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balance

... what it's all about

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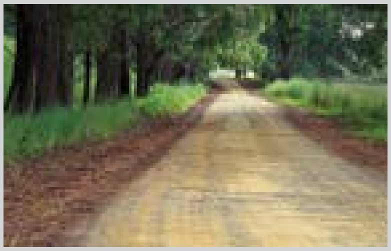
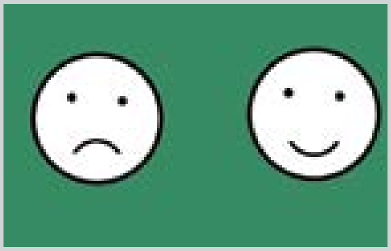




She always showed up ...

By Ruth Marzetti, executive director, TFL

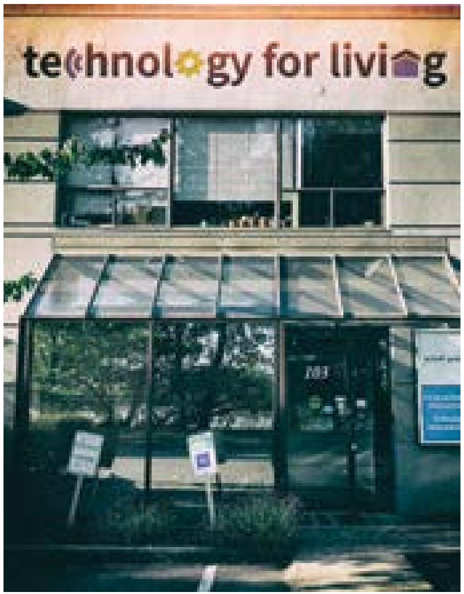
On December 20, 2021, our amazing colleague and dear friend Nancy Lear passed away suddenly after being hospitalized with pneumonia. Nancy was a dreamer, adventurer, writer, change maker and so much more. There was not a challenge she wasn't prepared to tackle, always with a polite demeanor and a cheerful outlook. Even when she had health issues herself, Nancy remained a calm, steady presence.

We have been fortunate at Technology for Living (TFL) that Nancy was also utterly determined to follow her dreams. She was born and grew up in Newfoundland (see Balance Dec 2019) and despite being fond of her home province decided to move to the other side of Canada, to Vancouver in 2014, to start afresh. Nancy was never intimidated by obstacles. Once she decided to move, she contacted a few people in BC, politely ignored their advice to take it one step at a time and arrived with her luggage and a temporary caregiver in Vancouver. As her brother said, Nancy's moto was: 'Move with me, or get out of the way.'

In her role as the first peer network support facilitator with TFL, Nancy's ability to 'roll with the punches' was a godsend. If something didn't work out the first time, she would change it up and try again. Over the years, she was a pivotal figure, creating many successful peer initiatives. She was involved in adding social peer events to Technology for Living's AGMs; developing and co-facilitating the peer writing workshop Peers on Pages (POP), which is now in its 3rd year; she was an integral part of the annual Simon Cox Student Design Competition; and an active participant with the Pathways To Independence project. And, of course, she was an amazing contributor to our Balance Newsletter.

One of Nancy's greatest passions in life was travel. She visited many places in the world. She was never intimidated by potential stumbling blocks that come when travelling with a disability, especially as an individual who is on 24-hr ventilation. It never occurred to her not to go (See Balance June 2020). Once back home, she would immediately start planning for the next trip. Even during the most intense COVID-19 restrictions, she was already working on her next big adventure: to go to Australia. Alas, that wasn't to be.

We were all privileged to have met you, Nancy. You will be missed.



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SIMON COX STUDENT DESIGN COMPETITION 2022 SUPPORTERS

RBC Foundation

RBC Foundation, in support of RBC Future Launch, a commitment to helping young Canadians prepare for the jobs of tomorrow. With a focus on networking, skills development, practical work experience and mental wellbeing supports and services, the initiative aims to help break down the barriers facing young people.

KINSMEN FOUNDATION OF BC

Kinsmen Society of BC's mission is to raise funds to support many worthwhile organizations and individuals facing the daily challenges of living with a physical disability to improve their quality of life and independence.

SHAWSABEY

The Axis Insurance group serve Canada with risk management and insurance services. We are proud supporters of this innovative competition where students design new pieces of assistive technology that have the potential to transform the lives of others.

