParaTracks may not be reproduced without the written permission of SCI Manitoba Inc. The opinions expressed in ParaTracks are those of their authors and do not necessarily represent the views of SCI Manitoba.



CPA MANITOBA IS NOW SCI MANITOBA

Our name has changed from Canadian Paraplegic Association (Manitoba) Inc., better known as CPA Manitoba, to Spinal Cord Injury Manitoba Inc., or as we prefer, SCI Manitoba.

Please know that our services remain unchanged only our name has changed.

This change was needed to better reflect the people we serve. Our membership consists of more than 1,200 individuals living with spinal cord injuries in Manitoba, but the term “Paraplegic” in our former name only described half of our members. The other half have spinal cord injuries at the cervical level of the spine, and are therefore considered tetraplegic. Our new name, SCI Manitoba, now accurately reflects all people living with spinal cord injuries in our province. This name change is now aligned with our national office which changed its name to SCI Canada, and also consistent with most of the provincial divisions throughout the federation that have also changed their name.

We would like to welcome you to visit our website which has been updated and completely redesigned to be more responsive to all devices and platforms. So whether you visit it from your desktop, laptop, tablet or mobile phone, you will enjoy easy access to all of our news, resources and stories.

As always, we value your feedback so please get in touch with us at info@scimanitoba.ca and let us know your thoughts, and share with us any ideas about other features you would like to see added to the website in the future.

Please take a moment to update your bookmarks with our new address on the web.



Spinal Cord Injury Manitoba Inc.
Lésions Médullaires Manitoba Inc.
Formerly Canadian Paraplegic Association (Manitoba) Inc.

SERVICES TOOLS & RESOURCES NEWS COMMUNITY ABOUT MPF CONTACT



CPA is now Spinal Cord Injury Manitoba!

< 1 / 4 >

The professional services you know and trust – with a new name.

[Learn More](#)



Manitoba Ombudsman - Investigation Report City of Winnipeg's Handi-Transit Service*

by Bernie Gaudet

In January of 2019, the Manitoba Ombudsman released their report on Handi-Transit (*now known as Transit Plus) in response to a 42-page complaint from the Independent Living Resource Centre (ILRC). The gist of the complaint is that Handi-Transit has not met its commitment to provide universal access to the public transportation network that is reasonably equivalent to the fixed-route system. Issues include unaccountability on the part of Handi-Transit, lack of engagement with consumers about service needs and service standards.

The Office of the Manitoba Ombudsman assigned a team to investigate the specific complaints brought forward and to undertake research in several other jurisdictions in North America to see how the City of Winnipeg's Handi-Transit compares to these. The Manitoba Ombudsman Report resulted in 19 recommendations brought forward to the City of Winnipeg Handi-Transit to improve overall services. Handi-Transit responded to each of these recommendations as part of the report.

According to Josie Fernandez, Manager of Client Services with Handi-Transit, "This was a good process for looking at and reviewing our entire operation." Ms. Fernandez added that an individual was hired at Handi-Transit to address the specific recommendations made in the report and to examine ways to implement changes in the system. The positive response from Handi-Transit to the recommendations brought forward by the Ombudsman is encouraging, however, it should be recognized that ultimately, for any changes that require additional funding, it will be up to Winnipeg City Council to approve the allocation of dollars and cents towards improving service.

Marie-Lynn Hamilton, Individual Advocacy Consultant from ILRC, does not share such a favourable view of the Ombudsman's Report. For example, an over-riding concern by the complainants that was not addressed in this report is that City of Winnipeg Transit employees are, in some cases, making determinations of consumers' eligibility based on in-house criteria not real world conditions. Ms. Hamilton is disappointed that the decision-making ability of City of Winnipeg staff to override medical evidence provided when applying for Handi-Transit is not discussed in the eligibility section of the report. The cumbersome and costly assessment and re-assessment process represents a barrier for people applying for Handi-Transit, as well as a financial strain on the City of Winnipeg, itself.

Below are the 19 recommendations (Manitoba Ombudsman, 2019) taken from the report followed by the responses from the City of Winnipeg to each of them. Details on how to access the complete report are found at the end of this article.

1. Recommendation: We recommend that the City of Winnipeg establish revised Handi-Transit eligibility criteria that considers whether a person with a disability can use the fixed-route transit system.

Response from the City of Winnipeg: The city advised that a review of the eligibility criteria would be a long-term project that would require appropriate funding and approval from Council and Manitoba Ombudsman should not be pursued until the Transit Service Master Plan is released in August 2019. The Transit Service Master Plan will outline the expansion and improvement of the fixed-route and specialized transit service and provide a long-range plan of five-year intervals. The review for the master plan will include an evaluation of the Handi-Transit service model and will outline recommendations for needed improvements and changes at Winnipeg Transit. By waiting for the completion of the plan, the city will create a more cohesive plan and not duplicate work.

2. Recommendation: We recommend that Handi-Transit ensure that the inactive account policy be included in any materials available to users of the service and the public in general, such as on the website or in printed information.

Response from the City of Winnipeg: To increase awareness, the city proposes to include the information about the 18 month inactive account policy in the initial acceptance letter, the Handi-Transit website, the proposed user guide, and have it as one of the primary recorded messages that play while registrants are on-hold.

3. Recommendation: We recommend that Handi-Transit should, in its public materials, provide clear reasoning to help clients and organizations better understand why and how Handi-Transit re-assesses clients.

Response from the City of Winnipeg: Handi-Transit agrees and currently provides information, in various methods, to individuals as to why they need to attend an assessment. Handi-Transit is committed to enhancing information to registrants and commits to upgrade information on the website and all written material including the proposed user guide.

4. Recommendation: Handi-Transit should consider an alternative member instead of the manager on the



appeal hearing panel. We suggest this individual be someone outside of Handi-Transit's internal eligibility decision-making process, and that Handi-Transit should consider an individual from the disability community.

Response from the City of Winnipeg: The city commented that it is critical to have someone on the appeal panel that understands the policies and processes of the service and the manager is best suited to provide that internal knowledge to the panel. However, it is not necessary for the manager to be a decision maker on the appeal panel. As such, the city proposes to have the manager of client services remain in a consultative capacity to the appeal hearing body but proposes to replace the manager. The city advised it is considering that a member of the Human Rights Committee of Council, who is a member of the disability community, sit as a voting member of the Handi-Transit appeal panel.

5. Recommendation: We recommend Handi-Transit provide a dedicated email address or web portal to receive complaints.

Response from the City of Winnipeg: Handi-Transit agrees and is in the process of creating an email address that will allow registrants/public to email in their complaints directly to the contact centre. The email address would be established with the following parameters: a response will be provided within 72 hours and a template is to be completed by the complainant to ensure that all the necessary information to investigate is included (similar to those used by 311).

6. Recommendation: We recommend that Handi-Transit evaluate whether to devise procedures to more effectively inform complainants directly affected by outcomes of complaint investigations, expanding on Handi-Transit's current approach to situations it deems critical.

Response from the City of Winnipeg: Handi-Transit agrees and will outline the complaint process on all its written materials on a go-forward basis and will include information on all methods of filing a complaint.

7. Recommendation: We recommend that Handi-Transit ensure that information about its complaint process – including how to make a complaint using phone, email, letter, elected representative – is clear and widely communicated. Public and internal materials, CSR and driver training manuals, should all set out the complaint process clearly.

Response from the City of Winnipeg: Handi-Transit agrees and will outline the complaint process on all its written materials on a go-forward basis and will include information on all methods of filing a complaint.

8. Recommendation: As the new scheduling system is implemented, we recommend that Handi-Transit review its functionality and impact to ensure it reflects reasonable equivalent service to the fixed-route transit system.

Response from the City of Winnipeg: Handi-Transit concurs and will be evaluating its new scheduling system after implementation to determine its impact on the level of unscheduled trips and will evaluate the need to use a priority system.

9. Recommendation: The list of criteria for a no show charge that appears in all public materials should be updated and refined to better reflect Handi-Transit policy.

Response from the City of Winnipeg: Handi-Transit agrees and will outline the appeal policy related to no show assessed charges on all its written materials on a go-forward basis and will include the information in the new user guide and all the no show letters sent out to registrants

10. Recommendation: We recommend that Handi-Transit revise the wording of its no show notification letters so that it does not assume the registrant contravened ridership policies. The letter should instead advise the registrant that a situation triggered the notification letter, and that a related no show charge may stand in the absence of information to the contrary.

Response from the City of Winnipeg: Handi-Transit concurs and will add text to its no show letter to state the following: A situation occurred with your ride which triggered this notification letter. Based on the current information, a no show charge may be applied. Please contact us to review what occurred and provide any additional information that may impact the no show charge decision.

