

balance

what it's all about

BCITS  technology for living  ISSN 1916-7709

DECEMBER 2018



Walt Lawrence Featured in Vancouver Sun

He's been paralyzed from the neck down for 50 years and that makes Walt Lawrence either the longest surviving ventilator-dependent quadriplegic in BC or darn close to it.

"He's outlived any statistical, predictive model. He's off the charts," says Karen Anzai, a spinal cord program educator GF Strong Rehabilitation Centre, as she looked at a graph on her computer showing expected lifespans of patients who are ventilator-dependent.

"I attribute it to his optimism, his resiliency, his religious faith and his desire to contribute," says Anzai, a rehabilitation consultant. "Plus, if you noticed his water cup attached to his wheelchair, he's constantly hydrating himself with water which may reduce any respiratory complications."

Pneumonia, lung infections and other complications often shorten the lives of individuals who use ventilators, but Lawrence, 67, has defied the statistics by at least 25 years.

He credits medical advances and a wide support system of family, friends, health professionals, non-profit organizations and many others for his vitality and longevity.

As a big-hearted gesture to show his gratitude, he's invited hundreds of his relatives, friends, health care providers and other supporters to a "Half Century of Thanks" reception

in the Tsawwassen Springs ballroom on Sept. 23 where he'll personally thank them for their helpful words, kind deeds, presence, encouragement, and their faith in him.

"It's not what I've done, it's what others have enabled me to do. I could fill BC Place Stadium with all the people who've helped me for the past 50 years," Lawrence said at GF Strong where the married father of two works as a Vancouver Coastal Health peer counselor for others with spinal cord injuries.

Besides explaining everything they need to know about assistive technology and bodily concerns like skin pressure ulcers, and bladder and bowel matters, Lawrence counsels spinal cord injury patients about finding ways to lift themselves out of their "deepest, darkest pits" so they can ultimately lead lives that are productive, even though they will be markedly different from what they planned or hoped for.

"After my accident, when I couldn't breathe on my own, talk or move, I would have traded my life for absolutely anybody else's. But here I am now. I wouldn't trade my life for anyone else's," says the always-positive Lawrence.

Lawrence says he had an idyllic childhood in Dawson Creek where he grew up in a close-knit family

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“I know how bad it is because I remember I cried enough tears to fill the Pacific Ocean after my accident. My goal is to help individuals see they still have value.”

and hoped for a professional hockey career. It was as a 17-year old with an invincible mindset that he dived into Lake Okanagan one day in August 1968, during a break while on his way to a hockey practice with a junior A league team in Kelowna. It was supposed to be an invigorating, quick dip but he misjudged the water depth and landed badly as he hit the sandy bottom, breaking his neck.

He was in the intensive care unit at Kelowna General Hospital for six months and then he was transferred to Vancouver's George Pearson Hospital for the Physically Handicapped (as it was then called) where he would spend 16 years, initially on the same ward as polio and tuberculosis patients.

“As a teenager, I had been a fixed-wing pilot, a hockey player with loads of potential. And then, in a split second, I became a quadriplegic

with a tracheotomy on a ventilator 24/7. Breathing on your own is NOT highly over-rated,” Lawrence says as he deftly navigates his motorized sip and puff wheelchair.

Lawrence weaned himself off full-time ventilator support years ago; now he's hooked up to a ventilator only at night in the home he shares with his wife Wendy, a nurse he met while in rehabilitation, and his two daughters, both adopted as babies from China.

Asked what kind of advice he gives newly paralyzed individuals, Lawrence emphasizes the importance of validating their regrets, physical and emotional suffering, and numerous personal fears and challenges.

“It is normal to look back and say ‘if only I had done this or that.’ I remember thinking this after my accident. If only I'd gone straight to the hockey rink, or if only I had taken a different dive in the water. But that doesn't get us anywhere except trapped in darkness and depression

“I know how bad it is because I remember I cried enough tears to fill the Pacific Ocean after my accident. My goal is to help individuals see they still have value. No one is a throwaway piece of a puzzle. We all know we are going to die one day but what do we do with our lives while we have them? It is a privilege for me to accompany them as they go through their fragile times.”

Lawrence recalls how, immediately after his accident, he convinced himself that since he was a fit athlete, he'd learn to walk again. But when he got to Pearson and met patients who'd already been there more than a decade, he had a reawakening, telling himself: “Oh, this might be permanent.”

