

Walter Tuchak, An Original Vancouverite

BY SIMON COX When the Olympics come to Vancouver, the Technology for Independent Living program (TIL) will be 40 years old. Walter Tuchak has been a client of the program for almost 30 years.

Walter agreed to be interviewed for **BALANCE** and he told me some interesting things about his life and living with a disability.

Walter is one of those unique individuals born in Vancouver. He was born at Vancouver General Hospital in 1945 and was diagnosed with cerebral palsy. Walter went to live at Woodlands when he was 2 years old and stayed there for 30 years before he moved to where he lives now. If



Walter Tuchak

you ask him about that time of life he says, "That was then and this is now."

Walter has lived in East Vancouver since 1980. His apartment is equipped with a remote control door lock, switch operated telephone and other devices provided and customized for him by TIL.

For 20 years, Walter has been a vendor and sells snacks from his home or at places such as Point Grey High School during night school events. He volunteers with the Family and Support Institute in New Westminster and is also looking for more work.

Walter is a big hockey fan. The Montreal Canadiens is his favourite hockey team and he loves watching the games. He also likes to visit places like the sea wall in Stanley Park and Grouse Mountain. During our long spell of snow this winter, it was difficult to get around and Walter was basically "housebound" for 3 weeks. He likes to travel and has visited Quebec City and New York, among other places.

I asked Walter, if he looked back on his life, what would he say? "I think I have done very well, but we all could do better."

Thanks, Walter, for your insight. ●

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Opinions

We want your opinions—really! Your feedback [or disagreements!] on **BALANCE** articles, things you would like to see on these pages, questions for our RTs or BioMed Technicians or other staff—are all welcome. Our goal is to make Balance as relevant to you as we possibly can, so please get in touch at info@bcits.org or by calling 1-866-326-1245.



A Message from PEADC

BY CHRISTINE GORDON According to Statistics Canada surveys, most British Columbians with disabilities struggle to find the personal supports that they need.

Personal supports, also known as disability supports, are the goods and services (like equipment, assistive devices, personal care attendants, or sign language interpreters) that enable people with disabilities to carry out the activities of daily living and fully participate in the life of their community. Personal supports help to level the playing field for citizens with disabilities and they are the building block for improving access to income and employment.

Since 2006, a coalition of community organizations called the Provincial Equipment and Assistive Devices Committee (PEADC) has been working in partnership with government to design a personal supports



Christine Gordon

program in British Columbia, beginning with equipment and assistive devices. The community developed a best practices approach called the Participation Model for Personal Supports and this approach has been adopted as the basis for integrating and streamlining the numerous programs in both the government and the community sectors that currently exist. The problem with having so many programs with so many different masters is that there is no unifying philosophy, vision or values, no emphasis on personal choice, too many barriers impeding access, a medical rather than a functional approach and little opportunity for follow-up training and support.

Two personal supports centres have recently opened, one in Victoria and one in Prince George, to demonstrate the Participation Model and to use it as the engine for change at local levels. Planning is currently underway in Greater Vancouver, Cranbrook and Nanaimo to create three more demonstration centres.

In Greater Vancouver, a number of service providers (including BCITS) are looking at how they can link their organizations to create a personal supports network. The network's goal will be to integrate the provision of equipment and assistive devices by network members (called network clusters) so that people with disabilities can obtain the information, support, and equipment and devices that they need through any point in the network.

Many of the groups that are involved in the community/ government partnership to redesign the delivery of personal supports think of it as making a revolution in an evolutionary way.

In practical terms this might mean, for example, that a person with a hearing need who contacted BCITS could be instantly connected with all of the resources that exist and begin the process of securing the aid or device that would help meet their goal for participation. Building a personal supports network will also mean that community organizations will begin to share things like information, databases, funding and human resources so that they can use these precious resources more effectively.