BC Rehab FOUNDATION

BC Rehab works toward a British Columbia that is inclusive and accessible to all people. Promoting projects and initiatives that increase accessibility so that all people — regardless of their physical capabilities — can thrive, participate and contribute in their communities.

LOHN FOUNDATION

The Lohn Foundation is a generous supporter helping organizations improve and transform healthcare in our community.

KPMG

KPMG in Canada is a socially responsible public organization committed to helping people thrive. The SDSDC encourages innovation through collaboration of people with mobility issues with BC's post-secondary students to find solutions that help overcome barriers so we can all lead more independent lives. KPMG is committed to supporting initiatives that create respectful, inclusive and barrier-free communities that allows all people to reach their full potential.

Increased independence in the home

TIL has recently installed an automatic door opener in Richard Quan's home. Here is his story:" Getting the automatic door opener has improved my life in so many ways. It has given me the ability to be much more independent and feel much safer in my own home since I know that I do not have to rely on others to open, close, and lock doors for me. Now, I can let my caregivers come and go as I need, and I can even accept deliveries. Previously, I had an experience where I got locked alone inside my home for several hours due to a smart lock malfunction and we had to call a locksmith in the middle of the night. It was so frustrating because if I was able-bodied, I could have just turned the lock and opened the door from the inside. But I couldn't, so I was just trapped and I felt so helpless. Until that incident, I had never realized just how important it was for my safety to be able to open doors. Now, I know that I will be able to get in and out on my own, and I won't have to find myself trapped inside ever again." If you are interested in an automatic door opener for your home, contact **til@technologyforliving.com.**

The Automatic Door Opener program is sponsored by the BC Kinsmen Foundation, the BC Rehab Foundation and the Technology for Independent Living (TIL) Program.

Bits & Bytes from TIL

Several SMART devices use batteries even though it may not be obvious. Some manufacturers engineer devices so batteries last a long time. Amongst TIL-provided SMART devices that need occasional battery changes/charges are for example: Ring Doorbells, August SMART Locks, Fingerbot, Switchbot, and the new Nest Doorbell.

As with all TIL equipment, TIL provides the initial batteries, but it is the members' responsibility to maintain their devices. That includes battery changes when needed.

If you have questions regarding batteries in TIL-provided devices, please contact us.

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

Did you know that, in these unusual times, you can request a virtual appointment with a TIL tech, instead of having a tech come to your home?

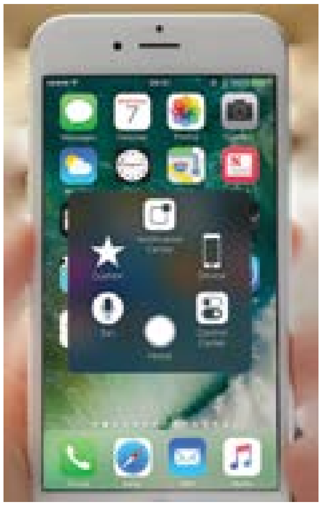
If you are worried about visitors entering your home, or live remotely and don't want to wait, a TIL technician can video call you and your care team to help install or troubleshoot any TIL-provided devices.

Accessibility Settings – iOS Touch

By Wayne Pogue

SMART devices are supposed to be helpful and make life easy. But often we need a little help to make them work for us the way they should. In the next few Balance newsletters, TIL is going to write about some important accessibility settings that can be found in many of our SMART devices (phones, tablets, voice assistants, etc). We hope we will be able to show how to make them work more efficiently.

We start by looking at some accessibility features on the Apple iPhone.



It is important to keep in mind that depending on which version of an iPhone you are using, and what software version the phone is running, these settings may be slightly different. Here are some iPhone "TOUCH" accessibility features that some of our members find helpful.

AssistiveTouch

AssistiveTouch is a powerful tool that allows the user to complete many typical gestures (go home, activate Siri, control center, lock screen, restart phone, etc) with the use of one finger. When AssistiveTouch is turned on, a dot becomes visible on your screen. Tapping on that dot with one finger opens a custom menu from where users can access shortcuts they have configured. All menus and gestures are highly configurable, allowing users to set it up for their personal needs.

Using a wired or Bluetooth mouse or joystick can make the iPhone even more usable for many of our members. The AssistiveTouch menu is where you go to add these "pointer" devices.