In the 1980s, when Man in Motion Rick Hansen was getting much attention for his relentless advocacy for those with disabilities, Lawrence was agitating for assistive devices, rehabilitation and home care options so that those with paralysis could move out of long-term care facilities into communal-style housing options.

Lawrence's legacy as a pioneer in the de-institutionalization of those with disabilities has been firmly cemented. Envisioning an independent life, outside long-term care facilities, paved the way for so many others.

“There was a group of five or six of us who believed we didn't need to live in that kind of environment. We wanted a better quality of life. I know that while I couldn't care for myself, I could still direct my care,” he says of the first community-based shared-care model, in which therapists would do house calls, attending to the needs of a handful of clients in each visit.

In the early 1980s, the Canadian Paraplegic Association (now called Spinal Cord Injury BC) helped with a cost analysis for independent living. Lawrence gives credit to then MLA Doug Mowat, a quadriplegic who has since died, for championing the cause. The idea got a big boost when the study that living in the community instead of the rehabilitation facility would be 30 per cent less expensive, not to mention better for the quality of life of such individuals.

In 1985, Lawrence and his friends moved into a co-op housing cluster called the Creekview Co-operative Apartment near Granville Island. He lived there for many years until he got married.

"At first, the respiratory therapist from Pearson had to come over to help with our ventilators, but then the Provincial Respiratory Outreach Program took over," he recalled.

"Getting into the community enabled us to see that there was much we could contribute to this world. Many of us became advocates on committees, volunteered and worked to change perceptions," said Lawrence, a Christian who has received numerous awards and distinctions over the years, including an honorary doctor of divinity from the Carey Theological College.

Fifty years after his life-altering injury, Lawrence says he has no plans to slow down, so intent is he in helping others with spinal cord injuries live good and productive lives.

"The former assumption was that because you couldn't move, you'd have to be looked after your whole life and couldn't contribute. But in the era of all these assistive devices and technologies, we can now manage much more on our own. We don't have to be totally dependent on others," says Lawrence, who counts Vancouver MLA Sam Sullivan as a role model.

Sullivan was humbled by Lawrence's compliment and said the respect is mutual.

"What Walt has done is incredible. He's been such a great leader and accomplished so much. He's given much of his life being a role model, helping people, showing them how they could figure out how to live full lives even after traumatic injuries."

Source: Vancouver Sun. Writer: Pamela Fayerman pfayerman@postmedia.com. Article originally titled, "Inspiring, long-surviving disability advocate Walt Lawrence grateful for 50 years of support." <https://tinyurl.com/y8dsphbl> ●

help us fulfill our vision

BCITS, proud home of PROP and TIL, is a registered non-profit and charitable organization. The funds to operate these programs come from the Ministry of Health, through the Vancouver Coastal Health region. We are very grateful for this generous support.

However, this funding does not cover all the costs to provide equipment to TIL clients. For example, a special telephone for a person with a high level disability can cost as much as \$1000 and an automatic door opener can cost \$3000.

We provide many devices like these to adults—at no cost—to fulfill our vision of people living in the community as independently as possible.

You can help us continue this work through your donation. Any contribution large or small will be gratefully accepted. 100% of your donation will go toward equipment and assistive devices.

Charitable Registration Number 807477070RR0001

I would like to support TIL's equipment program.

- I have enclosed a cheque for \$ _____.
- I will make a donation by credit card through CanadaHelps.org. [Donate in minutes by clicking on the DONATE button on our home page at www.bcits.org.]
- I would like to donate directly by VISA. I will call you at 604-326-0175.

Please be sure to fill in all your contact details, so we can send your tax receipt (for donations of \$10 or more).

NAME _____

ADDRESS _____

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Please return form to: BCITS, #103-366 E. Kent Ave S., Vancouver, BC V5X 4N6

thank you for your support



The 2018 AGM and Social

BY RUTH MARZETTI | This year, the BCITS AGM was held at Performance Works on Granville Island. In her report, our Chair, Christine Gordon, reflected on Walt Lawrence's 50-year milestone of living with a spinal cord injury. From there, she reflected on a feisty meeting held some 20 years ago when the Creekside discussions took place. There were members at the AGM who were present at the Creekside meetings. It is from those foundations that BCITS has grown and developed.

The membership re-elected the current board. On our website, you can read more about Board members Christine Gordon, Walt Lawrence, Ken Kramer, Don Danbrook, Terry Le Blanc, Ean Price, Anthony Chan and Nancy Paris.

