

balance

What it's all about.

BC Association for Individualized Technology and Supports for People with Disabilities

ISSN 1916-7709

June 2008

Welcome to our first edition

By **SIMON COX** Welcome to the first edition of **BALANCE**. **BALANCE** isn't exactly a newsletter or a magazine. If it was written just for our clients and members of BCITS (PROP and TIL) and featured articles relating to assistive technology and home ventilation services, then we would have a newsletter. But, we also wish, from time to time, to include articles, stories and viewpoints on a variety of subjects. That might make **BALANCE** a magazine or perhaps what we have is a "megaletter" or "newszine."

Our goal is simple: we want you to read **BALANCE**. We want you to look forward to the next edition and we hope you find **BALANCE** entertaining, informative, thought-provoking and challenging. We don't want this to be the average newsletter. We hope you'll help us accomplish this by sending your ideas on things you'd like to see and your opinions on what you do see. And, you're also welcome to write for us. See the Writers' Corner on page 7.

When we were planning to launch a new publication for all our programs, we brainstormed on what we'd call it. BCITS staff got together, wrote down our ideas and ideas from clients—good to completely off-the-wall—on a flip chart. They ranged from "The Daily Prophet" to

"The Shredder" to "Polski Ogorski." As you can see, we didn't edit the ideas!

When we were talking about all the possibilities and the vision we were aiming for, I said, "We want something like 'Balance.'" There was a pause and someone said, "Well, why **not** 'balance?'" And the name stuck. We all liked what "balance" suggests: balancing parts of our lives, like work and relationships. It also means equality and symmetry; and even harmony among different things. And, it's what we will aim for in this "megaletter." We'll bring you information on our programs and services, and disability-related news, but we'll endeavour to balance that with reading that is of general interest, fun and off-the-beaten-path.

So, we won't have a newsletter for PROP and newsletter for TIL from now on. What we will have is **BALANCE**.

We hope that works for you! ●

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balance

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

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We are pleased to have content from Balance reprinted in other publications. Contact us with your request and please cite BCITS, Balance and the edition date when reprinting.

BC Association for Individualized Technology and Supports for People with Disabilities is the home of Technology for Independent Living (TIL) and the Provincial Respiratory Outreach Program (PROP).

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From the Peer Support Group

BY JEANETTE ANDERSEN The reality is all ventilator users need to become a bit "techy." We need to know how to troubleshoot our respiratory equipment, so it's really important to read the manuals that came with your ventilator, suction machine(s) or BiPap. If you don't have the manuals, ask PROP to mail or email the information to you. And if you don't understand something, call PROP and ask them to help you.

PROP's respiratory therapists will teach you and your caregivers all you need to know about your ventilator and other equipment. It's also a great idea to take the training again with your friends and volunteers. I find that showing other people how to do a procedure (troubleshoot a ventilator, circuit, connections, etc.) gives me more confidence and, just as important, it takes some of the onus off friends and volunteers.

Make sure your caregivers, volunteers and friends practice using an

My TIL equipment

BY CATHY GRANT I've had my TIL equipment for many years. The device in my living room controls my TV on-off switch, channels and volume, my stereo on-off, stations and volume, lights, a speaker phone and a button that I can use to alert my care staff when I need to talk to them.

In my bedroom, the buttons control the speaker phone, TV and stereo, a light, and my bedroom and outside doors. I keep the buttons where I can reach them when I am in bed.

Ambu bag on you. An Ambu bag is your first recourse if you are not getting air. Once you are being "bagged," you and your caregiver can work together to solve the problem.

Often vent users have some independent breathing, but with a cold, pneumonia or a mucus plug, we can lose it temporarily. And that's when it's important to know where the Ambu bag is kept and how to use it. And you should have two Ambu bags: keep one with you and one in your bedroom, and always keep your bags in the same place.

One last tip: carry duct tape with you for a TEMPORARY fix for a crack in the circuit or a loose connector for example.

Please feel free to call Peers Heather Morrison or Jeanette Andersen at BCITS to ask questions, talk about similar experiences, or any concerns you might have. Be well. ●



On my wheelchair, I have a control door opener for the front door and my bedroom door. I really like the equipment, it works for me. ●

The BCIT's Team



Who's Who?

Try matching the pictures and captions.

Answers are below!