11. Recommendation: Before deducting a no show charge from a fare payment from account (FPA), Handi-Transit should notify the FPA registrant of the no show charge by letter so that they have a reasonable time frame to appeal and, if necessary, add funds to their account before the charge is processed.

Response from the City of Winnipeg: Handi-Transit agrees and will change its system so that FPA registrants are provided with a no show letter upon each occurrence. When a charge is triggered, Handi Transit will change the process to allow for 14 calendar days for an appeal of the charge. If the registrant does not contact Handi-Transit requesting an appeal within the 14 calendar days, the cost of the no show will be charged and deducted from their account.

12. Recommendation: We recommend that Handi-Transit revisit its approach to no show charges to determine whether these charges are an efficient and effective way to achieve registrant compliance with ride protocols, especially in light of the new scheduling software.

Response from the City of Winnipeg: Handi-Transit is willing to revisit the issue of no show charges and conduct a national jurisdictional review

13. Recommendation: Since the current driver manual does not contain detailed language prohibiting sexual



harassment, we recommend the detailed language regarding HandiTransit's sexual harassment policy from the 2012 manual be immediately restored to current and future versions of the driver manual.

Response from the City of Winnipeg: Handi-Transit agrees and updated information on the sexual harassment policy will be included in the next driver manual as of August 2018.

14. Recommendation: We recommend that verifying the proper functioning of the GPS/AVL equipment should be added to the pre-trip inspection checklist.

Response from the City of Winnipeg: Handi-Transit agrees and a daily check of the GPS/AVL equipment will be added to the pre-trip inspection checklist immediately and be included in the next driver manual of August 2018, as noted. Additionally, when the RouteMatch software is operational, it will require that drivers complete a pre-trip inspection checklist (including verifying the GPS/AVL equipment) before they may receive their schedule for the day.

15. Recommendation: We recommend that Handi-Transit enforce the contract requirement that operators wear safety vests.

Response from the City of Winnipeg: Handi-Transit agrees. All Handi-Transit contractors have been notified that all drivers will be required to wear safety vests. All contractors will have the same vests and inspections will be done to ensure compliance. As of July 1, 2018, failure to meet this requirement will result in a service recovery fee. The driver manual has already been changed to reflect that the wearing of safety vests is mandatory for drivers and not just recommended.

16. Recommendation: Given the obvious safety concerns about cell phone use while driving and the law against it, we recommend that Handi-Transit enforce the rules about cell phone use in vehicles and while driving, and clarify the direction for drivers.

Response from the City of Winnipeg: Handi-Transit agrees and all contractors have been advised that cell phone use by drivers will be governed by the same rules that are part of the new distracted driving laws. They will be advised that any complaints received about cell phone use by drivers will result in an immediate investigation and if found to be a violation of the law a service recovery fee will be issued. The service recovery fee has increased to \$100 for a first occurrence and a second occurrence will result in a suspension. Inspectors will perform random spot checks to ensure the standard is being followed.

17. Recommendation: We recommend that Handi-Transit inform registrants about acceptable fare payment methods and procedures for non-payment disputes so that they are aware of applicable policy in the event of driver error.

Response from the City of Winnipeg: Handi-Transit agrees. It will provide additional information related to fare payment methods and the fare payment dispute procedures in all its written materials on a go-forward basis and will include the information in the new user guide. Handi-Transit will include the information related to the fare policy (nonpayment of fares) in the original eligibility letter to registrants.

18. Recommendation: We recommend Handi-Transit abolish the 500 metre rule and provide service either within established city limits or within 1000 metres of conventional bus stops.

Response from the City of Winnipeg: Handi-Transit is currently reviewing this policy. On May 1, 2018, the Standing Policy Committee on Infrastructure Renewal and Public Works (IRPW) directed Winnipeg Transit to report back to the committee on the estimated costs and the estimated increase in revenue to extend Handi-Transit service to all areas of Winnipeg. The report from Transit is due at the Standing Policy Committee on IRPW in September 2018.

19. Recommendation: We recommend that Handi-Transit produce a comprehensive user guide.

Response from the City of Winnipeg: Handi-Transit agrees and will start researching and compiling information to produce a comprehensive user guide for registrants.

This report represents a significant move towards improving Handi-Transit/Transit Plus for all stakeholders simply by acknowledging that problems do exist. Will it ever be perfect? No, but the intention to make it better is there on paper from Transit Plus. Better communication with an improved user guide could explain to users why certain decisions are made, but a deeper examination of how funds are allocated by Handi-Transit may also represent a cost-effective way of improving the service. The time and cost involved in assessments and re-assessments (Recommendation #3) of applicants by Handi-Transit when medical evidence is already provided through the application process could represent one such cost-saving measure and avoid duplication of services.

We would like to hear from our members about their experiences with Handi-Transit.

Send your concerns to: Bernard Gaudet at bgaudet@scimanitoba.ca or mail them to Bernie's attention, c/o SCI Manitoba office.

Reference: Manitoba Ombudsman. Investigation Report on City of Winnipeg's Handi-Transit Service. January 2019

Copies of the Report are available and in alternate formats. Contact the Manitoba Ombudsman at 750-500 Portage Ave. Winnipeg MB, R3C 3X1, Telephone: 204.982.9130, Toll Free Telephone: 1.800.665.0531 or Email: ombudsman@ombudsman.mb.ca



Understanding Some of the Challenges Families with SCI Experience

By Maria Cabas

Based on the Family System Theory, family is a system in which every member is interconnected. Imagine a mobile where all the parts hang in balance – this concept of the family as a mobile was developed first by Virginia Satyr with the visual understanding that when one piece moved, the rest of the whole mobile moved. That is similar with what is going on in the family when someone was diagnosed with spinal cord injury. This is a traumatic major life changing event which affects the person with SCI and their family, bringing significant changes within the family. It is important for every family member to have an understanding of what has happened, about the SCI, and to be informed about the changes they may expect to family life. There will be a period of great adjustment post-injury for the person who has SCI and their family members. There is no "typical" family following SCI. Each situation is unique, and each family will eventually create a system that works best for them.

In this article, we will explore some of the challenges with which the family has to contend. There are some main themes that always come up in this situation. Issues include: accommodation, financial, equipment and supply, the importance of educating family members about SCI, health care, care giving, transport, navigating the system, relationship issues, sexuality and accessibility. We will not discuss all of them, but we can start with a few today.

Families play a vital role in supporting family members who have SCI but, in general, they have little prior knowledge of SCI. They need concrete information about the loved one with the SCI including diagnosis, prognosis, treatment, rehabilitation and adaptation to the new lifestyle. By learning what to expect post-injury, the family members need to develop the capacity and ability to support and assess the loved one with SCI in recovery. They have to be included in discharge planning meetings to know what to expect when their loved one leaves the hospital. All of that information could be overwhelming for the family members and for the person with SCI.

Between 45 to 50% of people with SCI need personal assistance with their daily activities. The person with SCI has lots of specific needs in daily care like getting in and out of bed, managing bowel and bladder issues, bathing, and daily skin check for pressure sore prevention and dressing. The lower the level of injury, the less assistance is needed. According to Statistics Canada in

2012, the number of family members responsible for care of loved ones with a long term health condition, represent one in four (28%) or an estimated 8.1 million. If your spouse or partner is your primary caregiver at the initial period, it is not recommended for long-term, because the role of the partner/caregiver can be blurred, which will create problems in couples' intimate relationship. If at all possible, it is best to have the Community Home Care Provider or a paid Personal Care Attendant (PCA) provide the majority of long-term care while a loved one provides occasional care. It is also important to maintain a healthy relationship with your spouse by still sharing as much life responsibility as possible and learning new life skills to help the relationship in the long run. It is important to help children learn that there are changes in the lifestyle of the family and they need to be prepared to pitch in if necessary. Focussing on your strengths and abilities post-injury can also help your family members become a team with lots of strengths and abilities. Communication is the key.

Financial stress/security could be huge issues after spinal cord injury for family; from meeting everyday living expenses like utilities, medical expenses, equipment and supplies not covered by other systems, transport and personal care, to achieving access to financial resources available. Sometimes financial issues become employment issues, too. Returning to work if possible sometimes takes a long time based on recovery. Some people were able to return to previous employment, either full time or part time but it requires a lot more effort and additional resources. Ongoing medical appointments and additional care needs are required. It is hard to find a flexible employer that understands and accommodates people with SCI and their special needs. Finding appropriate work after a SCI can be a challenge, in which sometimes more education and retraining is involved. Some people set up their own business. It will be even more difficult if the person with SCI didn't work prior to the injury. Changing policies of third party payers like Manitoba Public Insurance, Worker Compensation, Victim Compensation and government (Employment Income Assistance, Canada Pension) can also affect the financial situation. Sometimes the bureaucracy makes it hard to access the financial funds. Retraining and access to education could also be beneficial in finding a job after SCI. There is a strong association of employment and educa-



tion with quality of life after SCI which includes social inclusion, connecting with people and participation in the community.