Reachability

Reachability is handy if you are only able to reach the lower half of your iPhone screen. With Reachability turned on, when you swipe down on the bottom of the screen, the top half of the screen moves to the bottom.

Touch Accommodations

Touch Accommodations is especially helpful for our members who can touch screens but may have tremors or shaky hands. By using Touch Accommodations, you have time to ensure sure your finger is in the correct area of the screen before your iPhone recognizes it as a "tap". It can also be set up to ignore repeat touches on the screen, so if you do tremor, only the first touch will be treated as a "tap".

Call Audio Routing

Using this setting, you can auto-answer any phone or FaceTime calls after a set amount of time. You can also ensure you're able to communicate with the caller by selecting what speaker you'd like to use for all calls. You can have the iPhone automatically select how to direct calls, or have all calls go to the iPhone's speaker or a Bluetooth speaker.

INHALE / EXHALE

Improving sleep hygiene

myAir app offers visual data and coaching to help bilevel users monitor their sleep. If you are currently using a ResMed Aircurve unit, you can connect it to the myAir app.

- Start by creating an account at myair2.resmed.com.
- Download the actual app from any app store

Once you have connected the app to your account,
you will be able to:

- access your nightly sleep data
- identify if your mask fit is adequate
- check out trends about hours of sleep and more.

The app can score sleep quality which can help to improve your nocturnal routine. It also offers access to many articles and videos where you can learn more about improving your sleep.

CONTACT US!
If you need respiratory advice or support please contact the PROP team at
1.866.326.1245

IDEA CORNER

Replacement parts

The next time you need to replace your bilevel mask or nasal interface, consider just ordering the cushion or headgear piece. The mask cushion slowly degrades with daily usage and is often the first part that goes. The headgear will get looser over time and the Velcro may become less sticky. It is more cost effective to replace individual parts than getting a whole new mask.

Pulse Oximetry and Your Health

By Krysten Polsky

The air we breathe into our lungs adds oxygen to our blood which then travels through the left chamber of the heart and through our arteries. It is the very bright red blood we see when we cut ourselves. We need to have sufficient levels of oxygen in our blood to be healthy.

How do we find out how much oxygen we have?

There are two ways:

1) In the hospital, a blood test called ABG (Arterial Blood Gas) is used to determine if someone's blood has enough oxygen. During an ABG, a sample of blood is drawn directly from an artery, normally from the wrist. If the levels are too low, the person is said to be suffering from 'hypoxemia': not enough oxygen in the arterial blood. An ABG test is quick and accurate, but also invasive and difficult to do outside of the hospital setting.

2) Another method involves a 'Pulse Oximeter', a small device that typically gets gently clippe to a finger. Pulse oximetry is a simple, painless, and non-invasive way to test how much oxygen is in our blood. In medical terminology it is called 'measuring your SpO2' (**S**aturation of **p**eripheral **Oxygen**). The Pulse Oximeter test can be used in hospitals but also in home settings.

How does a Pulse Oximeter work?

A finger gets inserted into a clip. The Pulse Oximeter shines 2 lights from the top through your fingertip: one is a red light, and one is infrared light. There is a sensor on the bottom part of the clip that measures how much light gets through your fingertip. Blood containing *lots of oxygen* absorbs more infrared light, but more red light passes through the finger. Blood with *little oxygen* absorbs more of the red light and more infrared light passes through.

When to test?

People with certain medical conditions may have a blood oxygen level lower than normal. Some reasons healthcare professionals may suggest pulse oximetry are:

- To evaluate whether someone needs help breathing
- To evaluate how well a ventilator is working or if the settings require changing
- To determine whether someone needs supplemental oxygen therapy

If you have any questions about pulse oximetry, contact PROP or speak to a respiratory therapist at a clinic/hospital for more information.

NB: The Coronavirus (COVID-19) pandemic has caused an increase in the use of pulse oximeters. Recent reports suggest that the devices may be less accurate in people with dark skin pigmentation. The FDA is investigating this issue.

Looking back, looking forward

By Jane Stilwell

I was diagnosed with muscular dystrophy (MD) when I was ten, a year after my family had emigrated to Canada from England.

There were small, telltale signs that something was amiss but nothing major.

