Getting Your Life Back.
Specializing in Personal Injury.

BCCPD would like to thank Spring Advertising for creating the “What does disabled mean?” awareness campaign for us.

Spring is continuing to donate their time to help us on this campaign—stay tuned.

Thanks Spring!
What does self-care look like when you’re the primary caregiver for someone with a severe physical disability and you have a disability yourself? There are many of us in this situation and our answers no doubt vary widely. In this TRANSITION, we’re looking at the self-care challenges faced by caregivers who are aging or have a disability. I’ve had fibromyalgia for many years. Some of those years I received disability benefits, but I now work full-time. My spouse has a disease that has caused quadriplegia. He can stand for about a minute, so caregiving is a game of seconds and inches to which both our schedules are tethered. I help him with personal care including toileting, bathing, dressing, and getting in and out of bed. If I go out for the evening before he has gone to bed, I always come home to find one of his legs hanging off the side of the bed, throwing out his spine and causing a lot of pain. And, there is always the danger he will fall. This means a call to the fire department to come and pick him up.

At this point, there are not many options for us around his care needs. Reliance on personal care from a stranger, or even from a family member other than me, is a big step for my spouse to make.

Reliance on personal care from a stranger, or even from a family member other than me, is a big step for my spouse to make.

National Recommendations on Caregiving

In 2011, the Canadian Research Network for Care in the Community (CRNCC) prepared an InFocus report on informal caregiving. The Canada-wide project made these recommendations to recognize the role of informal caregivers and to ease the psychological, social and financial burdens on them.

Recommendations

- Recognize that caregiving is vital not only to care recipients, but also to the formal health system and the broader economy.
- Make it easier for caregivers to navigate health care systems.
- Assess the needs of both the care receiver and the informal caregiver as a unit.
- Include carers as part of the multi-disciplinary care planning team.
- Provide easy access to education, skills training, wellness programs and opportunities for work-life-caring balance.
- Provide compensation through policy tools beyond employment insurance and tax benefits to support carers who do not work for pay and provide care for chronic issues (e.g., stipends, travel reimbursements, respite).
- Broaden the definition in the Compassionate Caregiver Benefits to include medical crises and not only palliative care.
- Enable work-life balance for employed caregivers by flexible scheduling and the option of working at home without penalty.
- Assess the needs of both the care receiver and the informal caregiver as a unit.
- Include carers as part of the multi-disciplinary care planning team.
- Provide easy access to education, skills training, wellness programs and opportunities for work-life-caring balance.
- Provide compensation through policy tools beyond employment insurance and tax benefits to support carers who do not work for pay and provide care for chronic issues (e.g., stipends, travel reimbursements, respite).
- Broaden the definition in the Compassionate Caregiver Benefits to include medical crises and not only palliative care.
- Enable work-life balance for employed caregivers by flexible scheduling and the option of working at home without penalty.

For more information, or to download the complete InFocus Background, please visit http://www.crncc.ca/knowledge/factsheets/pdf/InFocus-InformalCaregiving.pdf.
A Snapshot of Caregivers Living with a Disability

A national study provides a look inside the lives of caregivers—the good, the bad and what’s needed.

BY CANADIAN CENTRE ON DISABILITY STUDIES

A study by the Canadian Centre on Disability Studies examined the:
- nature of informal caregiving provided by adults with disabilities
- nature of the barriers and impediments faced by caregivers with disabilities
- supports, mechanisms, and circumstances that can facilitate a caregiving role for people with disabilities

Caregivers with Disabilities
Who are they?
- adults with disabilities providing care to other adults with disabilities; in some cases, they provide care to each other depending upon the nature of their disabilities

Negative Aspects of Caregiving for People with Disabilities
- lack of time for other family members
- some respondents had to give up volunteer activities that were personally rewarding, as well as paid employment
- some respondents had to give up their own home care and other income support benefits to provide care to another
- one respondent had to leave her accessible home to move into her father’s less accessible home to provide care to him

Barriers Faced by Caregivers with Disabilities
- lack of integrated care delivery and planning system
- “One organization provides assistance with personal care and household tasks. A different organization takes my wife out so I can spend quiet time at home. We have to pay for respite.”
- disparity in supports available in rural/remote vs. urban locations
- barriers in the built environment: housing, community design, transportation. “Our house does not have a lift or ramp, so this limits my ability to provide care for my husband.”
- lack of recognition as legitimate caregivers. “Caregivers with disabilities are not included in our definitions. We do not have a good understanding of the particular issues of concern to caregivers with disabilities. I am glad I am doing this interview.”

In spite of the negative impact, most caregivers with disabilities felt there were some true rewards for their role, such as “great satisfaction”, “better connection to…””, “… a real closeness”, “It made me stronger”, “know my community better…”, “love of my family”, etc.

