

balance

... what it's all about

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What's in a name?

By Christine Gordon



Shakespeare's Juliet argued "that which we call a rose by any other name would smell as sweet". When BCITS was named as the umbrella for PROP and TIL after these programs left the BC Paraplegic Association (now Spinal Cord BC), we, like Juliet, did not put much stock in the name.

We needed a corporate home for PROP and TIL that satisfied the rules of the province and we needed it quickly. So, a small committee settled on the BC Association for Individualized Technology and Supports for People with Disabilities as the best descriptor of the work of PROP and TIL. We knew that most people would still identify with either the PROP or TIL names. We hoped that the corporate name would, at best, be used as a formality. Once the legal papers were submitted,

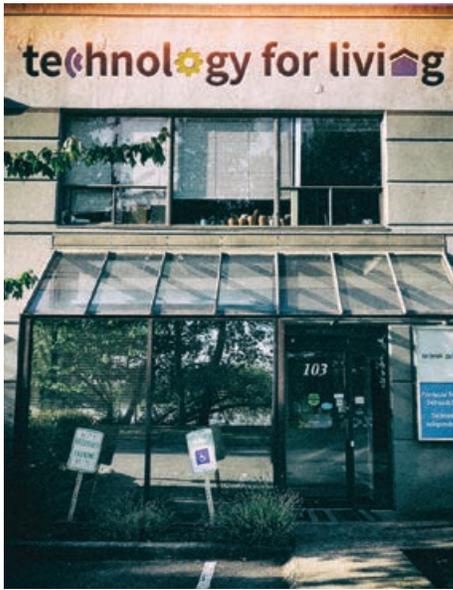
we promptly forgot about it because we had so much other work to do in creating a new society.

However, over the years, BCITS became cumbersome. Members did not know what the acronym stood for and staff became fatigued if they had to use the long form. Too many people got us confused with BCIT and we could not be more different. The Board of Directors put a name change on the "to do" list but it was always overtaken by more pressing matters.

This year, the Board and staff of BCITS settled to the task of name changing and realized, after much discussion, that our new name was hiding in plain sight. Our tag line Technology for Living seemed to us to satisfy our desire for clarity, brevity and suitability as an umbrella for the much-loved PROP and TIL.

I am happy to formally announce that the BCITS name will be replaced with "Technology for Living".

Dressed up slightly with some brighter colours and cleaner icons. We are still the same organization at heart. Like Juliet, we believe that our name is not as important as our deeds.



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Kinsmen Foundation 7th Annual Golf Tournament



In July, the Kinsmen's 7th Annual Golf Tournament, an annual fundraiser for our Technology for Independent Living (TIL) program and other programs, turned out to be yet again a wonderful event and community fundraiser. A big thank you to all who helped to make it a success, most of all: let's recognize all the golfers who came out in droves to support this fun and worthwhile event!



L-R: Jay Selvage, Mark Schroeder, Darcy Rota, Todd Watson, Dustin McLoughlin

After a delicious dinner it was a quick swap from golf ball to puck: Darcy Rota, a retired Canucks player who had been on the green meeting the golfers, contributed some signed Canucks shirts to the silent auction and they turned out to be a huge winner. The evening's event was eloquently emceed by Mark Madryga, Global BC's Chief Meteorologist.



Technology For Living executive director Ruth Marzetti accepting the funds raised for the TIL program during the event.

After the golfers were welcomed at the registration table the tournament opened with a pre-game lottery draw. The lucky winner of the draw was awarded the opportunity to try his hand at an ace-in-the-hole in order to win the substantial prize money offered by RBC.

BITS & BYTES FROM TIL

Good luck, Roger!

After over 13 years of dedicated service to the members of TIL and PROP, we are sad to announce that Roger Desmarais will be leaving our organization on October 4, 2019. Whether setting up TIL equipment, wiring PROP ventilators to run off of a wheelchair, maintaining respiratory equipment, or helping guide the programs, Roger has always shown utmost professionalism and dedication to our members, coworkers and the organization.

Although he will be missed, Roger has grand ideas for his future... and we wish him all the best in his ongoing journey.

Thank you for your dedication and service, Roger!

CONTACT US!