Looking forward, we are starting to implement the TIL strategic plan and PROP service users continue to grow in numbers.

At the end of the AGM, Paul Gauthier said a few words about the success of the Pathways to Independence peer group meetings. The next

scheduled meetings will be held January 15, February 13 and March 13. All meetings take place between 1-4pm at the Sunset Community Centre at 6810 Main Street in Vancouver.

Paul then transitioned us into the Pathways to Independence social, and the Fuse Wheelchair Dance Society entertained us with a demonstration, and an invitation to join in. The evening continued with refreshments, drinks and an opportunity to chat with friends.

Thank you to our corporate sponsors for providing the venue, food, drinks, and a photo booth: West Care Medical, RBC, Medigas and Hub International Insurance. Additional thanks to RBC who also provided volunteer assistance for the night.

For more information on Fuse, read the blog post at <https://bcits.org/wheelchair-dancing-101>. Fuse would like to recruit more dancers for their Saturday morning lessons, so contact Vince via their Facebook page at <https://www.facebook.com/fusewheelchairdance>.



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Balance is published three times a year by the BC Association for Individualized Technology and Supports for People with Disabilities (BCITS).

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BCITS is the home of Technology for Independent Living (TIL) and the Provincial Respiratory Outreach Program (PROP).

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TIL is funded by the Province of British Columbia Ministry of Health, BC Rehab Foundation (Automatic Door Program) and community fundraising. PROP is funded by the Province of British Columbia Ministry of Health through Vancouver Coastal Health.

Publications Mail Agreement No.
 41682526

Attention Gamers!



Our Biomed's know there is a younger generation (and some not so young) who are interested in adapted technology for video gaming. Our team has been considering how we can help our clients access video games.

In October, the Neil Squire Society kicked off their "Power to Enable" fundraising campaign at the Swish EA (Electronic Arts) offices in Burnaby. They demonstrated some EA games and assistive devices associated with gaming.

For around \$100, an adapter can be purchased for an X-box, and up to twenty switches can be added to enable the gamer to have control of the game. Also, the Neil Squire LipSync can be added to the adapter so gamers with limited hand movement can control the mouse using their mouth. Although twenty switches would be overwhelming, a couple of switches and a LipSync will significantly open up control of the game.

The Neil Squire techs are keen to meet with our Biomed's to work further on developing the switches at low cost. Neil Squire has some LipSyncs developed through their "Makers Making Change" project available for those interested in improving their gaming skills.

For more details, please contact Wayne Pogue at BCITS or contact Neil Squire at <https://www.neilsquire.ca/contact-us/>.

How Clients Like You Can Improve Community Services | BY ESTHER KHOR

This summer, I followed my colleagues Wendy and Irish, a Respiratory Therapist student, for a home visit. We were visiting Robb, a PROP client, who is living at home on 24-hour ventilation.

Home visits are part of the core services provided by PROP. In the last year, over 750 home visits across the province were provided by the respiratory team. The home visits were done with the support of one Registered Nurse and five Respiratory Therapists.

On this particular visit, we were trialing the EO 150, a home ventilator that is relatively new in the Canadian market. Since Robb is an expert on his respiratory needs, we wanted his feedback on the new ventilator. Over the years, PROP has received crucial feedback that resulted in finding respiratory equipment that is a good fit with a client's home setting.

During this visit, we exchanged Robb's ventilators, changed settings, and watched as Robb's chest rose with each breath. There were times when Robb was manually bagged, while his caregiver arranged the wiring of the equipment. During this whole process, Robb was calm and provided feedback about the EO 150 ventilator.

In the end, we could not adjust the ventilator to work smoothly, due to irregularities with the Bluetooth connection. So, we all agreed to bring the EO ventilator back to our Biomed's workshop for further testing. During the two-hour visit with Robb, there was a fair amount of trial



and error as we tested the ventilator together. However, we did it with Robb's direction and laughter.

After the home visit, I thought about Robb's contribution to member-driven programs like PROP and TIL. Robb has been a PROP client since 2001, and a TIL client since 1975.