1. **Kirsty Dickinson**, Manager Client Services. New Grandma.
2. **Seka Jovanovic**, Client Services Coordinator. New mommy.
3. **Clara Chalfour**, Administrative Coordinator. When not working & playing 'mom', enjoys recreational badminton & competitive shopping!
4. **Joanne Bengert**, Electrical Engineer. The One with the Messy Desk.
5. **Stephen Hendradajaja**, Biomedical Technologist. Family Guy.
6. **Jerzy Pacek**, Biomedical Technologist. Alias George Costanza.
7. **Wayne Pouge**, Biomedical Technologist. Winter Sports Enthusiast.
8. **Roger Desmarais**, Biomedical Technologist. Sign Language Expert.
9. **Rodel Mangahis**, Materials Manager. Original "Guitar Hero."
10. **Evelyn Klees**, Respiratory Therapist. Loves animals.
11. **Gillian Harney**, Respiratory Therapist. Addicted to Cruises.
12. **Andre Fontaine**, Respiratory Therapist. "Everyday is a good day!"
13. **Heather Morrison**, Peer. The Teapot Lady.
14. **Jeanette Andersen**, Peer. Strollin' the sea wall with my Legendair.

Jeanette Andersen has seen it all



BY JANE DYSON For this inaugural edition of *BALANCE*, we wanted to look back at the advances that have been made in respiratory and mobility technology and we thought about Jeanette Andersen's story.

When Jeanette was 16 years old, she walked into New Westminster's Royal Columbian Hospital feeling unwell. By midnight, she was completely paralyzed by polio. By the next morning, she couldn't breathe and was put into an iron lung. Jeanette says this "monstrous, ugly thing" was terrifying, but she was also thankful for it because she could at least breathe. Two months later Jeanette moved to the George Pearson Centre where she lived for more than 30 years.

Memories flow from Jeanette as we chat in her comfortable apartment at Noble House Co-op, her home since 1991. She says that, during the two months she was in the iron lung, she did not see her body. When she was finally well enough to be taken out of it, she was deeply shocked to see how her muscles had atrophied.

Jeanette has a vivid memory of the hot wool packs that were placed on her arms and legs to help promote her circulation. To this day, she cannot stand the smell of wet wool

When Jeanette was 16 years old, she walked into New Westminster's Royal Columbian Hospital feeling unwell. By midnight, she was completely paralyzed by polio.

and, for many years, she couldn't eat hamburger meat because of a well-meaning staff member who insisted on making her eat it raw to increase her strength!

When Jeanette was in the iron lung, she frequently heard about how great rocking beds were, but when she finally used one she was not impressed. The beds were considered to be something of a technological advancement for people who had left the confines of an iron lung. Rocking backwards and forwards, they were designed to stimulate the diaphragm with each forward and backward motion. Not surprisingly, they also made a lot of people feel nauseous and took a great deal of getting used to.

The invention of smaller, portable ventilators made rocking beds

and iron lungs generally obsolete. Jeanette gradually regained some of her breathing and only used a ventilator at night. But in 1985, her health deteriorated badly and she had a heart attack. Since then, she has used a ventilator full time.

Technological advancements not only provided Jeanette with better respiratory equipment, but also with more mobility and independence. Before the invention of electric wheelchairs, Jeanette was completely dependent on others for her mobility. "I'd have to wait for someone to wheel me around in my manual chair. The introduction of electric wheelchairs was a huge breakthrough. It meant I could go out on my own without relying on other people. Suddenly I was so much more independent."

Jeanette used to steer her wheelchair with one finger until the day she went to the bank and found she no longer had enough strength to do that. She changed to a sip-and-puff control that operates much more than just her wheelchair: she uses it to close her blinds, turn her lights on and off, control her TV, radio, and other household devices.

Jeanette explained how years of depending on others weakened her urge for independence. "After I'd been living at Pearson for some time, Simon Cox asked me if I would like a device that would enable me to change the channels on my TV. I said okay, but there was no rush. About



Jeanette Andersen

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Jeanette, continued from p. 4

a year later, he asked me again and I said sure. Well, the change in my life that that device made was amazing. It was a huge eye-opener for me. Looking back now, I can't believe I wasn't in a rush to have that piece of technology. You get so used to being totally dependent, the desire for independence starts to go. And it can take a long time for it to resurface."

The invention of automatic door openers was another "huge deal" for Jeanette. "Before they came along, I would have to wait for someone to pass by to open the door. If I went out on to the Pearson grounds, I'd have to wait at the door for someone to let me in. Those technological breakthroughs encouraged me to challenge myself to do more things. I would set myself a small goal everyday, and pretty soon I found I was setting myself several goals everyday. With every positive step, I wanted to take another one and then another."

In the late 1970s, Jeanette started working for BC's Ministry of Consumer and Corporate Affairs monitoring the media for deceptive advertising. Simon made her a device to help her operate a tape recorder. "I could never have done that job for so long without that invention." Jeanette worked for Consumer and Corporate Affairs for more than 10 years.