We are always happy to discuss any member's needs. Simply phone us at ☎ **604.326.0175** or send an email to ✉ info@technologyforliving.org

TIPS & TRICKS

Google Home Accessibility Beep

"Hey Google, I am not sure you are listening." The 'Google Home Accessibility Beep' can help. This feature let's you to know when Google is listening for a command, but you cannot see the activation lights. By turning on this feature, you will hear a beep when Google starts listening and another beep when Google stops listening.

What Does TIL DO?

By Wayne Pogue

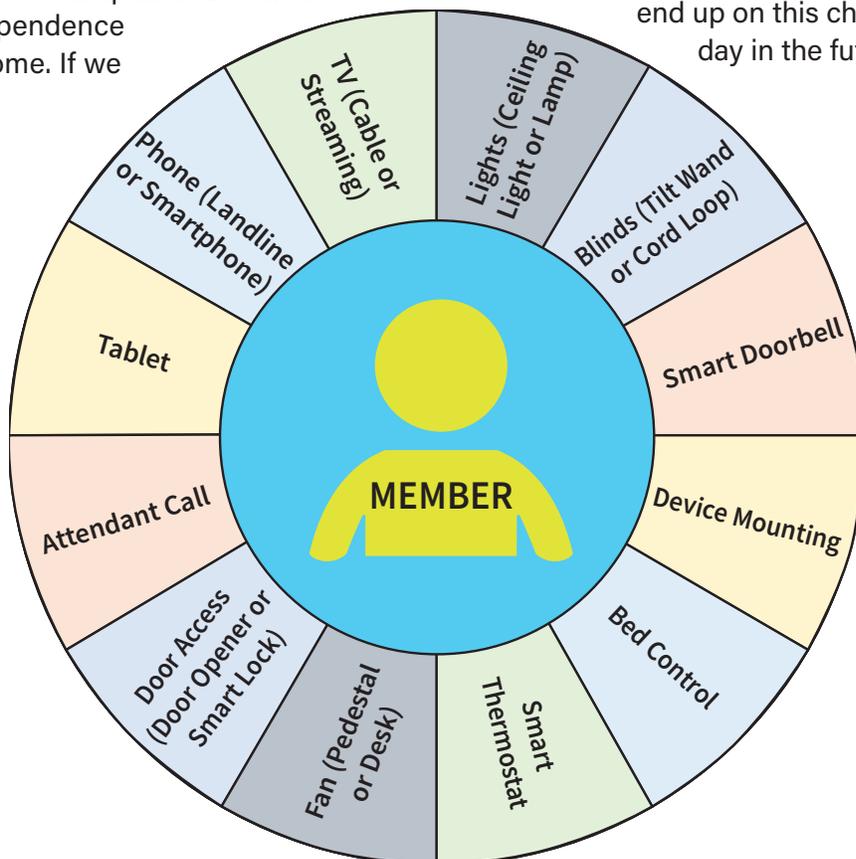
Whether people are new to TIL (Technology for Independent Living Program) or they've known of TIL for a while, members and OTs often get back to us with the question about what TIL actually does?

It's a complex question for us to answer because it depends on a lot of factors. Most of all it depends on what the member needs installed in their home to allow them more independence. In short: TIL can do a LOT. We provide Environmental Control and Home Automation Systems that allow members to electronically control their home environment using methods developed and/or altered especially for individual physical disabilities.

Often we start by asking the member what exactly they would like to control to help increase their independence at home. If we

believe it is something TIL can help with, we will then work with the member and their care team to assess in depth both the member's needs and abilities to find a solution.

This doesn't really answer the initial question of what we practically do on a job to job basis. We have created a chart to offer a visual guide to deepen the understanding of some of the main tasks we perform on a regular basis. Of course this guide is by no means complete. So should you have a question about something you don't see on the list: please contact us either by phone or by email which you can find in the contact box on this page. You never know: maybe it is something we can assist with. And, you never know, your unique need may end up assisting other TIL members and end up on this chart some day in the future!



ODDS & ENDS FROM PROP

PROP LOOKING FOR PARTICIPANTS THIS FALL

We are always looking for new ways to improve support for our members. Our trach and ventilation course is a province-wide, popular service to help family and hired caregivers develop skills to support ventilation at home.

This fall PROP is looking to update the education content for our ventilated members. If you have participated in a trach & ventilation course and would like to provide feedback, contact us at

prop@technologyforliving.org

And if you have never participated in our course, we still appreciate any feedback. Impactful learning for all caregivers is important and crucial to the independence of many ventilated individuals.

