

What it's all about.

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# The Advantages of Being Inquisitive and Flexible by Jo Dunaway

Roger Jones' first contact with what is now BCITS happened when he moved to Vancouver 22 years ago. He was left with a spinal cord injury as a young man, as a result of a car accident in his native Nova Scotia. From the beginning, he was determined to live as independently as possible-and this meant getting a job.

He knew independence in a workplace would be difficult because of his bathroom needs. He had designed an electric leg-bag emptier that would allow him to empty his urine leg-bag without assistance, but he needed someone to make it a reality. That's when he met Simon Cox.

"Simon took my idea and made it happen," remembers Roger. "It might sound like a small thing, but it was huge for me. It meant independence."

That was the beginning of an ongoing relationship. "Everybody at TIL has such a great attitude. They never say, 'We have a device we want you to fit into.' They start with you and work with you and with your ideas. They'll figure out how to meet your particular need."

A case in point is the touchpad device Roger uses to control ev-

erything in his bedroom from his bed."I have some use of my hands when I'm sitting up, but not once I'm lying down. Way back before it was common, TIL modified a universal remote control, so I could turn everything in the room on and off. They took something that was already around and modified it for another purpose. I've been using it ever since and am on my second version of the same device. The lights, the phone, the TV, the BiPAP machine and the HEPA filter, all run off this one device.

"When I changed from a CPAP to a BiPAP machine, I couldn't turn it on and off because it involved physically pressing buttons. So TIL made me a bracket that the BiPAP fits into and a switch pushes the buttons. They're now making a newer version for other BiPAP users."

Roger has an inquisitive and inventive mind. He likes to look at gadgets and wonder what they could do for him–like setting up a control centre for all his entertainment components or for his computer and its peripherals. He is also working on a way of controlling the thermostats in his house from his iPhone. Sometimes he needs help in making the adaptation."That's when I call Simon."

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"Everybody at TIL has such a great attitude. They never say, 'We have a device we want you to fit into.' They will figure out how to meet your particular need."

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Sometimes, he will get a design idea and look for the right company to make it a reality. "I was looking at the lap tray on an airplane and I thought, 'Why can't I have something like this on my wheelchair?"

He took the idea to his wheelchair manufacturer and the result is a sturdy tray across the front of his wheelchair that he can work on. The top lifts up for storing papers and his laptop, and, when it's not in use, the tray lifts up and fits down against the side of his chair.

A perfect accessory is the water bottle holder that Roger saw in a bicycle shop and thought, "That looks more stable than the usual cup holder on a wheelchair. Just mount it differently." And, spotting an ultrasonic jewelry cleaner has netted



He took the idea to his wheelchair manufacturer and the result is a sturdy tray across the front of his wheelchair that he can work on. him the perfect tool for cleaning his eyeglasses.

Roger's adventurous and confident personality is reflected in the work he has done for many years as an international consultant and speaker on disability issues. The airplanes, airports and accommodations he has encountered in centres, large and small, have contributed to a store of experience and an attitude.

"There are a lot of ways for things to go wrong and you have to learn how to deal with that possibility. On a trip to the Yukon, the ramp didn't materialize at the airport and I had to be carried down the stairs from the plane– all six feet plus and 250 pounds of me. On another trip, I arrived in Phoenix and my wheelchair went to Wisconsin. I was trapped in a hotel room for two days waiting to be reunited. You have to able to work with what happens."

One of Roger's earliest travel adventures was a vacation to Caracas, Venezuela he took with friends, including another person with a spinal cord injury.

"Caracas! It sounded so exotic!" says Roger. "But there were a few things we probably should have thought about–like we didn't speak Spanish and sidewalks there weren't set up to accommodate wheelchairs. Every time we crossed a street, our chairs had to be picked up and lifted over the curb. Nobody at the airport had any experience with power chairs and we arrived at 3 a.m. with our chairs dismantled and in cargo.

"But we had an entertaining and interesting two weeks. Then, when we were at the airport to return home, there was an armed coup that shut everything down and our five-hour flight to Toronto turned into 36 hours. You can't really be prepared for a coup, but it was quite an experience and I wouldn't not have done it!"

Nothing has dulled Roger's interest in travel. Last summer, he and his girlfriend vacationed in Nova Scotia and took in the jazz festival in Halifax." I hired staff out there sight unseen, something I don't usually do. But I had a recommendation from a friend and we also contacted agencies in the areas we were going to be in. Besides, my girlfriend has some training, so I knew we could manage on our own for a couple of days, if we had to. I hired nursing students and took my portable lift because it requires less training and can be used by slighter women as well as by men. So it gave me more flexibility in hiring."