Many of the groups that are involved in the community/ government partnership to redesign the delivery of personal supports think of it as making a revolution in an evolutionary way. We are bringing all of the idealism, energy and passion of the revolutionary and applying it to the dense machinery of government and community service provision. As evolution would predict, we are fully expecting that adapting to the Participation Model will soon be the only way of doing business.

For more on PEADC and the Participation Model for Personal Supports, you can contact the PEADC Co-chairs: Christine Gordon ifproject@bccpd.bc.ca or Linda Bartram lindabartram@persona.ca. ●

Your Ideas from the TIL Survey

BY KIRSTY DICKINSON Thank you very much to those of you who took the time to fill out the survey about our TIL program in the summer. We really appreciate your feedback; you are, after all, the best people to tell us how to improve our service.

I would like to follow-up on some of the suggestions made by clients during the survey process.

One suggestion was that we have technicians situated throughout the province to allow us to provide faster service. Our current funding level (provided by the provincial government), allows us to employ two Biomedical Engineering Technologists and we keep them very busy. BC is a large province and we now have over 500 clients. Sometimes we cannot provide service as quickly as we would like. We do our best to offer troubleshooting services over the phone, but recognize that we are not able to address every issue in this manner.

It was also suggested that we provide more manuals on equipment operation and information on troubleshooting. As the name

of our program implies, we try to provide you with the best tools and information to help you make the choices necessary for your independent living. This means that we have "done our job well" when we have given you the information you need to manage and troubleshoot your equipment. We revamped our website this year and hope to add troubleshooting tips and equipment information. Please visit us at www.bcits.org and send us your suggestions for frequently asked questions and troubleshooting tips.

Some of you asked for a list of the environmental control equipment that we provide. Technology is always changing and, at TIL, our approach is to customize equipment specifically for what people need. So we recommend that you tell us what it is that you are having difficulties with and we will work on a solution tailored to your needs.

If you need a service call or have any questions, please give us a call. We are here Monday to Friday 8:30 to 4:30 at 604-326-0175 or you can email us at til@bcits.org. ●

Dressing needs

If you have any dressing needs, please check out Disabled Services Clothing. I looked at their catalogue and found many innovative ideas.

- Custom Clothing: garments made for you
- Special Design Clothing Line: select from specially designed clothing constructed to accommodate special dressing needs (their line of capes sound perfect for wheelchair/scooter users in our climate: windproof, rainproof and warm.)
- Retail Clothing Adapted to You: choose a conventional garment and then personalize it with alterations or adaptations to suit your needs
- They carry sizes S - 2X, men's shirts up to 6X. If needed, zippers can be put anywhere in pants, hoodies, blouses, etc.

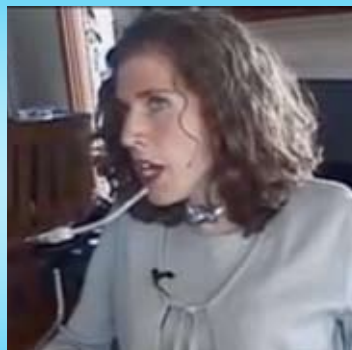
Easy Assistance Ordering
1-800-817-4365
<http://www.disabledservices-clothing.com>

~ from Jeanette Andersen

We're On YouTube!

PROP produced a documentary in 2002 about people living with ventilators. You can now see *Inspiration* at www.youtube.com/BCITS.

If you haven't seen this video, please take a look. And, it will give you a chance to meet some of the BCITS Peers who appear in the video.



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Speaking Valves

BY EVELYN KLEES Speech is a very important form of communication for most of us. For people with a tracheostomy tube in place, it is just as important.

If a "trach tube" has no cuff (balloon) around it, there is extra room in the trachea for airflow. This movement of air, directed up towards the vocal cords, is what allows speech to occur. If a person is also on a ventilator, their exhaled air is primarily pushed out through the exhalation valve in the vent circuit. So speech is often quite soft and words are halting because the person can only speak for the duration of the inspiratory phase.