CONTACT US!

If you need respiratory advice or support please contact the PROP team at
📞 1.800.326.1245

IDEA CORNER

New funding opportunity. The Insufflator-Exsufflator device ('Cough Assist') now available for 1 month trials **with prescription**. It has helped some ventilated individuals with weak muscles to move secretions. Not currently funded by PROP but maybe funded with extended health benefits. **Consult with your Respirologist** first to ensure the device is appropriate for you.

PROP manager wins VitalAire Respiratory Home Care Award

By Ruth Marzetti



Team members of the Provincial Respiratory Outreach Program (PROP) with PROP's medical director, Dr Road.

Esther Khor, manager of the Provincial Respiratory Outreach Program (PROP), was honoured to receive the much coveted VitalAire Respiratory Home Care Award presented at the national Canadian Society of Respiratory Therapy conference held in Niagara Falls, Ontario in early May 2019.

The award recognizes respiratory therapists who have made significant contributions to the field of respiratory home care services and/or who have influenced others toward high levels of achievement in the field of respiratory home care services.

This award is being conferred annually at the President's banquet during the Annual Education Conference if there is a recipient. It was a great honour for Esther to receive the award from leaders and peers in her field of respiratory therapy. The award recognises Esther's contributions to home mechanical ventilation services, and her influence on others in the field all across Canada. Esther believes in encouraging others

in her field to aspire for higher levels of achievement in the field of respiratory home ventilation services. She leads the committed, passionate team at the Provincial Respiratory Outreach Program (PROP) and encourages them to share their experience and know-how of optimizing home ventilation for PROP members across BC as widely as possible.

Technology for Living is incredibly proud of Esther Khor and the PROP team which consists of five respiratory therapists and one RN, serving the province of BC. We believe that the services offered by PROP are second to none. Esther and the team are committed in researching the most up-to-date, safe and comfortable therapies for all our members throughout the province of BC, who require respiratory services. Another important aspect of their work is to actively involve the members, their caregivers and other community healthcare providers in a collaborative approach to ensure the best education and service is given.

Congratulations to Esther and the PROP team.

PROP services continue to be driven by the commitment of the members. With their support and advice the PROP team are able to recommend and implement a variety of individualized solutions to fulfill the diverse needs of our community.

The Blanket Mover

Reviewing a new assistive device

By Nancy Lear



Assistive devices are a big, important part of someone who lives with an extreme physical limitation. The *Blanket Mover* is such a device. The name says it all: by using an electronic, hand-held remote control, you are able to move your blanket. In other words, when you are warm you activate it to uncover you and when you are cold you use it to cover up again.

How does it work?

The *Blanket Mover* has two adjustable poles moving back and forth in tandem on either side of the bed. The tip of these poles gets fastened to two corners of a blanket by manually connecting pole tip and blanket via squeeze clips. The poles themselves are attached to a base shaft which is located on the floor underneath the bed.

After the initial set up of the contraption, minor adjustments are made by a caregiver before actually using the *Blanket Mover* to ensure your blanket is at the correct height to suit your comfort as well as checking an appropriate level of tightness after the blanket is attached to the poles.

Check out this video at <https://tinyurl.com/y4j7vkpr> to observe the *Blanket Mover* in action. Viewers will notice the black control box which is being operated with the left hand in the video once the blanket has been removed. Via the use of buttons, the user can choose to either remove the blanket or cover up again.

A project introduced at the 2017 BCITS Simon Cox Design Competition

This assistive device was conceived as a term project by BCIT students and it was demonstrated at the BCITS Simon Cox Design Competition in 2017.

Since then improvements have been made to the initial iteration by ENABLE, a biomedical engineering student team from UBC, in conjunction with the Tetra Society, a North American non-profit organization that is dedicated to find solutions to overcome environmental barriers faced by people with disabilities.

The product has been tested in the community and it has now been declared operational for wider use. In the future some minor adjustments to the speed control and to the hand-held remote controls will be implemented but for now the *Blanket Mover* is a working, assistive technological device!

UPDATE: The biomedical engineering technologists with our TIL program have been able to integrate voice-activation into the controls of the current Blanket Mover model. Great news for peers who may need hands-free technology!



David Hill is taking a stagecoach for a test drive at the Wells Fargo History Museum, California.