After the hospital, the person with SCI sometimes returns home after the house has been modified to meet their needs (which can be very costly and may not be feasible in rental), and sometimes they go to alternative transitional accommodation. The family of the person with SCI is also affected by the shortage of housing availability and accessibility to rent or buy and modify, or move into public housing, which forces people to move away from their social network and support. Others found that the instability of renting meant that they were required to find alternative accommodation on short notice when leases were not renewed. Because of lack of accessibility they may not be able to visit family and friends or join them in social situations or accessing events at school for their children or sports grounds or other public places that are not accessible. Some people had to give up their accommodations when they were in hospital. Independent living is always encouraged and supported as opposed to living in a nursing home. The benefits include better health outcomes, fewer hospitalizations and easier reintegration in the community and increased quality of life and maximized life choices.

Transportation could be huge issues for somebody with SCI and their family. Purchasing and modifying a vehicle is very expensive especially if you do not have a third party payer. The transportation needs depend on the level of SCI. Travel may be required for medical appointments, work, social activities, maintaining family relationships, shopping, school, vacations and others. For somebody who uses a wheelchair for mobility, specific modification has to take place in a vehicle depending if they are able to drive or they are the passenger. Many people with SCI are trapped, relying on their family for transport which means sometimes the family has to miss work or school. There is a lot of reliance placed on family and sometimes friends to provide care and support for the person with SCI. Public transportation is not necessarily reliable all of the time or safe. Logistics could be a huge accessibility barrier. The ability to move around in the community gives people independence and reduces feeling of isolation. Public transportation needs to improve. The wheelchair taxis are not necessarily reliable, safe, flexible and affordable for everybody.

These issues discussed above are just a few of the multiple problems families with SCI experience. Life will never be the same in a family, but it can still be enjoyable even if it is different. It takes a long time to deal with the changes and feelings as a result of SCI but families are resilient. Each family member may need to learn to communicate well, have lots of pa-

tiency, work together and support each other better. Being honest with your feelings and sharing with each other helps the family members to cope and grieve with the changes. Sometimes the whole SCI reality feels like a bad dream. Everybody copes differently with the effects of SCI. Common feelings the family members experience are: shock, anger, fear, anxiety, confusion and out of control. Those feelings vary during the adjustment to SCI and they are normal. Getting back into a new daily routine will help families move on slowly and work as a team. Eat healthy, sleep enough, exercise, meditate, and take time for yourself. Those are some healthy adaptations and coping elements that can relieve your stress. Life will get better, and sometimes it brings family members closer by discovering strengths and abilities they did not know they had before the SCI injury. Don't be afraid to ask for help when you need it. Life goes on.

References

- Healthy Living: Relationships An article from the Pushin' On, Vol 19[1], 2001. University of Alabama at Birmingham www.spinalcord.uab.edu/show.asp?durki=36069
- Maire Sinha, "Portrait of Caregivers, 2012," Spotlight on Canadians: Results from the General Social Survey, Statistics Canada catalogue no. 89-652-X (September 2013).
- Nora Spinks and Nathan Battams, Families and Work in Canada (October 2015).
- Shona Bates, Rosemary Kayess, Karen R. Fisher (2013), Research into Maximising Life Choices of People with a Spinal Cord Injury, for Spinal Cord Injuries Australia, Social Policy Research Centre Report 01/13, Sydney.
- Statistic Canada 2012
- <https://www.myshepherdconnection.org/sci/coping-adjustment/role-changes>
- <https://www.spinalcord.com/family-friends-of-brain-spinal-cord-injury-patients>
- https://scia.org.au/wp-content/uploads/2017/08/SCIA-maximising_life_choices_Jan_2013v2.pdf

Wolsey Woodworking & Construction



Wheelchair Ramps designed and built to code
Wheel-in showers Accessible bathrooms
Doorways widened Home Modifications
MPL WCB, VAC and Family Services friendly

667-5787 Mike Hladky (SMR, U of M)



***Innovative Solutions
For Your
Homecare Needs***

www.nhcp.com

SERVICE • SALES • INSTALLATION • RENTALS

- Aids for daily living
- Bath Safety Equipment
- Compression stockings
- Incontinence products
- Mastectomy & wound care
- Walkers, canes & crutches
- Lifts Chairs & beds
- Scooters & wheelchairs
- Specialized seating systems
- Lowered floor van conversions
- Stair, van and porch lifts/ramps
- Overhead tracking systems
- Plus much more

9-1341 Henderson Hwy.

925-4599

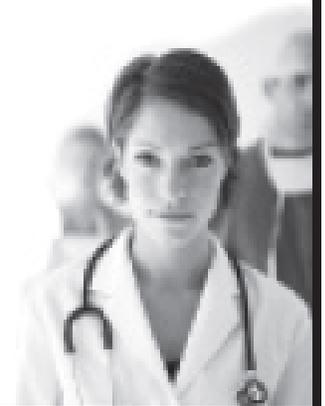
67 Goulet St.

235-0914

865 Bradford St.

786-6786

Direct billing DVA, Blue Cross, EIA, MPI, NIHB & WCB



Take Your Kid to Work Day 2018

By Serena White

Hello! My name is Serena and I am a Grade 9 student at Elmwood High School. On November 14, 2018 I went to the SCI Manitoba office for Take Your Kid to Work Day with my step-mom, Melanie White, who is a Vocational Counsellor.

I did a lot while I was there, but the first thing I did was read some of the things that someone with a spinal cord injury would read (Life Interrupted: For Youth with Spinal Cord Injury and Their Families) in order to get a sense of everything that they have to deal with. I thought the book was well put together and had a lot of information that would be useful for someone who has been injured and also be very helpful for their friends and family.

After I finished my reading I did the WOWI (World of Work Inventory) assessment and actually thought it was kind of fun. I later met with Laurence (Haïen), Senior Rehabilitation Counsellor for Vocational Services, and he told me my results. I thought they were very interesting and helped me solidify my ideas for future jobs. It said that I should try to find a job where I can be creative and use my imagination; it gave me a lot of recommendations for future careers

including Architectural Drafter and Marine Architect, which made me happy because I have been thinking a lot over the last year or so about becoming an Architect.

I joined the staff for their United Way Campaign lunch and found out that they provide funding to a lot of non-profit agencies, SCI Manitoba being one of them. In the afternoon I did a mock interview with Artem (Dolia), Rehabilitation Assistant. I was pretty nervous but learned a lot about the intake process and how the information is used to create a rehabilitation plan.

I had a good day at SCI Manitoba but decided that I don't want to work in social services because I am extremely introverted and am not very comfortable talking to people (plus my WOWI results said that I would be more comfortable in a work environment where most of my time is spent working in solitude and that I prefer to work with data and things, not people). I would like to thank everyone I met at SCI Manitoba for being really nice and allowing me to visit your workplace for the day.



How SCI Affected Me/Our Family

Mid-August at the cottage, Gerald, the eldest of our four children, yelled “Mom!! Dad fell!” From his posture, I immediately recognized paralysis. He was in severe pain. I almost had an “out of body” experience. So I literally closed my eyes for a second and mentally changed into my nursing uniform. I was no longer a mom, or that guy’s wife. I assigned jobs to the kids: “Gerald, go next door and ask Michael or Penny to call an ambulance – quickly. Girls, bring me the coats from the front closet, etc.”

It was raining. The wait for the ambulance seemed to go on forever. Finally they arrived and used a scissor stretcher to get Lloyd into the vehicle. Our neighbour Michael took the kids and said he would follow us to the hospital. I sat in the ambulance, feeling this was an emergency and I could not understand why the paramedic did not use his light and siren. Instead we drove slowly behind a young person riding a bike and listening to something through ear buds. My detailed recall of these moments feels crystal clear today – nearly 30 years after the fact. We got to the small town hospital and another two hours later the MD told me there were two high lumbar burst compression fractures. The pain in his knees was awful. During transport that pain suddenly disappeared. That felt ominous.

Lloyd was moved to a trauma centre and underwent a long surgery that involved bone grafting and hardware. The shock I felt started to lift around day five, when he graduated from ICU for a severe and persistent respiratory complication. The children, thank goodness, stayed with some fabulous friends who, as parents themselves, were excellent at responding to the children’s questions.