As a child, I always was a bit clumsier than other children. Eventually, the frequency of my tripping noticeably escalated. I also began to walk on my toes due to my heel cords tightening up. Finally, I had a biopsy. I feel very fortunate that my doctor at the time was very thorough, trying to get to the bottom of my ailments. Often MD can remain misdiagnosed or undiagnosed for a long time. A neurologist needs to be involved for a proper diagnosis.

At age 10, it is hard to grasp what this kind of diagnosis will mean. How do you wrap your head around a disease that will constantly and, in my case, slowly progress? The uncertainty of not knowing how quickly I would weaken caused a lot of anxiety. I was losing abilities gradually, one bit at a time. When you lose anything, there is grief. But for me that grief was and still is not a constant part of everyday life. I don't grieve all the time. Grief is more like a visitor coming back to stay for a bit and then it leaves again.

During my early school years, I didn't feel the impact of MD too much. Once I hit high school, climbing stairs and getting up from a seated position became tougher. But all in all, the disease progressed very slowly.

It wasn't until my early twenties that I started to have problems walking longer distances. At that point I got a manual wheelchair which I ended up using for a good 20 years. During that time, I would use it most of the day, but I was still able to get up and walk around from time to time.

It was also getting harder for me to drive in those years, and more difficult to get in and out of the car. Eventually I transitioned to a power chair. The one I am using today is my third power chair in 20 odd years.

I grieved a lot when I left the ability to walk behind. I think it was harder to come to terms with losing the capacity to walk relatively late in my life. I had many years to experience the joy of being able to walk. I wonder if I would grieve differently if I had become paralyzed earlier in life. It is such a momentous thing, losing the ability to walk. Of course, at the same time, I am also grateful that my disease progressed slowly enough that I had those years where I was able to walk. But, still, I keep wondering: if I had experienced a shorter period with an ability that I no longer have, would there have been less grieving?

After high school, I was employed full-time for 25 years as an administrator with UBC. My job entailed working at both BC Women's Hospital and Vancouver General Hospital, looking after the academic needs of medical students and post-graduates.

Getting that job was one of the lucky breaks in my life. My dad knew someone who had a daughter who was working for UBC. I sent my resume and got the job. I know that some colleagues I worked with wondered if I was going to be able to get the job done. I did.

I loved my work. But eventually it became too much to continue working full-time. In those days, the early 2000s, the system only allowed for full-time work. I really would have liked to continue working part-time, and my department would have been happy to accommodate part-time work. But the problem was with the way disability benefits were calculated. Working part-time, I would have started getting limited disability benefits. And then, any change in my work schedule would further negatively affect my disability benefits in the future, making them eventually not enough to live on.

I feel luckier than most. Because of the work I had, I was able to keep all my health benefits when I went on Long Term Disability (LTD) because eventually I required more and more care and equipment.

The new chair I have now is the first chair I have had to pay for out of my savings. Insurance companies now put caps on everything, which I think is wrong. Yes, people still get equipment, but it may not be the right equipment for their needs. People deserve access to equipment that enables them to have the greatest personal independence possible, even if they personally can't afford it.

I continue to look at life as an adventure. I am excited to live in a world where technology to support people with disabilities exists and continues to evolve. But it needs to be affordable.

My previous power wheelchair had built in features that allowed me to drive a vehicle, so I could get to work for example. My new chair has the same features, but they are now classified as add-ons, which my funding does not cover. I would have kept my old chair. I had it for 12 years, and it was in good working order. However, medical supply companies do not make parts for wheelchairs 7 years and older. This of course means we need to replace wheelchairs more often than necessary – forced obsolescence.

Yes, this new chair has better shock absorbers which makes for a smoother ride. But this chair also sits higher than my old one. This meant I couldn't fit into my car anymore. My old chair could be raised higher or lower on a pole. We could cut that pole off to address the height problem. The new chair is raised and lowered via a scissor lift, so that solution doesn't work. In the end, I had to get the padding in the ceiling of my car removed to be able to fit in. Another new feature the chair offers is Bluetooth connectivity which is good for those who use that technology. On the flip side, this kind of functionality depletes the battery charge a lot more quickly. I only needed to charge my old chair every 4-5 days. The new one needs charging every 3 days.

There are so many things that can cause disabled people unnecessary grief and frustration. If I were an engineer, designing for better accessibility would be fundamental. I have great respect for an organization such as TIL.