As Jeanette and I finish our chat, some friends arrive for dinner. As she gets ready to phone for a Chinese takeout, she says, "I could never have moved out of Pearson without PROP

and TIL. TIL makes it possible for me, a PROP client, to live independently in the community."

I am struck as I always am when Jeanette tells me her stories by how much has changed in her life. From an iron lung to a small portable respirator, from rocking beds to a sip-and-puff control with over 70 functions, Jeanette has seen it all. ●

Getting Organized!

Members of the BC Chapter of Professional Organizers in Canada (POC) have teamed up with BCITS on a volunteer project that is providing rewards for everyone involved.

The volunteer organizing team, headed by Wesley Brown, has been working with TIL client, Lorraine Tran. The team accepted this challenge: to organize her living space for maximum accessibility for a person with severe disabilities.

Each professional organizer brought her own expertise to the project, helping to organize bedrooms, bathrooms, computer area, closets, decorating and papers.

Susan Brown who worked extensively on organizing and shredding Lorraine's papers described the experience in this way: "Working with Lorraine has been an absolute joy. She really does have the best attitude in life."

Lorraine said, "Their kindness and their many talents, brought happi-

On the Web



WWW—or is it, WOW? BCITS also has a brand new website at www.bcits.org. Some of the same goals behind BALANCE went into creating the site. We hope you'll find it interesting, helpful and easy to use.

We will continue to improve and add to the site over the next few months. We'd love to have your feedback, so please come and visit us.



Left to right from top: Crystal Sackett, Lynne Davidson, Wesley Brown, Kerith Paterson, Susan Brown, Lorraine Tran, Brian Johnson

ness, a stress-free environment and the comfort of home back to me which was long overdue."

The POC's mandate is to provide a supportive environment for Professional Organizers, promote networking, and increase awareness of the field of professional organizing.

For more information, contact Susan Borax at 604-421-5952 or go to www.organizersincanada.com. ●



\$500,000 Gives A Voice To More People With Disabilities

VICTORIA – The BC government is providing a one-time grant of \$500,000 to the Communication Assistance for Young Adults (CAYA) program to expand their services to adults up to 35 years of age, announced Employment and Income Assistance Minister Claude Richmond.

“With this grant more people with severe communication disabilities will receive the supports needed to communicate with their friends and family – something that most of us take for granted,” said Minister Richmond.

Through the services provided at CAYA, clients and their families can

receive: an assessment of their high-tech communication needs, equipment through a loan bank, training on how to use the equipment and follow-up services, including technical support and maintenance. High-tech communication devices cost an average of \$6,000 and as much as \$12,000 providing many options, including text-to-speech synthesis, dynamic visual displays and access through switch scanning and Morse code.

“By choosing symbols and text on a portable computer, British Columbians – who otherwise cannot speak – can voice their thoughts,” said Jeff Riley, manager of CAYA.

Previously, CAYA provided specialized equipment and supports to individuals between the ages of 19 and 27. By extending the age limit up to 35, the \$500,000 grant will allow more adults to receive supports and services. The new grant builds on the one-time \$4.2-million provincial grant provided to CAYA in 2007.

“CAYA fills a unique need in this province by providing specialized communication supports to adults after they leave the public school system,” said Simon Cox.

The government is providing the grant to CAYA through BCITS which has worked with CAYA since the program began in 2005. ●



Above: Claude Richmond, Minister of Employment and Income Assistance speaks on the importance of communication.

Right: Jeff Riley and Simon Cox unveil the grant with the help of Shirley Bond Minister of Education and Deputy Premier.



Digital Phone Access... To Be or Not To Be

By JOANNE BENGERT With the advent of Digital Cell Phone Service and Voice Over IP (VOIP) technology, there seem to be more options than ever when it comes to phone service. However, if you require operator assisted call completion, make sure you ask the right questions before you switch over.

For many TIL clients, making a phone call usually consists of contacting the operator and asking the operator to call a specific number for them. Unfortunately many of the new digital and VOIP options either do not have operator assistance or the operator assistance is contracted from a larger company like Telus or Bell. So, if you are considering switching to a digital service there are a few questions you should ask before you make your decision.

Does the service provide Operator Assistance?

Is the Operator Assistance being contracted from a larger company? If you call the operator occasionally, this may be fine. However if you rely on the operator, you will not

be dealing directly with the company that is providing your phone service and the operator may be in Ontario.

Does the service provide Operator Assisted Call Completion at no-charge? They may require that you fill in some paper work similar to the B-Caller form from Telus.