He hopes when his health improves to visit a friend in Costa Rica who has established a resort hotel adapted for people with disabilities. "Accessible vans pick you up at the airport and take you places, there are accessible swimming pools and staff who understand your needs. It would add so much to an enjoyable vacation. We're hoping it could become a chain in various vacation spots."

The extensive travel Roger has done for his consulting company was demanding on his health and his organizing skills, as he juggled schedules, staff, travel, accommodations and care needs. But, he has garnered a wealth of experience and expertise which he is now channelBut most of all, says Roger, be aware that something can always go wrong, but don't let it throw you. "Try to be flexible. Be knowledgable. Have a backup plan. Work it out. Go with the flow. The more you prepare and the more you travel, the easier it gets."

ing into resources for other travelers with disabilities.

Recently, he has been consulting on an air travel information package for people with physical disabilities that is being produced through a partnership between Spinal Cord Injury BC (SCI BC) and Vancouver International Airport (YVR).

Roger says that, although regulations for travel by air, land or sea are set by the federal government, individual airlines may have additional regulations of their own and becoming informed is the key to successful travelling. For example, although personal attendants travel free on domestic flights, you may feel that you can handle short flights on your own. However, you could find that you are denied a flight on your own by an airline that has you designated as a traveler who requires an attendant. You should be aware of the policies of the different airlines that you may be using.

"Know your rights," says Roger. You can stay in your power chair right up to the gate, so you don't have to be in an uncomfortable airport chair. But once you're out of your chair, you won't see it again until you land.

"The onus is on me to make it easy for the airline staff to take care of my chair, so I attach signs informing them about things they need to know," says Roger."And I take anything fragile on board with me."

Know what travels free–usually anything deemed medical such as a ventilator, oxygen, wheelchair, portable lift, BiPAP machine–but get the list from your airport and your airline.

Know what you will need with you in the cabin. Know how to do the things that you will need to do. For example, practice in advance with your attendant how to do transfers from the airport wheelchairs.

Research possibilities that can make your travel easier or more convenient, advises Roger. For a good alternative to taxis, he has used TransLink to locate HandyDART equivalents in other cities and arranged for pickup from his destination airport. By Googling "paratransit," you may even be able to locate international equivalents.

But most of all, says Roger, be aware that something can always go wrong, but don't let it throw you.

"Try to be flexible. Be knowledgable. Have a backup plan. Work it out. Go with the flow. The more you prepare and the more you travel, the easier it gets." •

## balance

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## Ask Our Staff | Equipment FAQs

BY WAYNE POGUE

### TIL

#### My Gewa\* keeps flashing and beeping every 30 seconds, what does this mean?

This is how the Gewa indicates that the batteries need to be replaced. Once you replace the batteries, the Gewa will return to normal operation.

You may also find your Gewa isn't working as consistently anymore. This is another sign that your Gewa's batteries need to be replaced.

### My Kincontrol\* is acting up, is there a way to reset it without losing my programming?

Your Kincontrol doesn't actually hold "programming." All your programming is stored in the remote control attached to your Kincontrol, so resetting the Kincontrol won't effect its programming.

To reset your Kincontrol, unplug it from the AC power outlet, wait 30 seconds, then plug it back in. If you continue to have problems with the unit, contact TIL for further help.

### PROP

### My Laerdal suction unit (LSU) stops suctioning after about 2 minutes. Do I need to replace my suction machine?

No, your LSU is working normally. The LSU has a built-in "auto-shutoff" after 2 minutes to prevent the suction machine's motor from overheating.

## How long should my ventilator's internal battery last?

There is not a universal answer to this question. It depends on many variables, such as your settings. If you would like to know how long your battery will last, run your ventilator using your internal battery some day when you are going to be home for the day.

This is the only practical way of learning approximately how much internal battery time you have in your ventilator. This information is vital for planning purposes and PROP recommends you do this battery test once a month.

### Should I use my humidifier while travelling?

You can take your humidifier with you while you're travelling, just be sure the chamber is empty and the humidifier is turned off while in transit. You don't want water to spill into the electronics of the humidifier and damage them.

Also, ensure that you are only powering your humidifier using a 120V AC power outlet. The humidifier should not be powered by an inverter because the modification of the power signal could damage the humidifier.