A Time To Remember

By David Hill

I attend the Little People of America (LPA) conference every year. Two things are always a big, happy part of the trip: one is food and the other is entertainment.

Food excursions with friends are an absolute highlight. This year the conference was in San Francisco, and we went immediately to *The Cheesecake Factory*.

On the way to the restaurant it was impossible not to notice the significant number of homeless people living in the downtown area of San Francisco, where the conference venue was situated. Our group drew a lot of attention and not always the good kind: once we heard someone say clearly, "The circus is in town." We were very careful and stayed continuously aware of our surroundings.

All was forgotten when we actually got to *The Cheesecake Factory*. I ordered a mouth-watering, crusted chicken parmigiana with spaghetti. For dessert, I indulged in a wonderful chocolate mousse cheesecake. When leaving *The Cheesecake Factory*, the adventure took a not so tasty turn ... we came across a very foul smell in the elevator: someone had actually urinated inside! YUCK!!!

I am a big Star Wars fan. So, I absolutely had to visit *Mel's Drive-In Diner*. It is a special place for me because it was featured in the classic movie 'American Graffiti' which was directed by George Lucas. While shooting 'American Graffiti', Mr. Lucas was inspired to make the first Star Wars movie. In classic drive-in style, I ordered a cheeseburger and fries.

Another place with an emotional connection for me is *Wise Son's Jewish Delicatessen* inside the Contemporary Jewish Museum. Visiting this deli was important to me because of my Jewish heritage. I very much enjoyed the experience.

My friend and caregiver Aaron and I took a bus to the famous Pier 39 waterfront where we embarked on a scenic boat tour around the San Francisco Bay area. The boat went under the famous Golden Gate Bridge and the San Francisco - Oakland Bay Bridge. We also saw Alcatraz Prison and Treasure Island during the outing. All that traveling does build up an appetite...

While at Fisherman's Wharf, Aaron enjoyed a clam chowder bread bowl and I treated myself to a crab meat melt sandwich.

Another visit took us to the Wells Fargo History Museum. The museum showcases Californian historical artifacts and special exhibits with maps, relics, antique items like an old camera on a tripod, a telegraph machine, an old wind-up telephone, a stagecoach and gold dust.

But this was a conference and there is always much to take in or take part in. Of course, there are medical and general workshops. There are activities for children and teens. There are also many receptions;

talent and fashion shows; events show casing the Dwarf Athletic Association of America (which include sports like soccer, swimming, and bocchia); performances and exhibits by the Dwarf Artist Coalition; and a closing banquet.

Busy, busy, busy. And not only during the day! Every night there was fun to be had. In the main ballroom, dancing for all ages took place. And in the Barty Lounge (named after the LPA's founder, Billy Barty) there was entertainment for adults 21 and over.

I thought the talent show was a particular success with a variety of brilliant LPs of all ages. The show was produced in a Little People of America Got Talent format. The four judges gave wonderful opinions about all the acts.

A great moment for me took place after the closing banquet: I was able to meet the keynote speaker – Danny Woodburn, the actor who played Cosmo Kramer's little person friend Mickey, on the TV show 'Seinfeld' from the 90's. The 2019 LPA conference was, as usual, a wonderful summer highpoint for me.

LITTLE PEOPLE OF AMERICA, INC.

LPA is a national nonprofit organization that provides support and information to people of short stature and their families.

Short stature is generally caused by one of the more than 200 medical conditions known as dwarfism. LPA welcomes all 200+ forms of dwarfism.

**Find out more at
www.lpaonline.org**

LPA has more than 6000 members across the United States and internationally. It is organized in 13 districts and 70 chapters.

LPA provides social interaction, parent and peer support, medical support and education, scholarships and grants. Our members range from newborns to senior citizens, little people and average height. Dwarfism cuts across all religions, ethnicities, and economic levels. All are welcome!



A snapshot of David Hill and Seinfeld actor Danny Woodburn sharing a good laugh.

**IN THE NEXT ISSUE
OF THE BALANCE
NEWSLETTER David will
share his experiences
of friendships and
community at the
LPA conferences.**

Hello PROP/TIL Peer Members!



By Nancy Lear

Is everyone enjoying the beautiful BC summer weather, but also looking forward to some great autumnal excitement?

