

balance

What it's all about.

BC Association for Individualized Technology and Supports for People with Disabilities

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We Appreciate Personal Attendants and Caregivers BY REBECCA JENSEN

Let's celebrate National Caregiver Day on April 5 by acknowledging and appreciating the critical role personal attendants or caregivers perform in the lives of individuals with disabilities.

Without assistance, many people with disabilities are not able to accomplish daily tasks independently. Care attendants accept the responsibility of providing physical aid, as well as emotional and cognitive support to those who require it.

The position they fill is of great value to the people they assist, their families and friends, and to the community as a whole when people with disabilities are able to participate by contributing their time and talents. Feelings of self-worth, confidence, and connectedness are benefits to both sides of an effective caregiver/care receiver relationship.

Cheryl Lauder is a personal attendant for her brother, Gerald, who lives in Campbell River and has a spinal cord injury. She has been providing him with 24/7 care for over 30 years. Cheryl describes this care as similar to what a nurse does "only you don't get to go home". It is a job that requires a lot of "sanity", she

says, because it can be overwhelming at times.

Throughout her years of caregiving, Cheryl has found that the health care system can sometimes fail to treat her brother, and those like him, as individuals. This is why she decided to take on the challenge of assisting Gerald with his needs, rather than placing him in a group home. She describes her work with Gerald as difficult and mentally draining, but rewarding.

Her commitment to provide her brother with a comfortable environment allows him to enjoy a sense of security. She relishes her ability to ensure his needs are met and to make a difference in his life. Keeping her family together is what motivates her to keep going, even when she sometimes feels burnt out.

Cheryl makes sure she takes off one day a week for her own well-being. She has a horse and two dogs she enjoys spending time with. She also gets out into the fresh air as often as possible. She believes that being a successful personal attendant includes having a strong support

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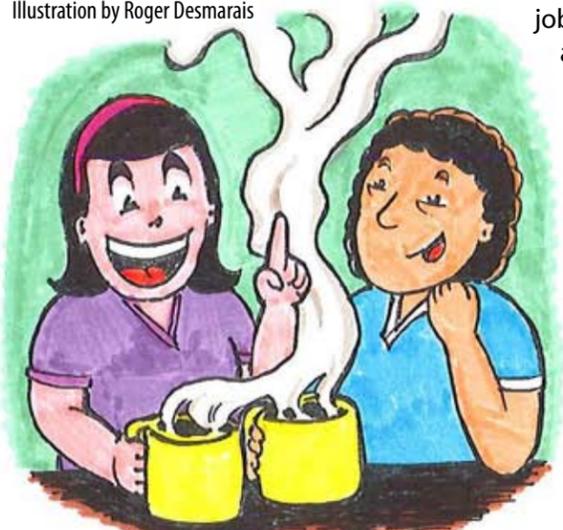
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system around the individual in need of care and not being afraid to ask for help from others.

Paul Gauthier, a New Westminster resident, has lived with Cerebral Palsy since birth. He has always needed 24-hour assistance with physical tasks in his daily life, such as getting from place to place, eating, and other personal care. He uses a power wheelchair and an accessible van, as well as Dragon software to access his computer technology.

Paul has been hiring personal attendants for 20 years and finds the process both challenging and empowering. He knows better than anyone what his needs are, so doing his own recruiting has given him the most flexibility and choice to select attendants to fulfill these needs. He feels he has been fortunate to find such amazing personal attendants with "hearts of gold" over the years.

Illustration by Roger Desmarais



AHH! COFFEE! FUEL FOR CAREGIVERS EVERYWHERE

Her commitment to provide her brother with a comfortable environment allows him to enjoy a sense of security. She relishes her ability to ensure his needs are met and to make a difference in his life.

A good personal attendant, Paul says, is someone who is willing to be flexible and is eager to learn, someone who has the right skills to do the job and who can physically handle the fast pace that Paul sets, and someone with a personality that complements his own. Attendants act as Paul's arms and legs, so it's important that he and his personal attendant are in harmony, both physically and mentally. He compares the relationship to figure skating. When both parties are being accommodating and communicating well, they glide along smoothly, but if the pair is not in sync, someone will likely fall.