David Muir, a person with a trach and vent, along with his physician, Dr. David Passy, created the Passy-Muir speaking valve. These special one-way valves are connected to the trach tube hub and allow for air to be exhaled out through the mouth and nose. This means that there will be a flow of air past the vocal cords, causing them to vibrate and produce speech.

There are additional benefits from using a speaking valve that can include:

- improved swallowing
- secretions are directed to the upper airway and this can improve the removal of secretions through the mouth
- improved sense of taste and smell

A speaking valve can vastly improve a person's ability to speak and have a very positive effect on their life.

However, a speaking valve cannot produce speech for a person who has lost their speech due to a disease process. It is also crucial that the client work with a Registered Respiratory Therapist (RRT) when they first try the speaking valve. It can be a real challenge for someone to begin exhaling through the mouth and nose if they have not done it for a long time. Also, some clients simply do not adapt to a speaking valve.

If you feel that your speech is not as good as it could be and you would like to try a speaking valve, please call PROP and make arrangements to have an RRT visit you. ●

On the Web



The Client Cafe is a new gathering place we've created on our website. We'd like the Cafe to be a place where you can:

- **read a story** about one of our clients or information from a Peer [someone who uses a ventilator or some of our TIL equipment]. We find these stories interesting and inspiring and we hope you will too.
- **share or seek information.** You can send a question using a simple on-line form to one of our Peers who will be glad to help. You can ask about your equipment or about our services. Or, if you have a helpful tip on equipment you'd like to share with others, we'd love you to send it in and we'll post it on the site.

Drop into the Client Cafe at www.bcits/clientcafe.htm. ●

Leading proposal selected for HandyDART services



FROM TRANS LINK A company that could provide all HandyDART services in Metro Vancouver through one seamless operation has been selected as the leading proponent to provide custom transit services for seniors and people with disabilities beginning in 2009.

As a result of TransLink's "Access Transit" consultation with the disability community, providers of the HandyDART door-to-door transit services and others, the system was redesigned to reduce the number of operating areas from eight to three. MVT Canadian Bus, Inc (MVT), rated highest in its proposals for all three service areas.

TransLink's Board of Directors has approved the start of negotiations to arrive at a contract agreement with MVT. In evaluating the proposals received, TransLink looked at a number of factors. These factors included experience, knowledge and resources, and the company's plan to manage the operations and the transition of the region's custom transit services, as well as the costs involved.

TransLink Chair Dale Parker says that given the specific needs of HandyDART customers for an effective door-to-door transit service, costs did not weigh as heavily as the other factors when selecting the leading proposal.

"Our 'Access Transit' strategy concluded that TransLink needed a new structure that, from a users' perspective, would operate as a single

system. We were looking at achieving this by reducing the number of areas from eight to three and reducing the need to hand off riders from one service provider to the next," he added.

Parker said TransLink informed all of the companies that submitted proposals for the contracts that it was critical to address the issue of employment for the drivers currently providing HandyDART services.

"HandyDART clients and their drivers have forged strong relationships that have added immeasurably to the confidence and comfort of the passengers and the sense of job satisfaction for the drivers. We've advised [MTV] that we expect them to take immediate steps to ensure that there is an absolute minimum amount of disruption to the continuity of those relationships," he said.

Parker noted that TransLink will continue to set and control HandyDART fares, look after the process for qualifying and registering people applying to use the services, and monitor the performance of the company operating the system.

In its proposals, MVT offered increased hours of dispatch services, an enhanced system to communicate more effectively with clients, and the use of its customized scheduling system to provide more trips. MVT said it would introduce real time monitoring of schedules and drivers and a longer, more comprehensive training program for new drivers. ●

Cell Phone Barriers

The Neil Squire Society is trying to identify potential barriers that might make it difficult for people with mobility impairments to complete cell phone retail transactions. The Society wants to make industry aware of these barriers.

They would like to talk with people who have no movement in their hands, and who use email and a Web Browser. Owning a cell phone isn't necessary.

Eligible participants will be asked to take part in a 2-hour test session which involves using 4 types of payment services.