Here is a sneak peek at what we are working on behind the scenes at Technology for Living. Coming to you this fall is the very first ever virtual writing group. *Peers on Pages* or *POP*, is a free workshop series run completely online.

That's right! You don't have to leave the comforts of your own home to participate. Using your very own TIL assistive devices, you can join us to write and maybe share your work? It absolutely does not matter what your writing level is. Together we will enjoy each other's creative outputs and company.

As your Peer Network Facilitator, I am also looking forward to participating in this exciting new project.

Stay tuned as Technology for Living will be sending out more information along with online registration forms and POP guidelines. Watch this space for regular updates as well.

technology for living

Take part in a **VIRTUAL** creative writing workshop

Peers On Pages

Limited spaces... Reserve your spot now

Join from your home

Using your TIL devices/set-up to type your stories

Peers Writing Project

Series of workshops

Tell your stories, share your poetry, write a blog...

Contact Nancy Lear at info@technologyforliving.org or **604.326.0175** for more information about technical support, dates & registration.

Access to life changing technology

By Elizabeth Rathbun

This article is based on a speech given at the Kinsmen Golf Tournament Fundraiser on July 11, 2019.

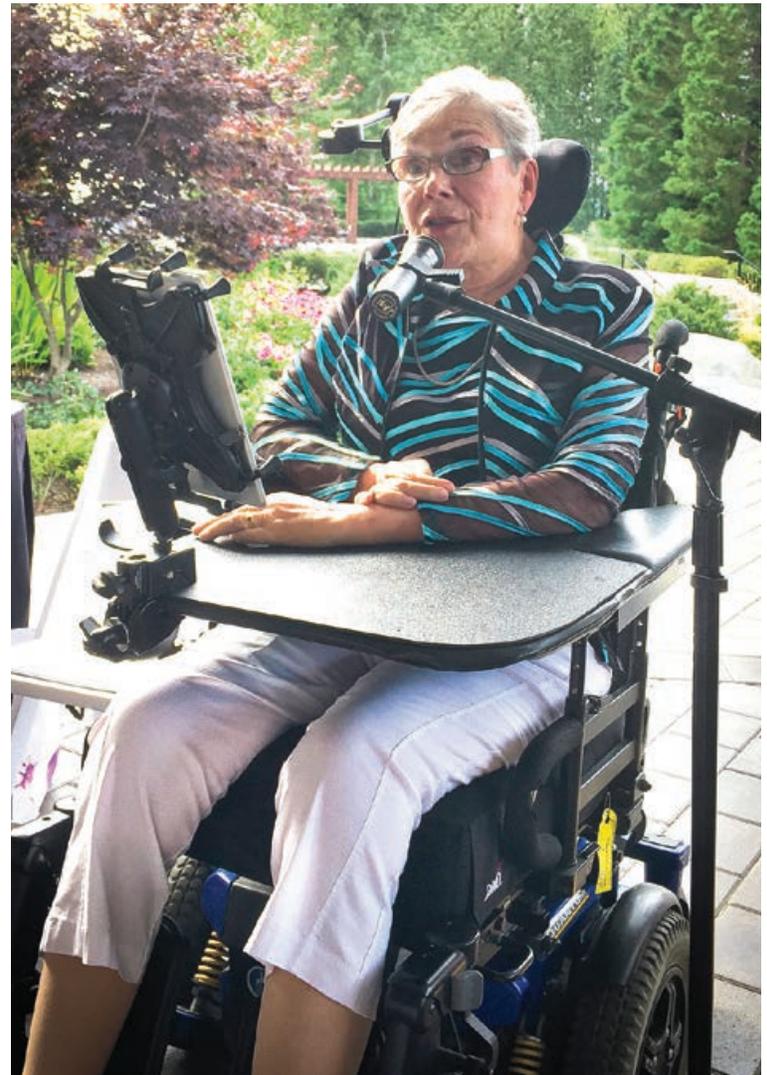
I require assistance in every aspect of my life and enormous personal care. I am deeply grateful that I live in an age of technology and constantly evolving innovations. Disabled people live in a different universe today.

Imagine this: you are a quadriplegic person in a power wheelchair. You have persons with disability status and receive the princely sum of \$1,183 per month as a single, disabled person or \$1,609 if you are a single parent with 2 children. You live alone in your accessible apartment; you have very limited hours of personal care provided by the government. You have no way of getting in and out of your house or your apartment independently. Until recently you had to wait for your care worker to arrive in order to leave or enter your home.