Paul recognizes that it takes someone special to be an effective personal attendant. It's not an easy job, and patience and respect are important components of success. He admires attendants for their devotion and willingness to be available when they're needed—and to fade into the background when they're not. For people who are experiencing a new disability and dependency, the situation is especially difficult. An attendant who can fulfill what that individual needs is a rare find!

Paul has enjoyed developing long-lasting friendships with his personal

attendants. He is honoured to be able to share his life with them and to positively influence how they perceive people with disabilities. He is grateful for the role that attendants have played in his life. They have facilitated his ability to be a family man, to work, and to be involved in advocacy. Without the assistance of attendants, Paul wouldn't be the gold-medal-toting Paralympian he is today! He is especially grateful for how personal attendants have allowed him to avoid being forced into an institutional setting and to enjoy the privacy of his own home.

Share Your Story

It's wonderful learning about the relationships people with disabilities develop with their attendants and caregivers, and how these amazing people make a positive impact.

Do you have a story to share about your experiences as a caregiver or as someone who has benefited from the role of a caregiver in your life? Would you like to comment on this article?

Please send comments or your story to info@bcits.org and feel free to include a photo of yourself. ●

The Magic of CSIL

BY PAUL GAUTHIER I'm very excited to be able to write about the Choice in Supports for Independent Living (CSIL) program that has changed the lives of so many people with disabilities in British Columbia. This year, 2014, is the 20th anniversary of this amazing program, and it means a lot to me that this is the year an Individualized Funding Resource Centre will have its debut—a project I've been dreaming about for some time.

The CSIL program was developed by people with disabilities, in partnership with the Ministry of Health. It has been enabling people to receive their home support through individualized funding, rather than through an agency. CSIL users describe the difference between CSIL and agency care as night and day. Through CSIL, the person with a disability is the direct employer with the power to find employees with the skill set and personality that best fits their life. The employees are hired by the individual to provide support when needed and in the way that is most beneficial. The CSIL program is offered to British Columbians with a disability who are eligible for home support.

Who is Eligible?

The Health Authority's case manager assesses your personal care needs to determine the number of hours you are eligible for. I suggest that you develop a Supported Lifestyle Plan which outlines your needs throughout the day and night, so you can be prepared to explain these needs to the case manager. After your hours have been determined, the

case manager will inform you about your options—an agency or the CSIL program.

In order to receive home support through CSIL, you have to be:

- Eligible for home support services and be assessed for home support hours from the Health Authority's case manager.
- 19 years of age or older
- A Canadian citizen or have permanent resident status and have lived in BC for 3 months
- Eligible for CSIL services, as determined by a case manager
- Able to demonstrate that you can safely coordinate and manage CSIL services (such as hiring, training and paying your employees)

CSIL Options

There are currently 3 ways you can operate the CSIL program:

- Direct Employer—for those individuals who are willing and able to manage their own home support services.
- Client Support Group (CSG)—for people who are not able, or not fully able, to manage their own home support services. The person with a disability, their friends, family or supporters form a non-profit society to carry out the duties of the employer.
- Representative—another option for people who are not able, or not fully able, to manage their own home support services. The person with a disability creates a Representation Agreement and the person named in the Agreement can act on behalf of the CSIL applicant.

Finding Help

CSIL is like running a small business. Like most small businesses, there is a learning curve, but you don't have to do it all alone. It is a lot of hard work at the beginning and you have to be ready to deal with everything that comes your way. However, the payoffs are huge—you get home support services in the way you want them and when you want them.

There are ways you can receive help to ensure you are able to manage your care independently, including hiring someone for payroll services or hiring a recruitment facilitator to assist you in finding appropriate employees. You can use your CSIL funds to get the help you need to run the program successfully.

I worked with Spinal Cord Injury BC to develop a series of educational manuals to assist people who need more information about the CSIL program. You can find the manuals at <http://sci-bc.ca/resource-centre/choice-in-supports-for-independent-living>.

The Individualized Funding Resource Centre, that is currently being developed, can also provide you with information and assistance with the CSIL program. Please don't hesitate to send me an email at Paul@IFresourcecentre.org—I may be able to help you with some of the tasks associated with the program, as well as getting started on CSIL. ●





Hiring and Training Personal Attendants

BY WALT LAWRENCE

As a person enters into a disability, often one of the biggest challenges is learning how to manage and direct your own care. This can include becoming an employer of one or several staff, and few of us have experience hiring, managing and training employees.