September arrived. I had to get the children, ages 3 to 10, back to Manitoba for school. Again, my good fortune provided a special person to make the four day drive with us. Then she stayed with me for ten days so I could visit Lloyd in the Rehab. He’d been flown home in a plane that took a stretcher. The physiatrist at the Trauma Centre had shown me some exercises and advised us to do them twice a day. Physiotherapy was done once a day and they did not work on weekends.

The next phase went on until mid-December when Lloyd passed his trial weekend at home. The gave me dosing instructions for Heparin, and then, as if I had time to waste, would not give me an extra syringe and needle in case I happened to contaminate something. The demands of taking care of the kids, the house, and

doing exercises with Lloyd once a day (twice on weekends), was wearing me down.

The immediate post-SCI period was stressful and overwhelming. But the long term effect was stressful too. I did not work until about two years after Lloyd had his injury. I was afraid of him walking in his size 13 feet up and down the stairs. There were money concerns that would have been much worse without his short and long term disability insurance. The ambulance, both air and ground, wanted to bill me because insurance initially denied coverage. Fighting the insurance company pushed me from tired to exhausted. Though Lloyd was really good at using a walker and eventually canes, he did not want to give up the wheelchair. He was also resistant to talking about the injury and its effects with me or anyone else – even his best friend. Decades later, it is still my feeling that he never did adjust emotionally to his SCI. I felt pushed away, and very hurt, because evidently I was not trustworthy with respect to his emotions.

Now with more time and distance, I feel regret that Lloyd did not reconcile his emotions and grief. This would probably have given way for a happier life while we raised our children. The one aspect Lloyd was able to comment on was his in-hospital Rehab. experience. I had never seen him cry before (nor after), but his lip trembled and his eyes got glassy when he said he felt that his dignity was taken from him, bits at a time, during hospitalization.

It took Lloyd forever to regain his colour and he never regained his energy or the positivity he used to have for life. Finally, I believe the adverse emotional reaction he had against health care workers and hospitals actually contributed to his early death. He chose not to seek a medical opinion when he experienced discomfort. Instead he died in an ER waiting room in sudden severe pain. The coroner found a huge tear in the descending aorta extending to both iliac arteries.

I remember walking out of that ER – with my four adult children, and one of their friends. This was another shock but this shock was not as severe nor as long-lasting as the one described above. It seems like I’ve lost the same husband twice. My youngest child says she can’t comment on how SCI affected her because she can’t remember what it was like pre-SCI. The older children have a hard time remembering pre-SCI too.

Does SCI impact the family? You be the judge. No two people with SCI are the same; therefore, all experiences for families are unique.



On Target

by Laurence Haien

In the interview that follows, Kristie Matheson talks about her educational program at Red River College, her subsequent search for employment, and the things she has learned along the way.

Could you tell SCI Manitoba readers a little about yourself?

I was born and raised in Winnipeg. I'm twenty-seven years old and currently reside with my dad. I am looking forward to living independently in the near future. I recently completed the Business Administration Diploma at Red River College, and I recently began working as a human resource assistant. I'm an avid reader and enjoy reading young adult, adult science fiction and fantasy. I'm a big fan of Marvel and enjoy playing video games. I like spending time at the lake, going out with friends and family, and cuddling time with the family dog, Kumah, a twelve-year-old husky, shepherd mix.

What is your level of spinal cord injury and how does it affect you?

I acquired a C-01, 02 incomplete spinal cord injury which affects my phrenic nerve, resulting in no use of my diaphragm. This means that I am susceptible to chronic lung infections. I had a tracheostomy from six-weeks of age until I was sixteen-years-old. My lung strength increased at that time, enabling the removal of the tracheostomy. I might require a tracheostomy as I age because my lung strength will diminish. Additionally, I experience right-sided weakness; but I'm independent with respect to mobility and the activities of daily living.

Tell me how you came to choose the Business Administration Diploma Program at Red River College?

Well, my educational path has not been straight forward. Originally, I was enrolled in the Disability and Community Support Diploma Program at Red River College but came to realize the program did not focus on what I wanted to do. I was always interested in advocating for the employment of people with disabilities. The Disability and Community Support Program focused on personal care and support work.

Why did you choose the human resource stream?

Initially, I was going to take the management stream in Business Administration but by the time I had to select my major, the management stream had been eliminated. Additionally, I spoke with other students who had selected the human resource stream and decided the fit was right for me. Also, I don't like math and marketing is not my thing so this eliminated options.

Did you experience any challenges as a student?

What supports did you access?

I began the Business Administration Program in 2014 and accessed the supports available through Counselling and Accessibility Services, such as, exam accommodation and counselling, which I used as necessary. Then in March, 2015 I was admitted to hospital for two weeks with pneumonia followed by a period of recuperation at home. So, I had to take time off from school.

When I returned to school, I decreased my course load. Emotionally, this affected me because I saw friends and classmates graduating before me. However, a positive outcome was that 11 other classmates and I competed in the Business Administration Entrepreneurship Tradeshow for the 2017/18 academic year and won. We had to create a business plan. Our business plan was called Men's Cave and provided grooming services for men, including hair, nails and skin.

An additional bonus to decreasing my course load and deferring my program completion was that I lived in campus housing and worked as a Resident Assistant during the 2017/18 academic year which enabled me to live independently and to enhance my skills.

Looking back at your post-secondary educational and considering what you know now, is there anything you would have done differently?

I would have maintained a reduced course load throughout the program. Having a reduced course load





improved my mental and physical health and enhanced my grade point average. Sometimes following the advice of the people around you is not the best option for you.

I would encourage people to reach out and ask for assistance, such as, exam accommodation, tutoring, or to network with classmates and instructors. Friendships may develop. This requires a shift in thinking. This has never been an issue for me, but I've seen others suffer unnecessarily because of their reluctance to reach out and ask for help.

Additionally, I think it's important to make time for yourself and to pursue activities that are of interest to you. Being in school does not mean you have to be a student 24/7. I sat on the Student Association Board and represented students with disabilities. A counsellor from the Counselling and Accessibility Support Centre spoke with me about this opportunity and I was friends with the Vice President External who wanted me to sit on the Board. My involvement with the Board provided me with an opportunity to do advocacy, to work with a wonderful group of people, to make personal and professional connections, and to benefit the school. It also gave me insight into school and administrative politics.

Could you provide an overview of your job search?

My job search has been challenging, not because I have a disability. There have been times when I suspected I was not offered a job because of my disability but, I feel that some people are inclined to always think they didn't get the job because they have a disability. I had the education and some experience but other applicants may have had more education or experience. I've done a lot of work and self-reflection regarding this over the years.

My preferred method of job searching was using job boards and corporate websites. I completed my course work in August 2018 and was putting in an average of 10 applications weekly. I experienced highs and lows during my job search. Rejection is part of the process. To combat this, I maintained my leisure activities which helped me stay connected to others and provided me with routine and structure. I signed up for a dance class. I went out for coffee with friends and just hung out. It's easy to get into a rut; it's important to avoid this.

I got my current position after I reached out to a temp agency. I think this is an untapped resource for many people. They'll match you with a job based on your education, skills and experience while also accommodating your needs. Securing a job is not easy. I did not secure my job until the end of November 2018.

Also, I think some people assume when they complete school and get a job that they've completed their education. You never stop learning, whether on-the-job or otherwise. I'm going to take the national Chartered

Professionals in Human Resources examination in June 2019; and my professional development will continue throughout my career.

Tell me about your new position?

I'm a human resource assistant. My main role is to perform data entry for new hires, do reference checks, and help with various administrative tasks.

I've made great connections with co-workers and other members of the human resources department. These people will help me enhance my skills and knowledge in the human resource field while also giving me hands-on experience.

Is there anything else you would like to share regarding school or work?

In terms of advice, I would encourage people not to be afraid to make a name for themselves. This has been a shift in my attitude since starting my program at Red River College. I have a sense of pride and accomplishment in saying that I sat on a Board, was the co-leader of my entrepreneurship group, actively participated in class and acted as the Vice-President of the Human Resource Club at Red River College. Soon, I will also be able to call myself a candidate for the Chartered Professionals in Human Resources. I believe my accomplishments have helped others see what I can do.

Thank-you, Kristie, for sharing your story with the ParaTracks readership.

**Brandon - Wheelchair
Multisport Event
April 27, 2019**



Brandon Wheelchair Sports and Leisure are hosting a wheelchair multisport event in Brandon on April 27, 2019 .