A friend of mine was very happy she managed to get a wheel-in shower installed in her apartment. But nobody had thought about how she would be able to turn on the taps. She contacted TIL. The team came up with a lever system that they added on to the taps in the shower and, for good measure, to the kitchen taps as well. Those guys are so smart!

I am new to PROP since I just recently got my first bipap machine. But I had heard about PROP before. I believe this was the first program of its kind in Canada. It is such an excellent program - surely other provinces are jealous of it. It provides outstanding 24/7 service.

Research is moving forwards as well. Scientists know now which genes are affected that can cause some of the neuromuscular diseases. When I was young life expectancy was said to be early teens to twenties. Today, one of my friends has a son with MD. He is 53. So, things have come a long way not only with treatment, but also with breathing assistance.

I have done a lot of volunteer work around MD, with people who are moving through similar experiences as I have had. I think it may be just as helpful for me to talk to peers about tough times I have gotten through as it is for them to talk to me. I have learned so many things that I would never have been exposed to thanks to talking to peers.

The SMART Space

An update by Benson Au

It almost feels like it was yesterday when Technology for Living (TFL) first opened the SMART Space at the George Pearson Centre (GPC). Our initial idea was to create a space to showcase the different technologies currently available to provide more independence to the residents at GPC. But the SMART Space has now been there for almost a year now.

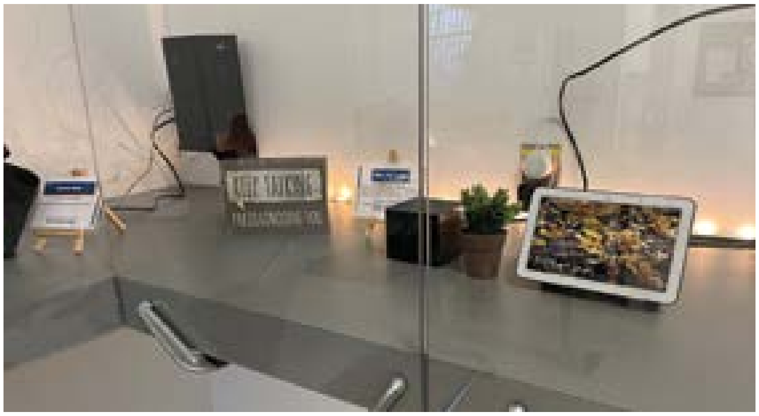
Like many worthwhile projects, it seems to have a life of its own. The SMART Space is sometimes used as a testing place for new technology; and other times, it is used to host movie nights with friends. Beyond the fancy devices and the super cool environment, for the residents who use this space it has become part of their home. Personally, I feel a deep sense of joy being part of the development of the SMART Space.

> **In my opinion, over time, the space has grown to be much more than what we originally hoped for.**

What I have observed is that this room has become a place for introductions, a place where friends are made, and a place where you come to play. When I ask myself, has technology, such as the devices available in the SMART Space, served the purpose we had initially envisioned? My answer is a firm yes! I believe that one of the best aspects of technology is its ability to bring people together. Now, when I enter this space, nearly a year after it opened, I recall countless memories that were made possible by the technologies we provide. Whether it's seeing a member operating their TV independently or using a switch to operate their iPad, moments like these create the most profound impressions.

As for the future of the SMART Space, I hope that it will continue to evolve and reflect the needs of the community. There are many diverse reasons why residents are using the space. For me, I hope it continues to create the best possible and cutting-edge technological space for the residents. I think the SMART Space has given the residents a glimpse of what's possible with technology.

That said, I am not certain about the future of the SMART Space as the era of GPC is slowly coming to an end and residents will be moving into a brand-new building soon. One of the initial impetuses for creating this space was to showcase new technologies that the residents could potentially have access to when they move to Cambie Gardens, the new community living condos. As a testing space for the residents to try things out, the SMART Space offers an opportunity to see how they could use it to grow ever more independent. If the technologies prove to be useful, TFL and GPC are able to look for funding and provide these technologies to the residents in the new building. I hope that this can happen, but I also feel a designated SMART Space should continue to be a part of the new living space, because it has become as much a place for technology as a place to make and meet friends.