Will the phone line work if the power is out? Most digital phones should come with a battery back-up, but VOIP phones may work differently.

Can the service provider offer a free trial so you can ensure that the service works the way you need it to? This advice comes straight from a TIL client who asked all the right questions, but realized after using the service for a couple of months that his needs did not match the new service. He suggested keeping your original phone line while trying the new one.

Hopefully this will help you navigate through the various options that are out there. ●

Writers' Corner

We have had several PROP and TIL clients say, "I'd like to write an article for you sometime."

And our answer is, "Please do, we love to have stories, ideas and tips from clients."

So, please consider this your invitation to send writing to us for consideration in a future edition of Balance. We cannot publish everything we receive and may edit your piece as needed. Send your articles, tips or creative writing to Seka at BCITS.

Gadgets

The Pegasus Mobile Notetaker allows you to write notes and drawings that can be downloaded to your PC at another time. The units may be useful for people with disabilities who are unable to take notes. A peer at school or at a meeting can take their own notes while having them transfer to the mobile notetaker of the person with a disability. Cost is under \$200.00 Available from www.pegatech.ca.



This **Jumbo TV Remote** from Innovage has big buttons and is almost a foot tall. For people with dexterity difficulties, visual disabilities or who use a mouthstick this may be a good solution. Recently spotted at London Drugs for approximately \$20.

One suggestion: if you buy it make sure you keep all the packaging just in case it doesn't work for your TV and you need to return it.

Other brands are available as well. Check out http://www.hytekmfg.com/features_bigb.html. ●





Q&A: Ask the BioMed

What can I do if the power goes out?

Our complete dependence on power is not always apparent when everything is working well. Then, one day, the “lights go out.” There is not much we can do except wait for BC Hydro to respond. It could be a few minutes, a few hours or even a few days.

What can people with disabilities do to prepare themselves for a power outage? Not only do our lights fail, but also our heating systems may not be effective and our telephones may not work. We may also not be able to cook or hear the news. For people on our PROP program, their ventilators will switch to battery backup and some may have to use manual “bagging” techniques before they are able to find a power source.

We could rely on other sources of power, such as backup battery systems or power generators (gas, propane etc.). But will they work when they are needed? Do you test them regularly? Power backups can be costly and we cannot all afford to have them installed.

The most effective way to handle a power outage is for everyone to develop his or her own personal network and plan. That means organizing people to help you in the case of a power failure. For example, find someone to check on you if a power outage happens in your neighbourhood. It could be a neighbour, friend or relative. They can stop in to see if everything is ok and, if not, help move you to a place of refuge.

A personal network is much safer than complete reliance on technology. We love our technology and it works well when we have power. If we don't have power, we need other supports. An expert in emergency preparedness will tell you most emergency plans fail because we are not personally prepared. Ask yourself, am I ready? Only you can develop your personal plan. ●

AGM Notice

The third Annual General Meeting of BCITS will be held on September 16th, 2008 at 6:00 pm at George Pearson Centre, Class Rooms 1 & 2, 700 W. 57th Avenue, Vancouver, BC.

Join Us

Are you a BCITS member? We'd like to encourage you to take the easy steps to become a member. Here's why. When we have a strong membership base, it helps to show we have the support of the people we serve, as well as members of the public. And this helps when we seek funding to keep our programs and services going for our clients.

As a member, you will receive notice of the BCITS Annual General Events and any other membership meetings. These gatherings help us to learn what members need and continue evolving to serve you better. Becoming a member is easy. If you are a client of the PROP or TIL program, please fill out the enclosed form and mail it to BCITS. If you are not a client and wish to become a member, please visit our website, www.bcits.org, to learn how. ●

Emergency Preparedness

The BC Coalition of People with Disabilities (BCCPD) is working with a broad network of disability organizations, including BCITS, and people with disabilities to build relationships with the emergency management sector. The Emergency Preparedness for People with Disabilities Committee (EPPDC) was formed in 2006 and is made up of people with disabilities, representatives from disability organizations and other emergency management stakeholders in BC.

BCCPD and the EPPDC recently completed a series of 3 workshops on emergency planning, response and recovery, and a report from these workshops will soon be completed. BCCPD has other related projects and publications that will help emergency planners and employers learn how to include people with disabilities in their emergency planning.

We will publish updates in *BALANCE* and you can also visit this website for more information: http://www.pep.bc.ca/hazard_preparedness/disabilities_information.html. PROP has also published: “Your Contacts and Emergency Planning” that is available on our website, www.bcits.org, under Publications, or by calling our office at 604-326-0175. ●