<http://brandonwheelchairsports.ca/>



'Take Your MLA to Work Day' 2018

By Melanie White

October is Disability Employment Awareness Month in Manitoba. The Manitoba Supported Employment Network (MSEN) is a non-profit organization/coalition committed to promoting and strengthening employment activities. MSEN embraces the idea that people with disabilities should have the same opportunities to pursue employment in the general workforce as any other citizen. 'Take Your MLA to Work Day' presents an opportunity to engage with Manitoba MLA's (Members of the Legislative Assembly) in a positive way that promotes inclusive hiring practices and highlights the outstanding contributions to the workforce made by Manitobans with disabilities.

On October 26, 2018 Darlene Cooper (Director of Rehabilitation Services) and I (Rehabilitation Counsellor-Vocational Services) visited the Spinal Cord Research Centre. There we met with Dr. Kristine Cowley (Assistant Professor, Physiology and Pathophysiology at University of Manitoba) and Flor Marcelino (MLA for Logan). Kristine provided a tour of the Spinal Cord Research Centre and invited us to her research lab, where she conducts clinical research designed to help develop therapeutic interventions that can increase functional capacity and decrease the risk of developing sedentary-related secondary consequences of SCI (spinal cord injury).



Melanie White, Dr. Kristine Cowley, Flor Marcelino,
Darlene Cooper, Jessie Shea

Afterwards, Darlene and I went to The Access Store where we met with the owner, David Tweed, and Ted Marcelino (MLA for Tyndall Park). The Access Store has been a leading supplier of urological, medical and

access equipment products for many years. As someone who has lived with an SCI for over 30 years and has firsthand experience using the products that he sells, David understands the needs of consumers with disabilities and recognizes that everyone has different needs. The Access Store exists not only to provide solutions but to share their staff expertise on accessibility to assist healthcare providers and other medical professionals with the knowledge they need to improve the lifestyle of persons with disabilities living in the community.

SCI Manitoba is recognized by the Government of Manitoba as a designated external agency, and mandated to provide services for people who sustain SCI in the province. Both SCI Manitoba members who participated in this year's 'Take Your MLA to Work Day' received vocational services, at one time or another, and with support from their Rehabilitation Counsellors were able to identify their vocational potential along with alternatives for obtaining employment consistent with their values, skills, abilities and interests. Sharing their success stories with MLA's in their constituencies allows representatives of the provincial government to see the value of the contributions made by persons with disabilities, both to the workforce and the community. It also reinforces that non-profit agencies like SCI Manitoba, who rely on ongoing funding from the provincial government, are essential services; these services result in positive outcomes for the members we serve and for our funders as well, as evidenced by the return on investment the provincial government receives when individuals like Kristine and David achieve their vocational potential and find success in their chosen careers.

These two participants contribute to the overall health maintenance of citizens with disabilities; in providing advanced understanding and knowledge and in products to ensure health and wellness.



Ted Marcelino and David Tweed



FIND YOUR MOBILITY

We have solutions for daily living. Visit us in person or online.

We have a full selection of solutions to improve your daily living:

At Home | At Work
In Your Community | In Your Vehicle

**THE
ACCESS STORE**
We Understand, Personalize and Deliver.

We direct bill: WCB, MPI, DVA, NIHB & Blue Cross

TheAccessStore.com

204-589-8955 | Toll Free 1-800-670-1670
324B Keewatin Street, Winnipeg



MANITOBA PARAPLEGIA FOUNDATION INC. (MPF) NEWS

MPF funds go to work in four main areas that are not supported by any other sources in Manitoba: special projects, product testing, research and direct aid to persons with spinal cord injuries who do not have the necessary financial resources for equipment and/or services. All requests for direct aid are initiated through SCI Manitoba. Individuals must provide information on their financial status, explain why they cannot meet the expense within their own budget, and identify any other potential sources to support the request including potential for contribution from family.

SCI Manitoba thanks MPF for its continued support to improving the quality of life of persons with spinal cord injury.

MPF has approved several requests for financial support during the past several months. Some of the highlights follow:

- Financial assistance was granted for the purchase of a backrest for an SCI Manitoba member. The backrest will enhance the member's quality of life by allowing for greater self-propelled mobility, as well as reduce the risk of acquiring further pressure ulcers by providing more adequate support.
- Financial support was provided for the purchase and installation of a new chair lift/valet seat in a SCI Manitoba member's vehicle. This equipment will allow the member to get in and out of their vehicle safely and independently.

- Funding was provided for a custom backrest for a SCI Manitoba member. The backrest will provide improved postural support and enhance safety, allowing for improved quality of life and increased independence.

Financial support was provided for a sliding board for a SCI Manitoba member. This will allow the member to transfer independently to the bed and other seating accommodations. Quality of life will be enhanced by providing more independence and less reliance on family to assist with transferring.

Visit MPF's website at: www.scimanitoba.ca/mpf. Applications for assistance are available through the website or by contacting the SCI Manitoba office at: info@scimanitoba.ca or 204-786-4753.

MPF Trustees:

Doug Finkbeiner, Q.C. (President)

Arthur Braid, Q.C. (Vice-President)

James Richardson Jr. (Treasurer)

Dr. Lindsay Nicolle

John Wallis

Dr. Kristine Cowley

Dr. Jan Brown

Leonard Steingarten

Ooops! By Ken Davis

Leave it to Ken Davis to find humour in life's ups and downs!

"Don't be upset Alex. When I'm done pushing this box of books into the closet, I'll show you the proper way to melt a horn onto the Barbie doll using the microwave."

After uttering those fatherly words, I slammed the joystick of my power wheelchair forward and drove at the 611-pound box of books on the floor, three feet in front of me. However, as my foot-pedals met the corner of the over-burdened box, something occurred that I hadn't even considered: my chair flipped over backwards.

I knew immediately that I wasn't dead, because I couldn't smell burning sulfur. Also, I could hear my 4-year old daughter screaming at the top of her lungs, and to reaffirm I wasn't dead, I suddenly felt my 2-year old daughter sit on my chest.

I opened my eyes.

"Hi Daddy," she exclaimed with delight.

"Makeda, must you sit on Daddy right now?"

She promptly turned her head sideways and in perfect clarity said, "you have boogers."

By this time my wife, Pam, had run up from the basement where she had obviously been flipping over miniature voodoo wheelchairs for fun.

"Kenneth Davis. How did you....? Do you have a concussion?" "I'm fine. Just get Makeda's finger out of my nose and get me off the floor."

After lifting a very unhappy daughter off my chest, Pam quickly settled Alex. She then slowly untied my legs from the sides of the chair and slid me across the floor. I no longer looked like

an upside-down turtle. Pam then decided I looked a little flushed and thought that she needed to make sure I didn't have a concussion.

"What's your name?"

"Steven Tyler. I'm the lead singer of Bananarama."

"Not funny," muttered my Aerosmith-addicted wife. "What are your children's names?"

"Grabby, Sleazy, Uppity, Jerky, Weepy, Hiccup and Melancholy."

Pam was not amused. "One last question. When is your birthday?"

"March 11, 1983." "You were not born in March of '83".

"No," I smiled, "but that's the day a special young woman from Neepawa* on the senior volleyball team made me a man. There I was, a young junior volleyballer on the Carberry* team..." "Yeah, yeah Romeo, I've heard it before. Now, how am I to get you off the floor?"

"Hoyer lift, my dear." "Good plan," Pam smiled.

As Pam pumped the lever of the Hoyer lift and slowly elevated me off the floor, she asked the question that seemed to be on both girls' faces: "are you staying in bed for a while, or are you getting up right away?"

"I don't have a choice," I smiled at Alex and Makeda, "I need to get up and melt a unicorn horn onto the centre of Barbie's forehead."

Both girls smiled and Pam looked puzzled.

"I don't even want to know," she said as she slowly wheeled me toward the bedroom.

*Fictional towns in southern Manitoba.



I Have Paraplegia: This is My Story pt.1

By Kellea Small

November 27, 2016 is the day my life changed forever. I was in a car accident but I don't remember much about the accident. I remember the doctor systematically going over my injuries, fractured C2, burst T12 incomplete spinal cord injury, broken rib and massive bumps on my head. I was transferred to Health Science Centre for surgery on November 29, 2016. My amazing surgeon pulled the shattered bones out of my spinal cord, and I am fused from the T-10 to the L-2. I was in a neck brace for 3 ½ months. On December 2, 2016, I stood up for the first time and attempted to walk. That is where my story really begins.

The Physiotherapist at HSC brought me to the exercise room in a wheelchair. I had to wait for my body to adjust to sitting up as I had been in bed for 5 days. Once I was able to sit up, the task to stand was the next thing I had to figure out. I took my first steps with the help of a walker but my brain had to figure out what was going on. My walk was very slow and I didn't realize I was lifting my left leg up high, because I couldn't feel most of it. The weirdest part is my brain couldn't get the messages to my feet, telling them to walk. I forgot how to walk. I had to watch my foot and put my heel down first, saying out loud heel, toe, heel, toe which soon became my mantra. My doctor wanted me in the Rehabilitation Unit at HSC, however, they were full and I was transferred to the Grace Hospital so that I could begin a physiotherapy routine as quickly as possible.