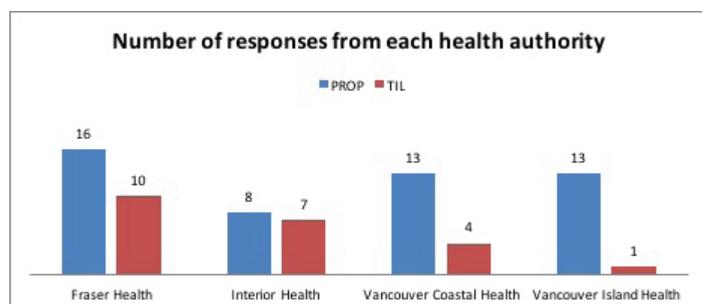
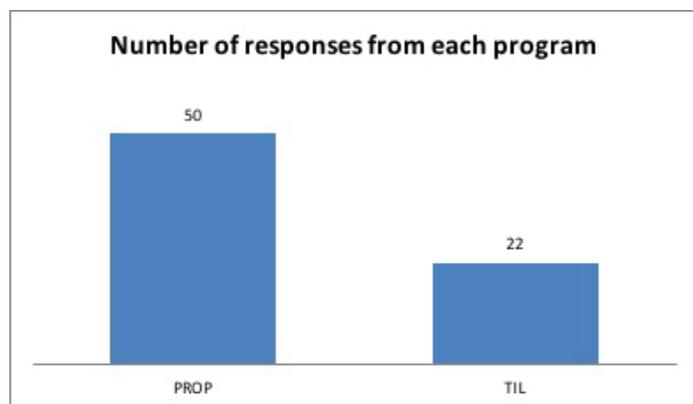
It is interactions with clients like Robb that help us improve our services. Client feedback is essential to us, and I hope many of you will work with PROP and TIL to achieve your goals to live independently.

A week after the home visit, I received an email from Robb suggesting that we try the EO ventilator again. I want to acknowledge that it is Robb and the many members of PROP/TIL who shape the landscape of community services with their input. Thanks, Robb! ●

BCITS CLIENT SATISFACTION SURVEY REPORT 2018

Summary

Seventy-two clients shared their recent experiences with BCITS services in a phone survey. The questions were chosen to gather data that will shape the organization's growth, to measure how well we are accomplishing what we are here to do, and to improve services where needed.



The method used to collect information from our clients was a mix of open-ended questions to measure our client's satisfaction through a rating scale, from "Excellent" to "Poor" or "N/A" for questions not relevant to the client.

"I'm blown away by you guys. I couldn't imagine my life without you."

"BCITS provides us with convenience in our daily lives and we're very happy with it."

What Did We Do With The Results?

The survey results were shared with BCITS staff and clients, and we will make changes and improvements in response to the results. The improvement action plan will include addressing issues generally, as well as addressing individual concerns directly with clients who identified themselves on the survey.

Our staff of Respiratory Therapists and Biomedical Technologists will continue to provide information in a variety of ways, including in-person consultations, articles in the Balance newsletter and videos on our website. We will try as many approaches to providing information as possible, including mailing out booklets or providing other sources of information to clients.

Client satisfaction data can become a powerful tool to make significant improvements to services. Some fixes can be simple and inexpensive, but still make a big difference in our clients' lives.

How Did We Measure Our Service?

The service measurement process included determining categories of service and forming questions that related to these categories. For example, some categories included user access to programs throughout the province, satisfaction with the BCITS service and service punctuality.

Some of the main questions addressed the following issues:

- Clients access to programs,
- Provision of services, as well as satisfaction with services,
- Opinions of staff professionalism and care,
- Training and knowledge provided, and
- General open-ended comments.

A moderately high percentage of respondents gave us a very satisfied rating for overall services they have received. However, this does not mean our work is done. One of our most important goals is to listen to all our clients, and the wide range of comments and suggestions received on the survey. Taken together, these comments and suggestions constitute essential feedback that is used to refine and improve our services.

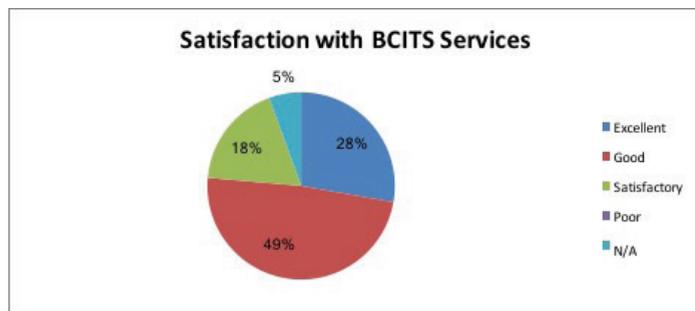
Our clients tell us there are areas of our services that need improvement and further attention. Some of our client’s widespread suggestions and desired improvements are in the following areas:

- Better response time,
- Better training on equipment,
- More hands-on experience with the equipment, and
- More follow ups.