A tale of two support systems

No human being is an island. We would be hard pressed in today's world to find a true hermit who has no contact with any other people. So, it follows that every human being who lives as part of a community gives to and receives from other people. This is of course a very simplistic supposition, but there is a great deal of truth in it.

In this article we look at two types of support systems for giving and receiving care in the communities we live in: a peer support system and the provincial health care and support system. When this article was initially conceived, we planned to write about peer support, very specifically about our peer program here at TFL (Technology for Living). The article was planned around our then peer support coordinator, Nancy Lear. And then Nancy sadly died.

You will already have read about Nancy and what an incredible woman she was in the story on the cover of this *Balance* issue. We decided that this article should be about how she shaped, grew, and nurtured our peer community with all her savviness, her experience, and her heart.

A few peers came forward to participate in this article because they wanted to share what Nancy meant to them as a peer and as a friend. But despite all the respect, kindness, and love which shine through their thoughts about Nancy, there is no denying that her story also brings up intense feelings of anger and worry. Both are important and, together, tell a tale of two support systems.

The peer support program at TFL

Nancy had both the advantage and the disadvantage of being the first person in the role of paid peer support coordinator at TFL. While there was a job description, she made the job and the program her own, building it up from the ground up. And she made a huge impact in the wider community.

As Linda McGowan, a participant in the Peers on Pages (POP) program, puts it: "Nancy shared information and experience about respirator care. With enough time and patience, she found ingenious ways to make things work. She encouraged all members of the disabled community to do the same."

Taylor Danielson, the community coordinator at TFL, suggests that in pure practical terms the peer program Nancy helped to create is essential to ensuring peers get the support and equipment they need. It works, he says, because of collaboration and partnership: between peers, TIL (Technology for Independent Living Program), and PROP (Provincial Respiratory Outreach Program).

Living with a disability is often labeled as a condition that needs to be "treated" by professionals. Nancy didn't see it like that. She understood peer support as an opportunity to think creatively and non-judgmentally about the way individuals experience and make meaning of their lives. This school of thought contrasts with those where all actions and feelings are diagnosed and labeled by professionals.

Ean Price, the innovation strategist with TFL, fundamentally agrees with Nancy's approach to peer support: "If you have someone who has knowledge like 'this is what I use, this is what I do' that builds huge confidence instead of talking to a health care professional. Looking into someone's eyes and saying, 'You might be scared right now but we will help you get through it, we have been there' - that's what peer support is." This is what Nancy did every day.

Peer support is based on mutual giving and receiving help. At its heart are three key principles: respect, shared responsibility, and mutual agreement of what is helpful. Ean continues: "Being a burden is a familiar feeling for people with disabilities." That sentiment echoes with Nicole, another peer. She takes it one step further: "I have heard it said too often that disabled people complain all the time. Actually, we really *want* to be productive members of society." This is what the peer support under Nancy's leadership set out to facilitate.

Nancy believed that peer support is an inclusive model that creates room for all people to fully experience "being who they are".

An overarching goal of peer support is to respectfully challenge assumptions about disabilities, made possible by seeing a person for who they really are and where they have come from.

One way for her to explore this was by creating *Peers on Pages* (POP), which provides training and mentorship for people to write their own stories in their own voices. Linda, a member of the group, comments: "POP is a creative writing group. It was primarily organized and supported by Nancy. She was determined to make us all qualify for a Pulitzer Prize and kept insisting: 'You can all be good writers.'"


Nancy Lear (left) and her colleagues Susan (centre) and Taylor (right).

The peer program will continue without Nancy. It will be different, but she has created such a strong foundation, and left such a legacy of good will and energy, it would do her an immense disservice not to keep going. Taylor calls Nancy "the embodiment of what it means to be a peer". He adds: "Her steadfast dedication to supporting her fellow peers was a shining example of how we should be moving forward and growing our peer network within Technology for Living. She knew each of us had our own strengths, and by working together we could advance the causes closest to our hearts to make a future better for everyone. Nancy was taken from us too soon, but her legacy will forever be the foundation of the peer network at Technology for Living."

The provincial health care and support system

Nancy died in the hospital on December 20, 2021, from a heart attack after having been admitted for pneumonia. For Nancy the heart attack was a very sad, possibly unavoidable, end to a life. But what came before this was far from inevitable in many people's opinion. Nancy did not receive enough funding to pay for 24 hours a day care, leading to her deteriorating health. Nicole shudders to think about Nancy's situation: "I was shocked about her death but not surprised. It was only a matter of time before someone passed away in this climate of underfunding. Nancy was not only unable to move due to MD (muscular dystrophy), but she also had a trach, that's a very specific need. It's absolutely dangerous if you don't have the care you need."