Today, everything has changed. Disabled people can be independent like never before. Your home can be wired to open and close doors using voice commands with the Google Home app. And by opening my own door, the world is opening up to me.

It is now possible for me to make phone calls without using fingers so that with or without a caregiver present I can use the phone. Sometimes I may not want to; but that's a different story. I can turn lights on or off; adjust the heat; set the security system; and control the TV. I am in the driver's seat, in control of my life. That's all made possible with the support of TIL and the Kinsmen foundation.

Almost everything disabled people need is very expensive. My own 13 year old wheel chair will cost \$25,000 to replace. There is not much support for people in need especially if you have some moderate resources yourself and a partner with an income. Suddenly the government subsidies are not there.



How it began.

I'm 67. My MS was identified when I was 33 years old. It took months of detective work to find the correct diagnosis.

At that time, I was married with a nine-month-old. I had a job that I loved as an arts administrator with the Vancouver Chamber Choir. My parents were elderly. My father had been recently diagnosed with Alzheimer's.

My husband and I had planned for me to continue working after having a second baby. We wanted to have our kids close together to enjoy doing family activities like ski trips and kayaking trips.

We did have that second baby in 1988 after much soul searching and consultation with family, friends, and a genetic specialist at the UBC MS clinic.

For 15 years, I had only minor non-progressive symptoms, mainly numbness in my fingers and an inability to do things like tying my shoelaces and using the computer without looking at my fingers.

At some point my husband told me: "There are so many people who want to help you, but **you** are going to have to do the heavy lifting."

Workplace, disability and stigma

During the early years, we led a very active family life and traveled as far as Australia. By 1998 I thought I was home free and returned to another great job as assistant director of Festival Vancouver. I ignored the fatigue which struck unexpectedly in the early afternoons or the disproportionate stress and irritation with the job.

Workplaces are very challenging for disabled people. Should you disclose a diagnosis to your boss and colleagues? Is there concern that you would be over-

looked for bigger projects and the promotion you had worked so hard for. But if you don't disclose, what happens when the invisible disability becomes suddenly visible?

This is all part of the stigma that many people with disabilities experience. My own stigma is rooted as far back as my childhood. When I had to wear leg braces I did not want to be seen with them in public. I certainly did not want to get into a wheelchair. It's not that I was unsympathetic towards disabled people. I just didn't want to be one. It is hard work to free yourself from this learned, internalized stigma.

Also, many disabled Canadians live in poverty which carries its own stigma, a story for another day.

The changing nature of personal relationships

What I experienced was like a spinal cord injury in slow motion. It required continuous evolving adaptations, equipment, and care.

I had my first clue that things were changing when I went for a run at our family cottage in Ontario in 2001. On that run it became apparent that my right foot was not rising and moving forward as it should. I walked, tried again, walked, tried again, and then walked back to the cottage.

I called to my husband and said: "Something's wrong. We have had a good 15 years. I need a referral to another neurologist." This new symptom is called foot drag.

I've since experienced many "new" deteriorations. Each takes the wind out of my sails and leads to a new round of appointments with specialists and OTs.

Marriage is an Iron-Man challenge for people with disabilities. It's a rare marriage that can navigate all the challenges successfully, to love each other for who we really are. We began to get to know each other anew after having been married for 20 years.

More than 50% of marriages fail after an MS diagnosis. The person with MS ends up alone – sometimes with children to look after. MS affects women in far greater numbers than men.

I am a lucky woman. My husband decided that when the going got rough he was not leaving. At some point my husband told me: "There are so many people who want to help you, but you are going to have to do the heavy lifting." I've been blessed with the support of family and friends.

The many sides of help

I want to talk about help – about getting it, receiving it, and appreciating it for what it is and for what it is not.

Marriage, children, and my relationships with caregivers have been central to making my life work. When I was new at having caregivers, I said to my OT that I

didn't want to make the big effort needed just to get out of the door for a small errand. She reminded me that I'd once planned a camping trip on the Bowron Lake circuit for a family of four: "Elizabeth, if you can do that, you can do this!" My response was: "But I don't want to." She said, "You have no choice. And, you are good at it."