### My Legendair ventilator's display is too dark/light. Can I adjust it?

Yes, your Legendair's display contrast can be adjusted. To adjust the contrast, hold the alarm/silence button down and press the up/down arrows accordingly.

\* GEWA and Kincontrol are systems used to control devices in the home. Do you have a question about your equipment? Send it to info@bcits.org.





### Beauty or Breath: Your Choice!

By Esther Khor Can your hair products affect your breathing or the breathing of people around you?

Yes, they can! Especially if they contain formaldehyde. When I think of the word "formaldehyde", images of a Grade 8 science lab with jars of specimens come to mind.

In 2011, a department of health issued a warning about potential health risks associated with hair products that contained formaldehyde. These hair smoothing treatments are common in many hair salons and are often labelled as a "keratin treatment" or a "Brazilian blowout."

People with asthma are more likely to experience adverse reactions to the formaldehyde in hair products. The symptoms range from throat irritation, breathing difficulties, wheezing, headaches, fatigue and rashes on the skin.

The Occupational Safety and Health Administration in Oregon and Health Canada have recently tested various hair products that contain high levels of formaldehyde that are not listed on the label. This is unfortunate because formaldehyde is a chemical that has links to an increased risk of cancer.

So, the next time you start to put products in your hair to keep your lovely locks in place, look at the label and think about the affect it can have on you and people around you.

## Help Us Fulfill Our Vision

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

However, this funding does not cover the costs to provide equipment to TIL clients. For example, a special telephone for a person with a high



level disability can cost as much as \$1000 and an automatic door opener can cost \$3000. We provide many devices like these to adults—at no cost—to fulfill our vision of people living in the community as independently as possible.

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

Thank you

Simon Cox, BCITS Executive Director Charitable Registration Number 807477070RR0001

### Yes, I would like to support TIL's equipment program.

- □ I enclose a cheque for \$ \_\_\_\_
- □ I will make a donation by credit card through CanadaHelps.org. [Donate in minutes by clicking on the CanadaHelps button on our home page at <u>www.bcits.org</u>.]

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

NAME

ADDRESS

CITY & PROVINCE	POSTAL CODE
PHONE	
EMAIL	
Please return this form to: BCITS, #103-366 F. Kent Ave S., V	Jancouver BC V5X 4N6

#### How To Extend iPhone Battery Life BY STEPHEN HENDRADJAJA

With all the great apps on the iPhone, it's easy to run down your battery. There are ways to conserve iPhone battery life, but many of them involve turning off services and features. So it becomes a choice between all the cool things that the iPhone can do and having enough juice to do them.

Here are 15 tips to help you extend your iPhone battery life.

- 1. Auto-lock sooner.
- 2. Turn off equalizer.
- 3. Turn on auto-brightness.
- 4. Reduce screen brightness.
- 5. Turn Bluetooth off.
- 6. Turn 3G/4G off.
- 7. Keep Wi-fi off.
- 8. Turn off location services.
- 9. Turn data push off.
- 10. Fetch email less often.
- 11. Do fewer battery-intensive tasks.
- 12. Sleep and wake less.
- 13. Buy an extended-life battery.
- 14. iPhone 4S and IOS5: turn off other location settings.
- 15. Turn off unused apps.

For the full article including iPhone images, please visit our Equipment Tips and Manuals page at www.bcits.org/tipsmanuals.htm.



### **New Resources | Cheat Sheets**

by Miranda Whiteley, RRT

It's not always easy to troubleshoot and change settings with the Respiratory Therapist over the telephone. We all have our own unique learning styles and while, some people learn well by listening and doing, others prefer to get information in a written format.

With this in mind, PROP has developed "cheat sheets" for our clients to use as a reference when seeking RT support over the telephone.

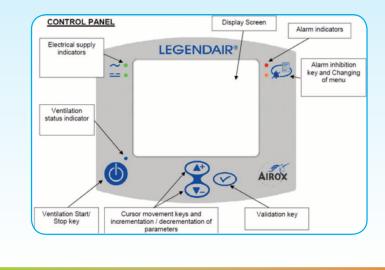
#### For our Bilevel Equipment, we have cheat sheets for the:

- Harmony, Synchrony II
- BiPAP Synchrony
- System 1
- VPAP III STA.

### For our Ventilator Equipment, we have cheat sheets for the:

• Legendair and the PB560.