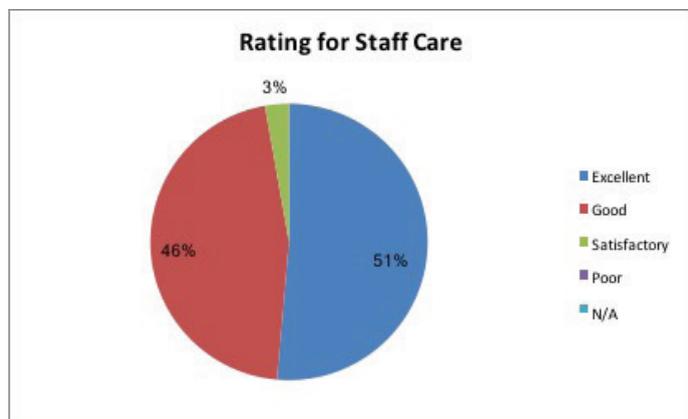
THE COMPLETE SURVEY IS AVAILABLE ON REQUEST.

“I don’t think there’s anything that you guys can do [to improve]. You guys have done a great job.”

“It might be better to have the survey online so that we have more time to think about our answers. Access to information and what is available to us is important – we only know about the services through our OT.”



| | Exc. | Good | Satis. | Poor | N/A | TOTAL |
|--------------|-----------|-----------|-----------|----------|----------|-----------|
| PROP | 17 | 25 | 7 | 0 | 1 | 50 |
| TIL | 3 | 10 | 6 | 0 | 3 | 22 |
| TOTAL | 20 | 35 | 13 | 0 | 4 | 72 |



| | Exc. | Good | Satis. | Poor | N/A | TOTAL |
|--------------|-----------|-----------|----------|----------|----------|-----------|
| PROP | 29 | 20 | 1 | 0 | 0 | 50 |
| TIL | 8 | 13 | 1 | 0 | 0 | 22 |
| TOTAL | 37 | 33 | 2 | 0 | 0 | 72 |

Yes, I Accept Your Invitation to Join BCITS

The BC Association for Individualized Technology and Supports for People with Disabilities (BCITS) Home of Provincial Respiratory Outreach Program (PROP) & Technology for Independent Living (TIL)

Name: _____

Address: _____

City/Prov: _____ Postal Code: _____

Telephone: _____ Email: _____

**Please mail this form along with any applicable membership fees to BCITS:
#103-366 E. Kent Ave S., Vancouver, BC V5X 4N6. Thank you.**

Please Check One

- Membership for Registered BCITS Clients** Please mail completed form to BCITS (the cost of postage constitutes your membership fee)
- Non-client Membership** Please mail completed form along with \$20 annual membership fee payable to BCITS.

BCITS  technology for living 

LETTER TO BCITS

Dear BCITS:

Perhaps you should print this in your newsletter. I'm responding to your piece in the July 2018 edition of your Balance newsletter which I just received about the withdrawal of support for BCITS' Technology for Independent Living (TIL) services.

How can I say it any other way than this: it's very disappointing to hear about the departure of Sammy Guest and Kevin Choi. It's great that Kevin is moving on to a medical career, inspired by his work at TIL. However, it's very disappointing to say the least to hear of the funding cut from the former gaming grant.

As a wiser, more experienced person than me once said, "as a person with a disability, you must be organized and you must get political." That's not to say anything one way or another about this government specifically, but it is very clear we are not the majority. We are an under-represented group that must advocate vigorously for ourselves. A



minuscule percentage of the provincial budget can make a massive difference to people who depend on TIL's service to meet their needs for freedom and functionality, not to mention productivity and employability. These services are not frills, they are the essentials of life. It's one thing to say we can wait two weeks for a technician, but when a quadriplegic's controls don't work, and he or she can't open the door, two weeks is a murderously long time.

So, whether you like this government or not, get your pen, laptop, desktop or whatever out and write a letter. Tell the government that what they did is totally unacceptable. We do not have the power of numbers, but we do have the power of the vote. We can multiply that by as many people as we know to voice our dissatisfaction.

Let's get together, like a good team, and get that support back where it belongs.

*Sincerely,
Art Jonker ●*