Over the 2 weeks at the Grace Hospital, no one said "You have a spinal cord injury." I just figured I needed to regain strength in the lower half of my body. I honestly think I was still in shock. I heard the doctors say that my recovery was going to be long, 18 months to 2 years. In my mind, I was going back to work in a few weeks, 3 months tops! Things hit hard during a physio session when I found out I could not lift my leg with a very small weight on it. I had to leave the room and almost melted down in the washroom, but my fantastic physiotherapist, Donna, brought me back and asked me to move my leg without any weight attached. I did it! Donna explained to me that the movement was still there, the message was getting through and I just had to



build up strength. It was in that moment that I began to realize the seriousness of my situation.

And then I finally cried. I remember it like it was yesterday. An occupational therapist asked me to join a group of patients who were making cookies. I made my way to the recreation room, pushing myself to walk with a walker and sat down; thinking its cookies...how hard is this going to be? I started to stir the batter and realized that a simple task I wouldn't have otherwise thought about was difficult. The pain and weakness in my back was horrible and at that moment I knew that recovery was going to take a long time and I would have to take this day by day. I burst into tears.

I was at the Grace Hospital for 2 ½ weeks, pushing to leave so that I could be at my son's Christmas concert. I started a routine of daily physio and working with the doctors to address my pain and learning how to not give up. Sadly, my team was only in place at the hospital. If I had been in HSC Rehab, a plan would have been in place prior to me leaving the hospital. At the time, we had no idea how much needed to be done to get me home. Having a system's meeting with everyone who was going to be involved in my care makes so much sense now, but with Christmas quickly approaching, staff on holidays and my Manitoba Public Insurance file in transit to an out-of-town MPI office, I was on my own. My husband had to get the house ready; I started to google physiotherapists in our area. I found an office close by, called and told them my situation, and they set up an appointment. Then, I was discharged. Nothing can prepare you for a feeling of complete and utter fear of being on your own, barely being able to move without wincing in pain, the unknown of recovery and being provided with 3 days of pain meds while everyone is saying "Goodbye, Good luck and Merry Christmas." I waited on a bench for Clint to pull the truck up. I remember every last kilometre of my ride home, the last set of tracks we had to go over and the bumpy gravel road. I didn't want to leave my house ever again.

I met my physiotherapist, Bryan, in December 2016, shortly before Christmas. He reviewed all the paperwork from the hospital, and I remember him asking me why I was there. I thought it was such an unusual question, but I told him about the accident and that I was told I would need physio. So we made an appointment to start 3 days a week as soon as the holidays were over.

I went home and started to Google. In most cases, I'd say stay off Google, but through my searches I stumbled across an article, "Incomplete Spinal Cord Injuries: "The Early Days-Craig Hospital" <https://>



craighospital.org/resources/incomplete-spinal-cord-injuries-the-early-days. I started reading, and then I froze. It outlined everything I was going through, and I remember looking at Clint and asking “Do I have a spinal cord injury?” We just sat there, completely unsure, but I knew immediately that I was dealing with way more than I ever thought.

Being home brought on new challenges. Clint had a railing built in the garage and a railing put in place at the front door before I left the hospital. He also knew I would not be able to sit in the living room without an



adapted chair. I required a power recliner to help stand me up or stretch out, whatever I needed. Everything I used to do stopped abruptly. I could barely stand for more than a few minutes; I couldn't cook, lift anything, do laundry, sweep or do anything that was just part of my regular every day. But we figured it out, had many amazing people bring meals and Clint became a caregiver. We mastered how to shower, change a neck brace without moving and got through the basics. My Occupational Therapist, Ashlyn, was assigned to my case through MPI, but was unable to get out to our home until January 2017. The house needed to be adapted so that I could use the shower safely and be comfortable in my own home. Our main shower now has a handle, shower seat and support arms on the toilet. The tub has 2 handles for helping me in and out, but I couldn't start using the tub for almost 9 months, until I had more strength.

Next challenge was how I was going to get to physio. Driving was impossible as I was in a neck brace

and even if my neck was not fractured, I didn't have enough strength in my legs to press the gas and brake. So, we found Handi-Transit in the RM of Springfield. They were amazing and set up my Monday, Wednesday, Friday pick up and drop off schedule. Honestly, from January to March 2017, Wally and Alana were my companions, making sure I was safely on and off the bus so that I could focus on physio. On Monday, January 4th I got to physio. I looked at Bryan and asked if I had a spinal cord injury. He told me I did and was not sure if he should have told me or not at our first appointment because he didn't want to upset me. Now that my brain was able to fully process my injuries, I only had one thing to do. Fight like hell to regain control of my body.

I spent 15 months in physio. In April 2017, I began driving so I then started physio every day, 5 days a week. To say these sessions were hard is an understatement. There were days it took everything in me just to get out of bed. There were days I didn't want to push my body because it hurt too much and then there were days that I was ready to go and work like crazy. My physio highlights include finally walking 2 miles on the treadmill, regaining some balance, doing one modified burpee and using 8 pound weights. The biggest change is that I regained enough strength and balance that I no longer use a walker! I do use a cane and have a leg brace as my left leg continues to be weak, but I couldn't be happier with the results. I have stopped going to physio daily as there are no more significant gains. It's hard to think of it that way, but I do have to keep active so that I don't lose the strength and balance that I've worked so hard to regain.

Over the past 15 months, there have been so many other challenges that I've had to face and figure out, which is just part of my life now. I connected with the Canadian Paraplegic Association which is one of the best resources I could have found. I was almost embarrassed to go to the appointment, feeling that since I was able to walk, I was in the wrong place. The counsellor there assured me that I was exactly where I should be and that whether I was walking or in a wheelchair. As hard as that was to hear, they provided me with a wealth of information. I was able to share literature with my family as even they don't fully understand the things I deal with on a daily basis, but how could they? It took me months to finally realize the enormity of my situation and through many ups and downs, I know that adjusting to a new life is hard, but something I have to do. I can choose to be positive or negative and I'll tell you that finding a positive is the best thing to do, not the easiest all the time but the best.

Stay tuned for PART TWO to follow in the next issue.



Navigating the Return to Work

By Melanie White

Rehabilitation after an SCI can be a long and challenging process. Depending on the level and extent of your injury, you may need to take time off work for weeks, months or years. Returning to work after an extended leave of absence can be a stressful experience for many; but it doesn't have to be... if you want to increase your odds of success in managing the return to work, planning is absolutely essential. Knowing your rights and responsibilities can help to make the transition back to work a little smoother. Knowledge is power, and the more information you have the better you'll be able to advocate for yourself if and/or when you encounter any challenges along the way.

What are your rights?

1. **Protection from discrimination:** Discrimination results in barriers to workplace equity because it blocks access to equal opportunities. Workplace policies typically apply to everyone, but some employees may not be able to meet certain expectations because of their disability. Employers are required to change any rules, practices, expectations or procedures that may have a discriminatory impact.
2. **Reasonable accommodations:** The employer has a duty to accommodate any disability-related needs of employees so that they can perform to the best of their potential. However, the employer isn't expected to provide an accommodation if doing so will result in unreasonable difficulties related to health, safety and/or financial considerations (often referred to as undue hardship).
3. **Privacy:** In most cases, employees are required to give details on their medical condition; however, there are limits on what employers can request and how much information you have to reveal. Obviously, your employer is entitled to find out how your disability will affect job duty performance because it is their responsibility to protect your health and safety while at work. A diagnosis of your condition is not necessarily needed, only details of how the condition may have an impact on your job and any restrictions or modified duties recommended by your doctor as a result. Your medical information should only be shared, within the workplace, on a need to know basis and must be kept confidential.
4. **Union representation:** Your employer should ask if you would like a union official to represent you during the return to work/accommodation process. Unions have a responsibility to assist supervisors to find accommodation solutions for employees returning to work. Also, accommodation measures must be supported by your union regardless of what has been specified in the collective agreement. Failure to do so, once all other options have been explored, may result in a union being held liable by the court.
5. **The right to appeal:** If an employer rejects an accommodation request claiming undue hardship, evidence

must be provided as proof of same. You are entitled to a solution that meets your needs, as long as they're medically verified. If you are not satisfied with a decision made by your employer, you can appeal the decision at a higher level within your organization and your supervisor should advise you regarding the appeal process. If you feel that you're being discriminated against on the basis of your disability, you can contact Employment Standards or Manitoba Human Rights Commission (see below) for more information.