If you would like a copy of the Cheat Sheet that corresponds to your particular unit, please contact us at <u>prop@bcits.org</u> and we will be happy to either email or mail a copy to you. You can also see the Cheat Sheets online on the Tips and Manuals page at <u>www.bcits.org/tipsmanuals.htm</u>.



### **CPR Training an Essential Skill for All of Us**

BY ESTHER KHOR Most of the people who come to PROP's Tracheostomy and Ventilator classes are primary caregivers or health care professionals that work in the community with our PROP clients. Many ask if we provide any other courses, but unfortunately we do not.

However, I'd like to suggest Cardiopulmonary Resuscitation (CPR) training as an excellent option. CPR is an essential skill that can benefit anybody.

Every year, over 20,000 Canadians have an out-of-hospital cardiac arrest. The heart stops beating, blood flow is compromised and oxygen is slowly deprived from the brain and body. Then, the clock starts ticking because it only takes 4 to 5 minutes for brain cells to start dying. Furthermore, paramedics can take up to 10 minutes to arrive on average.

If CPR is performed, it occurs in about one quarter of these out-ofhospital cardiac arrests. Since most of these cases occur in residences, there is a good chance that caregivers are one of the first responders. The way a caregiver responds in this situation can be life-altering.

CPR training is so valuable that it has been introduced in some high schools' curricula. In fact, 4 provinces in Canada have made CPR training mandatory in schools. However, this does not include British Columbia.

Places likes Seattle, Norway and Denmark have made CPR mandatory in schools and have made widespread training their mandate. The hope is to improve survival rates Since most of these cases occur in residences, there is a good chance that care givers are one of the first responders. So, the way a care giver responds in this situation can be lifealtering.

of people experiencing cardiac arrest and ensure intact neurological function.

I want to mention that CPR alone does not "restart" the heart. It simply preserves blood circulation to avoid death of the bodily tissues. It preserves the body for advance support, like defibrillation. This is why you see many Automated External Defibrillators (AEDs) in public places. They are as common as fire extinguishers and just as important for saving lives.

Contact your local Red Cross or community center to see how easy it is to sign up for this life-saving training. With 85% of out-of-hospital cardiac arrests occurring in residences, do not miss out on an opportunity to help sustain a life.

If this article opens up a dialogue about emergency planning and CPR between you and your client, that's a step in the right direction. Let's do this!

## Almost Guilt-Free Chocolate Chip Banana Bread by Miranda Whiteley

With Easter in mind, I thought I'd share one of my favourite dessert recipes with you. This Banana Bread is easy, healthy and tastes amazing! There are a few ingredients that may require a trip to your local health food store, but give this recipe a chance-you won't be disappointed!

Preheat the oven to 375 degrees. In a large mixing bowl combine:

14 cup coconut Flour 1 tbsp. cinnamon 1 tsp. baking soda

In a medium mixing bowl combine: 3-4 very ripe, mashed bananas 5 large eggs 3 tbsp. liquid honey 1 tsp. vanilla extract ½ cup of dark chocolate chips

Mix the wet ingredients into the dry ingredients.

Grease, or line with parchment paper, a bread/loaf pan.

Bake for 50 minutes, allow to cool for 30 minutes.

Slice and enjoy!

### Yes, I Accept Your Invitation To Join BCITS

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

clients	
Name: Please mail completed form to BCI	TS
(the cost of postage constitutes yo	ur
Address: membership fee)	
🖵 Non-client membership fee	
City/Prov: Postal Code: Please mail completed form along	with
\$20.00 annual membership fee pa	yable
Telephone: Email: to BCITS.	

Please mail this form along with any applicable membership fees to BCITS - The Home Of PROP and TIL, #103-366 E. Kent Ave S., Vancouver, BC V5X 4N6



Ask the BioMed BY-ROGER-DESMARAIS



A client of the TIL program enjoys watching TV late at night while his live-in caregiver sleeps. The client uses an earpiece connected to an amplifier so the caregiver's sleep is not disturbed.

### **TIL Request**

The expensive 3.5V Lithium battery in the amplifier needs to be replaced often. The client requested an alternative solution to power his amplifier.

### **TIL Solution**

**Please Check One** 

Membership for registered BCITS

It took quite a few tries, but we succeeded! We created a "fake battery" from a piece of hard plastic and connected it to an AC Adaptor that draws power from a wall plug.

Now the client can enjoy his nightly TV shows without the battery running out!

Tell us your unique technology needs! We may be able to design a custom solution for you. Please contact our BioMedical Technologists at <u>info@bcits.</u> org or 604-326-0175.