So, if you may be in the position of hiring employees, here are some things that I've learned about finding and training staff: early steps, general questions I'd recommend asking in interviews and key things I watch for in my personal attendants. Some of my preferences may not be as important for you—such as the person's cleanliness—so substitute questions into the interview process that matter to you.

Hiring

The first questions you need to answer are:

- What do I need my personal attendant to do?
- What do I want them to do?
- What do I look for in my employees, such as personal qualities or skills?

Ask yourself what you are looking for in an assistant. At first, I thought I needed an expert, an ICU nurse and a respirologist. Then I realized I really didn't need that kind of expertise. What I needed was to become the expert myself, so I could be comfortable training others.

My main objective then became finding someone that didn't neces-

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sarily have expertise in the health care field, but had a desire to learn and was a person that I would like to work with. For me, this meant someone who shows initiative, has good listening skills, is caring, and fits well with my family and lifestyle. That's what I need, want and look for in my staff.

Finding Employees

- Place an ad in Craigslist, local papers, local notice boards, colleges and/or schools. Provide a phone number that has an answering machine/voicemail and, if you choose, an email address.
- Ask applicants to call the number and leave a message. This can be the first step in screening applications. You can get an impression of the person's communication style and language skills.
- Call the promising applicants to set up a meeting.

Standard Interview Questions and Tips

- What is the person's work history?
- Do they have a driver's license and do they live near you?
- Where have they lived and for how long?
- Are they available part-time or full-time?

- Do they have other commitments that could make their time inflexible?
- Skill is not what is the most important—attitude is. Impress upon the applicant that anyone with the right attitude and desire to learn can acquire the needed skills.

Things to Notice

- Observe the applicant's way of communicating with you, such as eye contact or nervousness.
- Is the person checking or answering their cell phone?
- Were they early or late for the interview?
- How is the person's appearance? For example, are they clean and tidy? If they have soup stains on their shirt, chances are you will too!

Your Interview Questions

- Ask questions that are important to you, that will help you get to know the applicant.
- Ask the person what would people say about them that is positive and what would they say you could work on.

Training

I found the best way for me to teach an assistant is to keep things simple at first. I carefully explain two or three of the most important things I want to convey. Don't overwhelm the person with information.

Teaching and learning both take time. Be thorough in your training, and give your new employee lots of opportunities to ask questions and to fail because that is how they will learn the most.

When possible, teach the person through demonstration, rather than just through a verbal description. If you can, have someone who is already trained show how the task is done, while you explain what is happening. Before the training session, explain to the staff that will be demonstrating that you will be directing, while they show how the task is done.

I'd also recommend easing the personal attendant into the work environment. For example:

- for their first shift, they only watch another personal attendants
- for their second shift, they may assist the primary personal attendant and start getting comfortable with taking direction from you
- their third shift can be the same as the second shift, with a little more assistance with care.
- for their fourth shift, the worker may perform more tasks, while being watched by the experienced worker.

Creating a Positive Workplace

If your employees feel at risk when they don't do something right, they won't feel as comfortable trying. Create a learning environment that is comfortable and not intimidating. Expect your employee to feel a little pressure and discomfort—after all, it is a new job! Put yourself in their shoes. How would you feel?

I think one of the key things I have learned over the years is to commend (or encourage), instead of condemn. You do need to give feedback for someone to learn—what is being done well and what can be improved—but your tone will make all the difference. Using this positive approach on an ongoing basis, will help both you and your employee have your needs met.

Remember that you're equipping a person long-term for their profession, whatever that may be.

Being Comfortable as the Expert

When you have staff, you not only become an employer, but a teacher. And what are you teaching? You are teaching the person about you. You need to be the expert on you.

You are teaching the employee your needs, how you would like them to be met and why you feel it is important to have the task done in a certain way. The key is conveying those needs in a clear, understandable way, and remembering that no one knows your needs better than you do. Be patient and help the employee to understand what you would like them to know. ●

Meet Patrick Cho

We would like to welcome a new Registered Respiratory Therapist (RRT) Patrick Cho.

Patrick joined BCITS in October 2013 and we are looking forward to working with him. He has a Bachelor's of Science from Simon Fraser University and he is also an RRT.