There is a \$65 honorarium for your time.

Sessions will take place in February and March at Neil Squire's Burnaby offices.

To learn more about this project, please contact:

Harry Lew
Manager of R&D,
Neil Squire Society
Ph: 604-412-7599
email: harryl@neilsquire.ca



Q&A Ask the RT

Hello! This is your friendly neighborhood RT with some answers to questions that you may not have asked yet, but may crop up for you.

BiPAP users

Q. My mask is hurting the bridge of my nose, what can I do?

A. If you see redness on the bridge of your nose, you can try loosening off the straps of your face mask and see if that helps—without causing leaks in your mask. If this does not help, then try putting a small band aid on your nose before you use your mask. Some opsite, duoderm or mole skin may also work. This will act as a buffer between your nose and the mask and reduce the redness and soreness.

Q. How often should I clean my mask?

A. You should wipe it off every morning and then clean the cushion (silicone seal) every week. If you see any dirt or grease on your cushion—which you should watch for—you may need to clean it more than once a week.

Wash it in warm, soapy water, rinse it really well and let it dry. You should wipe out the plastic frame of the mask with a damp cloth and perhaps wash it once a month as well. Remember that if you wash your headgear, it will need to be air dried—it should not be put into the dryer. Since air drying takes a while, having a second headgear on hand to use is a good idea.

Q. How often should I be changing my filters?

A. They should be checked once a week. Change them if you see they are getting dirty or the colour has changed. Different filters will need to be changed at different times; it depends on what bilevel unit you are using.



Q. Do I need to clean the tubing that goes from the mask to the machine?

A. It is a good idea to clean it once in a while, but it does not need to be cleaned as frequently as your mask. I would suggest that you wash it once a month, in warm soapy water, rinse it well and hang it to dry. Look at the tubing closely. If you see dirt or anything else on the tubing throughout the month, then you may need to wash it again. It is also important to check for pin holes, cracks or other damage. If any damage is visible, then a new hose should be used.

Q. Should I clean the actual bilevel unit?

A. The only thing you need to do with the bilevel unit is remove any dust or lint from the outer casing using a damp cloth.

Q. How often should I replace my nasal pillows or the cushion on my mask?

A. It depends on how often you use your mask. If you are using it for 6-10 hours every night, then you should replace the pillows every 6 months, especially if you are washing them every week.

Q. Do I need more than one mask, hose, filters, etc.?

A. Yes. You should always have a back up supply. You should have an extra hose or two, if you are using different lengths with your unit, extra cushion/pillows for your mask and extra filters. You can order these from PROP and we will send them to you.

Q. How often should I clean my humidifier?

A. You should clean the humidifier once a week when you clean your mask. Take it apart, wash it in warm, soapy water, rinse well and dry it. Do not use antibacterial soap because this discolors your chamber and your masks. When it's dry, put it back together and make sure there are no leaks, especially around the base or the top that may not be pushed on tight enough.

Q. Can I top up the water in my humidifier?

A. Yes, if it is not heated. No, if it is heated. If it is heated, and getting low on water, you should empty the chamber and add fresh distilled water.

That's all for now. If you have any other questions about your equipment or how to use it, please call PROP at 1-866-326-1245. ●

Understanding Your Ventilator Settings



BY GILLIAN HARNEY, RRT

So what do your ventilator settings mean and when should they be changed or moved to a different setting?

This article explains some of the settings that you may see on your ventilator. I have tried to keep this as easy to understand as possible. I know when someone throws technical terms at me, I get a blank look on my face and try to act as though I understand what they're saying. If any of you have a blank look on your faces, then I know that I have not done a very good job of explaining these settings. I'll do my best!

Generally, you do not need to change your ventilator settings once it has been established what is required to meet your breathing pattern needs.

You may need to adjust your settings in some situations, for example, when you get a cold, experience any wheezing on a regular basis or your condition changes. In these cases, you should always consult with your doctor and let PROP know that your settings need to be changed. One of the RT's will assist you in doing that, either over the phone or in person.