Employment Standards
Manitoba Labour and Immigration
Room 604 - 401 York Avenue
Winnipeg, Manitoba R3C 0P8
24 hour Inquiry Lines
Telephone: (204) 945-3352 or Toll-Free: 1-800-821-4307
<http://www.gov.mb.ca/labour/standards/index.html>

Manitoba Human Rights Commission
7th Flr-175 Hargrave
Winnipeg MB R3C 3R8
Telephone: (204) 945-3007 or Toll-Free: (888) 884-8681
TTY: (204) 945-3442
Fax: (204) 945-1292
E-mail: hrc@gov.mb.ca
<http://www.manitobahumanrights.ca/>

What are your responsibilities?

- Work with the accommodation provider on an ongoing basis, request accommodation when needed, and advise your employer of any changes in your accommodation needs.
- Provide documentation from a medical professional to clarify any restrictions with consideration of the most effective accommodation. Cooperate with any experts who are asked to provide guidance on the situation, as failure to comply may result in delays during the accommodation process.
- Keep an open mind and be an active participant in any discussions regarding possible accommodations. Allow your employer a reasonable amount of time to respond to any requests.
- Achieve the agreed-upon job performance standards once accommodation is provided

Remember, you don't have to go it alone. If you are having difficulties with a return to work and are in need of support and/or advocacy, please contact your Rehabilitation Counsellor at SCI Manitoba for assistance.

A Guide for Managing the Return to Work. Canadian Human Rights Commission. Retrieved 14 Jan 2019, from https://www.chrc-ccdp.gc.ca/sites/default/files/gmrw_ggrt_en_2.pdf



Self-Advocacy in Medical Treatment

By LéAmber Kensley

Be prepared to Ask or Give the Right Information

When visiting an Emergency Room, Urgent Care Centre, or even your doctor's offices, good communication is needed to ensure you get the right treatment. This means **you have a right to ask** questions and understand the information you receive. As the patient or advocate, you need to say why you are there, what occurred and if your condition changes since it began (time, date, intensity); you should have either your medications with you, or a list of what you are taking. It is also important to say if you are taking over the counter or herbal medications, as they could change what medications can be prescribed. Know your spinal cord injury; identify it as level of injury, complete or incomplete and Asia scale. Let staff know about any chronic conditions like allergies, diabetes and special diets. An E.R.I.K. (Emergency Response Information Kit) for both at home and travel is an excellent way to have this information on hand. E.R.I.K.'s are available through WRHA, Paramedics, Homecare or you can download the form online (<https://livelearn.ca/article/health-care/making-a-health-emergency-plan-make-e-r-i-k-a-part-of-it/>). It is also advisable to carry the three pocket information cards provided by SCI Manitoba on autonomic dysreflexia, deep vein thrombosis and sepsis; as these are common secondary conditions relevant to people with a spinal cord injury. This is not to show any disregard for what the professionals know, but to provide information that may be specific to your diagnosis.

Once you have provided your information, medical staff ought to explain what they are doing, why they are doing it and the expected results, including possible wait times. **Remember, there are no stupid questions, if you do not understand something, ask.** You have the right to a second opinion, and to know what options there are for treatment. If you are unable to ask questions, having a designated advocate (family member, friend or other support person who is aware of your medical history and is with you), as a second set of ears is an option. The Manitoba Institute for Patient Safety has an excellent guide to help a person know their rights when receiving medical treatment, available at: <https://>

www.safetoask.ca/assets/fv_1_know_your_patient_rights.pdf.

If you are hungry or thirsty when waiting to see medical professionals in hospital, ask if you can have anything to eat or drink, particularly if you have a condition like diabetes that requires proper, timely nourishment to maintain your sugar levels. You may need a procedure that cannot be done unless you have an empty stomach. It is important to know when you last had anything to eat or drink.

If you feel that you are not getting the care you need, hospitals have patient advocates and there is a Provincial Ombudsmen's office. You have the right to ask for these supports.

Great healthcare starts with you.

Your Nine Patient Rights and Responsibilities:

1. You have the right to ask questions and get answers.
 - **3 questions to ask:**
 - What is my health problem?
 - What do I need to do?
 - Why do I need to do this?
 - **You need to:**
 - be clear about the details of your consultation.
 - understand the treatment or medication and possible side effects.
2. You can seek a second opinion.
 - This means talking to another doctor.
 - When do you need a second opinion? If you are not satisfied with your doctor's diagnosis or treatment; When you are facing a risky or costly treatment (like surgery); When you are not clear if the treatment will work; When you need more information about your options.
 - Ask your primary doctor for a referral to another specialist.
3. You can ask about your healthcare provider's experience and training.
 - Know more about your doctor's or health care team's education, background and training.
 - Politely ask for information from your doctor.
4. You have the right to be informed before you willingly give or refuse consent.
 - Get all the facts before making a decision.
 - Know the: benefits and risks, possible side ef-



- fects, treatment choices, who will give the treatment, how the treatment will be done, results of refusing the treatment.
- Parents or guardians decide for children up to 18 years old.
 - The age of consent is 16 years old in other regions.
5. You have the right to get your personal health information.
- You can get information in your medical records (with limited exceptions).
 - You say who can and can't look into your personal health information (PHI)
- Your PHI includes:**
- Your name, address and Personal Health Identification Number (PHIN)
 - Facts about your health, healthcare history and family history.
 - Facts about the care you are receiving.
 - Facts about payment for your healthcare.
6. You can get help from a patient advocate.
- Get a patient advocate when you can't speak English or French or you are too ill.
 - A patient advocate is "a person you choose to support you or act on your behalf". Often, people trust the counsellor's they know at SCI Manitoba and request their presence at appointments. He/she will talk to your family doctor or nurse. He/she can be a trusted relative or friend. He/she must have time to help you. You should name your patient advocate before you need one.
 - Print the **Patient Advocate Form**.
 - Read the roles and responsibilities of an advocate.
7. You can decide the type of care you do and do not want to receive
- You can make your own health care decisions.
 - If you can't speak for yourself ask your advocate.
 - Make a Health Care Directive or Living Will. It contains the treatment you prefer when you can't speak for yourself.
8. You have the right to voice your concerns
- You can speak without interruptions.
 - You can: ask questions, share your opinions about your care and say your complaints and concerns.
9. You have the right to report any unplanned harm.
- Your doctor should tell you when a critical incident (CI) happens while being treated.

- A critical incident (CI) is: An event that harms a patient while receiving health services. It causes injury, disability, or death. "It is not related to the patient's main health condition." (Patient Safety Definitions, MIPS)
- If you feel that a CI occurred, you may report it.
- Call the Critical Incident Reporting Line at (204) 788-8222 in Winnipeg, or Regional health authority office in Manitoba.

*Adapted from the MIPS **Know your Patient Rights** (full version).*

Know where to go: ER or Urgent Care

According to the WRHA, the ER is your best bet when you've got a life-threatening or potentially life-threatening condition, like severe chest pains, stroke or trauma.

The WRHA also provides a handy list of conditions that should definitely send you to the **ER**:

- Heart attack
- Stroke
- Major trauma
- Severe head injury
- Loss of limb in an accident
- Severe difficulty breathing (due to an allergic reaction or another cause)
- Sexual assault
- Domestic violence
- Severe bleeding
- Any time a person is unconscious

Fracture a bone? Need stitches? Severe flu symptoms? If your regular doctor's not available, get yourself to an **urgent care centre**.

- Fever or flu symptoms
- Fractures or sprains
- Minor burns
- Headaches, earaches
- Nosebleeds
- Rashes
- Sore throat
- Urinary problems
- Vomiting

Still not sure where to go? Call the 24-hour Health Links helpline at 204-788-8200, or toll-free at 1-888-315-9257. (<http://healingourhealthsystem.ca/files/emergency-vs-urgent-care.pdf>). You can also contact your counsellor at SCI Manitoba to help you be the best advocate you can be for yourself.



Ochre River Rescue - Part Two

By Curtis Halbesma

Continued from the September 2018 issue..... I told Peter I was going for help. There was no cell coverage on the mountain so I was going to run until I could call someone.

I started to tape up my shins with self-adhesive tensor tape so that I could run through scrub brush without cutting myself. I drank a little water and ate some trail mix, but not too much because I didn't want to get a cramp. I asked him where the car keys were and then proceeded to my next question without getting them. Peter suggested we mark down his GPS location on my phone. I also wrote out his 3 symptoms. "What should I ask 911?" "Find out what we should do. Is this really serious or should we keep going?"