Before becoming an RRT, Patrick did research in cancer drugs and medical devices. He studied at Thompson River University to become an RRT, and did his clinical training at Surrey Memorial and Vancouver General Hospital. After graduating, he worked at the Royal Columbian Hospital before coming aboard.

Patrick is very excited to be given the opportunity to work for BCITS and is looking forward to helping the clients of PROP!



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The Importance of Listening BY CHERI RYTER

I have been working as a health care provider for over ten years and, specifically, with a client who uses ventilation for the last three years.

I remember, before I had exposure working with individuals who are assisted with ventilation, I had a fear of the unknown. I avoided taking employment with people who used ventilation because I didn't feel qualified. However, my attitude changed when I accepted a position with a client who had mastered the skill of directing his own care.

I was put at ease during the interview process. I had questions about tracheas and ventilation, but before my questions were answered, I was asked, "How do you rate your listening skills?" I replied, "I think I'm a pretty good listener." He said, "If you are a good listener, you will know everything you need to know. I'll direct you to do things exactly the way I want them to be done." He also told me he'd been using ventilation for forty years and "the person who knows me best and how to care for my needs is me!"

Believe it or not, when he said those words to me, the fear of working and assisting someone who uses ventilation was gone. I realized, right in the first interview, the key component to my new employment opportunity was to be a good listener.

My client is a family man with a wife and two children. It is a unique environment to work in because I have to understand healthy boundaries appropriate for working in a family environment. I need to continually

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remind myself why my presence is needed. I am there to provide assistance with personal care and every-day activities. I am not there to mediate, offer opinions or be an interruption to his family. I also need to be sensitive to private conversations and quietly excuse myself when needed.

Even though I have been a care-provider for many years, I am always learning new things. Working for my current employer, I have gained skills and awareness I would never have received anywhere else. Because he directs his own care, I've learned how important it is to listen to what my clients want and how empowering it can be to assist someone toward their independence and their daily goals.

The last three years have been so rewarding. I can honestly say, I never dread going to work and, when I leave work, I feel satisfied. I know I was the hands that helped my client gain some independence. ●

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. **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 www.bcits.org.]
- I would like to donate directly by VISA. I will call Clara Chalifour at 604-326-0175.

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 E. Kent Ave S., Vancouver, BC V5X 4N6

A Message from the BioMed Technologists



BY WAYNE POGUE

As you know, our clients depend on our technologists and their expertise when it comes to the technology they use to live more independently.

Our technologists love to help our clients, but we can't personally assess and troubleshoot every situation, in person, that our clients run into throughout the year.

That being said, BCITS clients' personal attendants are a valuable resource for helping BCITS technologists troubleshoot and rectify technical issues. In many cases, the issues are resolved by the personal attendants before BCITS is contacted.

Not only does this assistance help our technologists, but it is a great resource for BCITS clients as they get their technical issues dealt with in an expedited way.

So, on behalf of BCITS, and the technologists that rely on the assistance of personal attendants, we would like to offer our sincerest appreciation and a big thank you to BCITS client attendants.

Thank you! ●



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)

Name: _____

Address: _____

City/Prov: _____ Postal Code: _____

Telephone: _____ Email: _____

Please Check One

Membership for registered BCITS clients

Please mail completed form to BCITS (the cost of postage constitutes your membership fee)

Non-client membership fee

Please mail completed form along with \$20.00 annual membership fee payable 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



PROP Training for Tracheostomy and Ventilator Dependent Clients

by Elaina Zebroff

About once a month, PROP offers a comprehensive two-day Tracheostomy and Ventilator Management Course taught by one of our own Registered Respiratory Therapists (RRTs).

The training covers a wide range of topics related to respiratory care needs, keeping clients safe and independent, emergency planning, and ventilator management.

PROP clients, personal attendants, and family and friends of clients are welcome to take the training. It is important to note this course is not a regulated certificate course. It is a course provided by PROP to serve our clients' needs.

Historically, PROP training has occurred at our office in Vancouver. However, not all clients reside in

the lower mainland and therefore attending PROP training can pose great difficulty. Our RRTs do travel and offer off-site training when required.

If you are a client who lives outside the lower mainland and have questions regarding off-site training, please contact the PROP office for further details. ●



Illustration by Roger Desmarais