Caregiving is about the relationship far more than it is about the list of tasks on the care plan. The quality of receiving must match the quality of the giving. There is an unspoken reciprocal, dialogue between caregiver and recipient. And there is a spoken dialogue which is a rich exchange of stories, cultures, family histories, mistranslations, misunderstandings, and hysterical occurrences.

The people who provide professional caregiving are resourceful, flexible, patient and intelligent. They are proud of their work and reliable to the extreme. They exercise self-discipline and they display discretion and immense courtesy. And they deserve the same from me.

Very often the first response to living with an extreme disability or neuromuscular disease is to lose hope and become (clinically) depressed. Until very recently, depression and mental health issues carried yet another stigma. We are slowly overcoming this, learning that depression is treatable. The initial commitment to seeking ongoing treatment is the responsibility of the disabled person but encouragement to seek help by friends, family or colleagues can be enormously helpful.

Navigating the healthcare system

Disabled people have to navigate a complicated and siloed healthcare system.

I have eight specialists. My current diagnosis is "quadriplegic with severely advanced secondary progressive MS". I also have several co-morbidities: major epileptic seizures; osteoporosis from the steroids which kept me walking; scoliosis because the muscles on the left side of my trunk weakened faster than the muscles on the right; bladder and bowel issues; spasticity in the upper body; and mysterious neuropathic pain.

Most significantly I have COPD (chronic obstructive pulmonary disorder). I have only 33% of the lung volume of a healthy woman of my age.

Of the eight specialists, my respirologist and my physiatrist are the most important. I had never heard of a physiatrist until I needed one. Now I call her the patron saint of rehabilitative medicine.

Specialists are a brilliant resource with knowledge and experience in abundance; but they do not make decisions for you. They give you choices and every one of those choices involves compromises.

I have also worked with many OTs, seating specialists, physiotherapists, and case managers. Organising chronic care and all of the ancillary assistance you will need is a full time job.

Living in an inter dependent world

Our society prizes independence, autonomy, and self-reliance. Yet in truth we live in an inter dependent world. Disabled people have much to teach about living in this world. While we certainly need help, we need to remember (and be reminded): we can and do contribute to this new understanding of the way society works.

I live with limitations and discomfort. But I remain an avid student of world literature, geo-politics, and climate change. I cherish music, our delightful garden, food, and talking to people.

When a TIL biomedical technician visits my home, they meet a complex person with a very complicated medical and personal history who is leading an adult life. I am thrilled to have them visit and enjoy the connection, humor, and their ingenuity in solving problems, like providing me with the invaluable head clicker to turn the pages of my e-book.

Technology for Independent Living (TIL) and the Kinsmen Foundation

A few very forward thinking, generous individuals saw a need and said: "There's an opportunity here — we can do something". These members of the Kinsmen Foundation went ahead and set up the TIL program at Technology for Living (formerly BCITS), an invaluable resource for those of us who live with disability.

What the Technology for Independent Living (TIL) program provides are tools that enable us to overcome loneliness and isolation, offering independence, pleasure and diversion. TIL's inventory can greatly increase the ability of disabled persons to live in spaces specifically designed for them and their needs. This is a huge, truly important advancement. Thank you, in the fullest sense of the word.

Awareness & education: A key to promoting independence

Over the next few months, Ean Price, the Innovation Strategist with Technology for Living will be setting up a pilot project with five TIL members, using video conferencing to introduce new affordable technology and to streamline the set-up process with technical support from Marie Cambon, who will be available to further assist members in the Lower Mainland. If successful, this pilot will be offered to PROP and TIL members across the province.

Stay tuned for an in depth report in the December issue of the next Balance.

te**ch**nology for livi**ng**



“ With guest speaker
Elizabeth Rathbun ”

AND SOCIAL!

All our members are cordially invited to attend the Annual General Meeting on

 **Tuesday, September 24, 2019**  **6.00 - 6.30**

 **PERFORMANCE WORKS GRANVILLE ISLAND**
1218 Cartwright Street, Vancouver BC V6H 3R8

 **Parking in the vicinity**  **#84 or #50 bus route**

 **technologyforliving.org** or **604.326.0175**

After the **AGM** : **SOCIAL from 6.30-8.30** with **Door Prizes**, a performance by the **Fuse Wheelchair Dance Society**, a **Photobooth** and some **Light Refreshments**

PATHWAYS TO INDEPENDENCE SOCIAL