There is no government in the world that dedicates sufficient financial support to social and health causes, and to home care in particular. But the situation feels more dire now with the additional impact of the COVID pandemic, now going into its third year. Nicole continues: "I have found it impossible to get carers during the pandemic. There's not enough money to pay my carers what they deserve. And it feels like it's getting worse every year."

Ean agrees. He remembers a very good friend from nearly 15 years ago who died too young, in his early 20s, who also found himself in a situation where funding may have been a contributing factor to his premature death. Ean's friend Jim (not his real name) was like any young man: eager to leave his parents' home and get a post-secondary education in a big town. He tried to obtain CSIL funding. CSIL or **C**hoice in **S**upports for **I**ndependent **L**iving is a valuable and important self-directed option for eligible home support clients offered by the BC government. But Jim's family was overwhelmed by the application process.

Jim ended up moving into a shared living accommodation with a promise from his case manager and the care facility that carers would be on hand to take him to school and out to make friends. As soon as he moved into the shared home, budget cuts put an end to these promises. Just like Nancy, Jim ended up staying in bed with not even enough time with carers to allow for occasional trips outside. Ean explains: "It is important to leave your bed regularly, no matter how bad you feel. It's helpful for the airways. Transferring into a chair, getting to the bathroom, repositioning the body, and other micromovements help you stay healthy." Without those opportunities, his friend Jim, just like Nancy, ended up catching pneumonia and passed away quickly.

There are support groups, like IFRC (Individualized Funding Resource Centre) and ACE (Association of CSIL Employers), which are working ceaselessly to try and improve the situation. They are lobbying the provincial health authorities for more funding. But obtaining sufficient funding has always been an uphill struggle and with the increased pressure of paying for pandemic-related health care bills, hope to obtain appropriate government funding is at an all time low.

Having the choice to living independently at home, rather than being institutionalised, is at the heart of what both Ean and Nicole, and many other peers, are fighting for. When a peer has access to CSIL, they can direct their own care. For example, they decide *who* comes into their home to provide that care.

As Ean puts it: "It's up to me to direct my own care. In a care home that decision is not mine to make."

There are many disabled people who feel they are being pushed into the care home alternative while waiting to receive funding from the government to pay for care in their own home. That wait can be long. And, even after successfully obtaining funding, Nicole points out that it is often not sufficient: "Since the pandemic made the funding situation worse, my life is on hold. I am not living to my full potential because I don't have the care I need."

Ean insists the way forward is to grow diverse care options, looking for opportunities to make it possible for disabled people to live independently at home, receive the care they need and not be seen as a financial burden. He explains: "When I was young and there was no one available to support me, I was told to go to the hospital for extra help, whether I was sick or not. I basically got a hospital room to stay alive for another night. I can't remember how much it exactly cost in those days for a night in hospital. It may have been around $10,000. Today it will be a lot more. That is very expensive! It is a lot cheaper to live at home with a carer and it helps to have a job to be a productive member of society."

Even though Taylor feels deeply sad about the loss of a friend and colleague, he is unwavering in his commitment to fighting for more support: "Nancy was unquestionably one in a long line of many people failed by a healthcare system that is actively crumbling around us while we are still inside the building. The healthcare system needs stronger patient protections and advocacy services. When you have been wronged, failed, or inadequately supported by the system and you seek recourse you are met with a faceless government bureaucracy which for all intents and purposes is Goliath to your David."

After Nancy's death feelings of sadness, loss, and anger have reverberated through the peer community. People were not ready for her death, but her premature departure has also instilled an increased fighting spirit in the people she worked with and for. As the peer support coordinator, Nancy was at the forefront of building a strong community at TFL. Nancy was committed to a model of integrated support, where a vibrant peer support system and a well-funded and quality state care system were mutually beneficial – not a tale of two support systems.

"Every time I talked to Nancy, I thought anything was possible," mused Nicole. "She was all about bringing people together, motivating people. Right now, staying strong and positive is difficult. But having peers around helps, and organizations like TFL and IFRC help too. Nancy's death was such a loss but fighting on is the way forward!"