Neither of us were particularly afraid, but I did wonder if this was some kind of heart failure. I thought, if he is dying I don't want to look back on this moment with regret. So I said, "If this is the last time I get to see you, I want you to know that you have been an awesome friend. You're an asshole at times, but I love you." To which he replied, "I think we know that." I kissed him on the top of his head and then I ran like a rabbit for help. I ran for about 10 minutes when I got a prompt to check my phone. I had one bar. But then it disappeared. I moved back and forth for a bit, then ran for another minute. One bar. I called 911. I could hear the operator but he could not hear me very well. "I'm on the Ochre River Trail in Riding Mountain and my buddy needs help." "Hello? Pardon? I can't hear you." I tried a couple of more times with various phrases but nothing really worked. "Do you need ambulance, police, or fire department?" Of those choices? "Ambulance." That got through. Over the next couple of minutes I could get through "Ochre River Trail. North parking lot." He

asked, "Are you with him now?" "No." Then my cell lost all coverage.

I decided to keep running. After about 20 more minutes, through trail that I would never have been able to get Peter through, I reached a cliff overlooking another mountain stream. I stopped – still no cell coverage. I took off my jacket to cool down a little (my jacket resists catching branches and thorns so I decided to run in it). An eagle flew overhead. I thought, "If it cries 'Woe, Woe' like in Revelation I'm going to lose it." There were two more eagles flying over the stream, playing with each other.

Birds of prey – falcons, eagles, hawks – always give me a feeling of God saying, "I'm here. I'm watching over you. I'm aware." I lost it. I cried. No, I bawled. Hands on knees, stumbling backwards, sobbing loudly. "What's going on? I've left my friend to die in the woods. I'm running to meet an ambulance and then what? We'll hike back in for 2 hours with a stretcher to find my friend's dead body? And then I'll have to call his wife and his kids and tell them their dad died? How can this be happening?"

After a minute or two, it was time to wipe my tears off my face and get back to running. It took about an hour from when I made the first 911 call until I got to the parking lot. Later, we figured it was about 8KM. That's a bit slow for a run for me – but I did have sopping wet hiking boots on. There were also several places where I slowed down to navigate nature, or where I just ran out of steam. It had been 6 hours since a simple breakfast of oatmeal, dried fruit, protein powder, and coffee. Calling 911 again, they said they had received the first call and were out looking for us. They had sent ambulances to both the north and south parking lots of the trail.

It turns out Parks Canada was doing a training day and happened to have helicopters in the area. I could hear them fly overhead. The cell connection was clear so I gave them Pete's GPS location as well as a list of his symptoms from the morning. They particularly liked the GPS numbers. He kept me on the phone for about 20 minutes, occasionally putting me on hold so he (Paul?) could relay information to Parks.

He did a quick check if I was ok – well, I was thirsty, hungry and alone in an unmarked parking lot without the car keys. But basically I was fine. He told me not to call anyone so that Parks could get through on my phone.

I might not have been able to call, but I could text peo-





ple. I texted Julia, then my Mom, then my house church, asking them to pray. The message was brief. “I’m at Riding Mountain Park on a hike with Peter. He isn’t doing well. I had to leave him and run to where I could get cell coverage. I’m waiting for ambulance.” Not much more I could say. The 911 operator had told me not to contact Darlene until I had something to say. “Call her when we have someone with Peter. Not that he is alone in the woods.” I asked God whom I should text. “Everybody ” I thought Darlene would probably find out sooner than I thought, so I texted Shawn to go give Darlene the message with instructions not to call so my phone could stay free.

Then I waited. I ate the rest of the dried fruit mix I had taken from my pack. It started to rain. I got cold. I sat huddled beside the wheel of the car, wondering if I should break a window to get inside and change into clean clothes. Parks said they would send a nearby staff member to pick me up but that they would be a while. I texted Julia more, just to talk with someone. Parks called back a couple of times, finally saying that they had located Peter and someone was with him – to which I replied, “So he’s alive?” Perhaps not my best worded response.

Back to Peter. After I left, he thought, “Is Curt right? Am I dying? Should I pull out my phone and video tape my last words to my family? No, I am going to live.”

He realised that in a swamp, the moisture and cold will come from below. He got out his sleeping pad and got on it. His boots were soaked. He took them off and got into his sleeping bag. Smart. He said he thought, “God is good. God is good,” and fell asleep. An hour later, he woke up and heard helicopters overhead. He didn’t think they were for him; it hadn’t been long enough for them to be called, prepped, and flown to the location. But he got out the fly from the tent, which is bright orange, and wrapped it over himself. Also smart.

The helicopter crew spotted my pack close to Peter, found a place to land roughly a 100 meters away, and jumped out to get him. Apparently getting him back to the helicopter, through a swampy area, wasn’t too easy. They used his sleeping bag and some branches to make a stretcher but still got his butt wet along the way. When he finally got in, he thought, “Hey, I get to ride in a helicopter ” and also “**Curtis is not here.**

That means he is still down there.”

More to come in future issues...

**P
a
r
t**

**T
W
O**

Staff Email Addresses and Phone Extensions

204-786-4753 or 1-800-720-4933 (within Manitoba only)

Ron Burky	Executive Director	rburky@scimanitoba.ca	224
Adrienne Conley	Executive Assistant	aconley@scimanitoba.ca	222
Denise Balliet	Accounting Officer	dballiet@scimanitoba.ca	221
Darlene Cooper	Director of Rehab. Services	djcooper@scimanitoba.ca	225
Laurence Haien	Sr. Rehab. Counsellor, Vocational Services	lhaien@scimanitoba.ca	234
Kelly Tennant	Rehab.Counsellor, Health Promotion Services	ktennant@scimanitoba.ca	223
Melanie White	Rehab. Counsellor, Vocational Services	mwhite@scimanitoba.ca	226
Bernie Gaudet	Rehab. Counsellor, Transitional—Vocational Readiness Services	bgaudet@scimanitoba.ca	227
Maria Cabas	Rehab. Counsellor, Aboriginal Services	mcabas@scimanitoba.ca	228
Gail Burnside	Rehab. Counsellor, Hospital Services	gburnside@scimanitoba.ca	229
Delcy-Ann Selymes	Rehab. Counsellor	dselymes@scimanitoba.ca	231
Jared Funk	Rehab. Counsellor Assistant	jfunk@scimanitoba.ca	235
Artem Dolia	Rehab. Counsellor Assistant	adolia@scimanitoba.ca	232
LéAmber Kensley	Rehab. Counsellor, Indigeneous Enhancement Services	lkensley@scimanitoba.ca	204-781-0313



Spinal Cord Injury Manitoba Inc.
Lésions Médullaires Manitoba Inc.
 Formerly Canadian Paraplegic Association (Manitoba) Inc.

MEMBERSHIP APPLICATION

YES!

Count me in as a member of Spinal Cord Injury Manitoba Inc. All members receive "ParaTracks" SCI Manitoba's newsletter and voting privileges at the Annual General Meeting.

Members also receive discounts at various health care supply stores:

Stevens Home Health Care Supplies (10% off supplies & equipment), The Access Store (10%), Northland Home Health Care (10% off medical supplies) and Disabled Sailing membership (25%).

PLEASE ENTER MEMBERSHIP FOR:

NAME:

ADDRESS:

CITY: PROV:

POSTAL CODE: PHONE:

E-MAIL:

(PROVIDING YOUR E-MAIL ADDRESS WILL HELP SAVE ON MAILING COSTS)

SIGNATURE: DATE:

I wish to select the following category of Membership:

- MEMBER: \$15-\$24
- SUPPORTING MEMBER: \$25-\$99
- SUSTAINING MEMBER: \$100-\$249
- CHARTER MEMBER: \$250-\$499
- PATRON MEMBER: \$500 AND OVER

All Monies donated remain in Manitoba to support SCI Manitoba Inc. An income tax receipt will be issued for any amount over \$15.00. Sustaining, Charter and Patron Members will receive recognition of their generous contribution in the context of events such as our Annual General Meetings or in the programs of other SCI Manitoba functions.

- NEW RENEWAL

Make cheque payable to: Spinal Cord Injury Manitoba Inc.
 Mail to: 825 Sherbrook Street, Winnipeg MB R3A 1M5

IMPORTANT!

By signing above, you are consenting to the use of your personal information (name and address only) by SCI Manitoba for the purposes of sending out SCI's newsletters, membership cards and receipts, reminder notices and meeting notices.

SCI Manitoba does not sell or trade personal information and does not rent out its mailing lists.

For more information

Phone: 204-786-4753

Fax: 204-786-1140

Toll-free within MB: 1-800-720-4933

Email: info@scimanitoba.ca