Here is some other information about your vent settings. I hope this will be helpful.

You may need to adjust your settings in some situations, for example, when you get a cold, experience any wheezing on a regular basis or your condition changes.

Assist/Control/ACV/CV

Assist/ACV - this is a setting that **assists** you to breathe based on your own inspiratory effort (when you want to take a breath).

Control/CV - this setting means that the machine does all the work (**controls**) and breathes for you at all times. You don't have to make any effort to take a breath in.

Volume/VT

This is the amount of air (**volume**) that is given to you with each breath.

Breath Rate (BPM)/Respiratory rate (RR)

This is the number of **breaths per minute** that the ventilator gives to you— sometimes called **breath rate** or **respiratory rate** depending on the ventilator you are using,

Inspiratory Time (I:E ratio)

This setting decides how much time (in seconds) that you will spend breathing in and out (**inhaling/exhaling**) when you are taking a breath.

Breathing effort/Trigger/Sensitivity

When you breathe in, the effort that you have to make to take a breath in and start the ventilator is called your **breathing effort**. On most ventilators, this can be set to make it effortless for you to take a breath in. Some ventilators call this a **sensitivity setting** or a **trigger setting**.

Normal operating pressure

When you are breathing on your ventilator, some form of indicator will show you what pressure you require for each breath. This is called your **normal operating pressure** and this will sometimes vary if you have increased secretions, get a cold etc.

High Alarm

This alarm is a safety alarm to limit the amount of pressure that you get with each breath, so if you get bronchospasm, mucous plugs or are coughing, for example, this alarm will go off.

Low Alarm

Another safety alarm goes off when you have low pressure (leaks), way below your normal operating pressure, or you have become disconnected from your ventilator. This alarm is always set based on your normal operating pressure.

Sigh

Not all ventilators can be set to give you a sigh. If they can, they allow you to receive larger breaths at certain times.

That's it folks. If you have a blank stare, please do call me with your questions. And tell me I had better stick to my day job. Cheers, Gillian ●

Personal supports

Clients may be interested in a website on personal supports for people with disabilities.

This site contains information about and links to programs that provide equipment and assistive devices or other personal supports in BC. You can search for programs by functional needs (e.g. seeing, mobility), organization (e.g. provincial, federal, non-profit), or type of support (e.g. education, equipment).

Text reading and ASL options are available on the site.

Learn more about this resource, that is part of the Province of BC website, at <http://www.personalsupports.bc.ca>.

A new company with a stylish and attractive product! Peak Advanced Interiors have imported quality European designed tables, kitchen and bathroom furniture that are height adjustable in your home or office.

They also have a line of adjustable wash basins, bathtubs and shower beds that can be adjusted manually or electronically. They have installed a demo kitchen cabinet unit with an electric power option at the Victoria Personal Supports Centre. It is great to see good attractive design of assistive technology.

If you are in the mood for a little shopping, contact Nancy or Ryan at Peak Advanced Interiors. See their catalogue on line at <http://www.peakadvancedinteriors.com/>.



≡ Library to Go

The Vancouver Public Library offers downloadable audiobooks and ebooks in a collection called **Library to Go**.

You can download and listen to or read books on a computer or portable listening device, like an iPod. There are lots of books to choose from including mysteries, romance, science fiction, biography, computers, language learning, personal development, comedy and more!

Here is the link to VPL's Electronic Books page:

http://www.vpl.ca/electronic_databases/cat/C88

If you scroll down this page you'll find the link to **Library to Go**. On this page, there are several FAQs about different formats, computer requirements, and other helpful tips. The following are the links for more information about each format type:

eAudio FAQ

http://www.vpl.ca/electronic_databases/generic/ebooks_faq#LibraryToGoEAudio

eBook FAQ

http://www.vpl.ca/electronic_databases/generic/ebooks_faq#LibraryToGoEBook