My Pandemic Experience

Part 1, 2020

By David Hill

On March 11, 2020, the World Health Organization (WHO) declared the novel coronavirus (COVID-19) outbreak to be a global pandemic.

The BC government never called the restrictions it put in place to curb the virus a "lockdown" like other provinces in Canada or countries around the world. But when I think back to spring 2020, it sure felt like we were under one. The intense restrictions were in place until early May.

From March to May, I experienced feelings like stress, depression, and a constant unease because I wasn't sure what was going on. Like most people, I had never lived through an actual pandemic. Other events even remotely comparable, like the SARS outbreak in 2003, seem like minor incidents compared to the events we are living through right now.

My day-to-day routines changed a lot. Of course, I had to spend most of the time at home because of the restrictions in place. My regular schedule fell away. I felt like the pace of my life changed, like a pendulum in an old clock starting to lose momentum. But new things barged in unexpectedly out of nowhere for me.

I am talking about video-calls. By now everyone, including myself, has gotten used to Zoom meetings. But when they first appeared in my life, these planned meetings took away a lot of spontaneity from life. There is a lot more planning involved about when to do what using this method of interaction. This new dynamic made me feel very uneasy.

I was trying to adjust, but I felt extremely disoriented because of the strangeness of it all. I felt the world was out of control. In late spring, I felt so bad that I met with a friend from my church who shared some counselling advice and introduced me to some anti-stress pointer exercises to help me relax. These helped me to take baby steps towards working my way out of the constant anxiety I was experiencing.

Finally, by the middle of May, I was able to go out and meet with friends. They quickly became part of my personal bubble. This was right after my birthday. What a great present and a real relief!

Sadly, the newfound freedom lasted only for a short while before another Corona wave hit. But, during the short blip, I really enjoyed being able to attend church in person again. Back stuck at home for a second round of restrictions, I did my best to occupy my time. I tried to focus on things that were most important to me. I pursued opportunities to spend time with family members in my personal bubble and made an effort to go outside on walks to get fresh air. I did feel a little better than during the first period of restrictions because at least this time I was able to do things with friends within my circle. I ended up watching many shows on Netflix and Disney+ with friends and family members.

During the August long weekend in B.C., we were able to go on a camping trip which was a sign to me that maybe things were improving. We stayed at a cabin in 100 Mile House with friends, and I even met some new people. It was like the summers I was used to: playing games and enjoying summer foods including s'mores! I felt such a relief.

But there were always reminders that 2020 was not quite as normal as I felt for short moments during our camping trip. For example, our church services had moved out of the church and into the park. During one service, I had a photo taken with a couple that was going to get married within a few weeks.

I ended up being invited to the wedding and, thanks to COVID, I attended my first drive-in style wedding! What an experience.

During the fall, I continued to meet with people in my personal bubble, often outside, and enjoyed a nice family Thanksgiving. The Christmas holidays were different but still good and enjoyable. Like every year, I went over to my grandparents' apartment on Christmas Day evening and had turkey dinner. But it was a lot simpler and smaller because not as many people came over as in other years.

In the end, I would say that, all in all, 2020 was not as bad a year as I feared it would be in the spring when it all felt glum and ugly. Little did I know that 2021 was not going to turn out to be the fantastic year I and many people had hoped for.

To be continued.

New PROP team leads

Sherry Shea and **Miranda Whiteley**, both Registered Respiratory Therapists (RRTs), have accepted the role as our new PROP team leads, effective immediately.

Sherry and Miranda bring a lot of experience and skill to the position as well as much enthusiasm. They will be job sharing, each working in the team lead role on alternate weeks while performing their regular RT duties during the other week. Sherry and Miranda will both be working four days a week.

We would ask you to join us in welcoming Sherry and Miranda to this role and to the TFL leadership team.

The SIMON COX

7th STUDENT DESIGN COMPETITION

A WINNING FORMULA

People with disabilities + Students =

Simon Cox Student Design Competition

This is a virtual event

Technology for Independent Living has teamed up with universities and colleges from around British Columbia. Together they are hosting this prestigious and innovative competition to create assistive technologies in a team environment of students and people with disabilities.

To view this year's entries and to attend this online event

Please check for the event's YouTube link at technologyforliving.org on May 7, 2022 after 9AM.