Summary of Findings
- caregivers with disabilities are providing an invaluable service, but are not recognized as such by most caregiver stakeholders, researchers, policies or programs—or by society in general
- they offer a multitude of services to care recipients
- they have a wealth of lived experience and knowledge about disability, support systems, and coping mechanisms, etc.
- they face similar challenges to non-disabled caregivers, plus the impact of their own disability

Recommendations
- raise awareness about this population among policy makers, international, national and provincial caregiving agencies, older adults, the disability community, health promotion and professional organizations
- education/promotion programs targeted at professionals, service providers, policy makers and researchers
- sincere recognition of the care provided and the need for supports
- coordination and sharing of supports with the caregiving pair

For more information visit the Canadian Centre on Disability Studies at: www.disabilitystudies.ca


BC COALITION OF PEOPLE WITH DISABILITIES
Rhythm of Care: Journaling for Caregiver Renewal

BY LYNDA MONK, MSW, RSW, CPCC

“...My in-breath of self-care is the doorway to true mature compassion.”

- Gail Straub

As caregivers, we dance what I call the “rhythm of care.” We move between caring for ourselves and caring for others. Sometimes the self-care side of the equation can run dry, our emotional cups can feel depleted, we can become exhausted, we risk suffering from burnout and compassion fatigue. Then, we are unable to care effectively because we have very little left to give in these emotional states.

Caregiving does not have to be a road leading to depletion. Caregiving and caring itself are at the heart of living a meaningful life. Caregiving can infuse us with a deep sense of purpose, self-identity and satisfaction, whereby we can experience joy and fulfillment from our caregiving roles.

Most of us probably shift between both ends of the caregiver well-being continuum—at times exhausted, other times enlivened by the nature of caring itself. It is critical to have self-care practices that replenish and nourish the caregiver’s soul. Our soul is the deepest essence of who we are. In my years as a caregiver, both formally in my work as a crisis response social worker and helping professional, as well as informally in my role as a mother to young sons and a daughter to aging parents, including my father who suffers from Alzheimer’s disease—one of the key ways that I replenish my energy, patience, passion and compassion is through my regular reflective journaling practice. Journaling can help you access the healing qualities of solitude, stillness and silence, even briefly in the midst of it all, allowing you to hear your own thinking, express your emotions and nourish your mind, body, heart and spirit.

Writing can help you to heal and replenish. Research tells us that expressive writing has the power to help us transform our physical, mental and spiritual health. In fact, expressive writing has been proven to:

- decrease heart rate
- lower blood pressure
- strengthen the immune system
- enhance feelings of calm
- improve self-esteem
- cultivate life balance
- reduce stress and anxiety

Journaling can help you come home within yourself, come back to centre and support you to become fully present in the moment. This mindful and creative approach to self-care can result in feelings of calm and manageability, even in the most overwhelming situations.

You might wonder when you will find the time to write for yourself, to journal. It’s true, journaling does require that you give it a bit of time, but it is something that gives back. When I don’t have time to write in my journal, I know that is the perfect time for the five-minute journal entry. Or two minutes, if that is all the time I can steal between running my son’s bath and putting the dishes in the dishwasher.

“Sometimes one doesn’t have time to write. In fact most of the time we don’t have time to write. Most of the time we do not have time to be with ourselves. And when that happens, it is time for the five-minute journal entry.”

~ B.N. Holzer, Author of A Walk Between Heaven and Earth

A personal journal on writing and the creative process

Research shows that you do not have to write for a long time to experience the healing benefits of expressive writing. For example, one research study by Dr. James Pennebaker showed that when people wrote about their stressors and upsetting emotions for 20 minutes a day for four days, they experienced decreased stress and trauma symptoms, and improved overall health.

Here are four expressive exercises to help you get started with caring for the caregiver within through journaling.

Connect with your strengths.

Journal for ten minutes about all of your strengths as a caregiver. Notice how it feels to write about all you are doing well, about the gifts and strengths you bring to your family and to others you might be caring for. If you get stuck, simply start the next sentence in your journal with the following: “One of my strengths or gifts as a caregiver is ______ (fill in the blank).”

Experience joy. Pick five recent moments, as a caregiver, that brought you joy. Write them down. Then pick one of these moments and describe it in as much detail as you can. Notice what it feels like to write about your joy. How can you create even more joyful moments as a caregiver?

Process difficult emotions. Your journal is also a place to sort out challenges, make difficult decisions and express painful emotions. A journal can offer you healing, renewal and catharsis. Getting your feelings down on paper can serve as an emotional purging or release which is a lot healthier than bottling up stressful feelings inside.

When we can release, let go and/ or process difficult emotions, this clears the way for us to be more present, mindful and happier as caregivers.

Express your gratitude. What we focus on grows. Your journal can be a powerful place to manifest more of what you want in your life, by giving thanks often for what you already have. You can simply list three to five things you are grateful for from your day.

Journaling is a self-caring act. May your imagination, your needs and your heart lead the way. Anything you write is right! Try it yourself. Relax. Write. Reflect. Replenish.

Self-care and personal renewal are among the best gifts we can give to ourselves and this in turn benefits those we love and care for. Journaling helps you remember that you are enough, that you are doing enough. Journaling gives you a chance to simply be. Journaling is a self-caring act. May you experience the healing and transformational power of writing—you deserve it!

LYNDA MONK, FOUNDER OF CREATIVE WELLNESS, REGULARLY TEACHES, COACHES AND SPEAKS ABOUT THE HEALING POWER OF WRITING. GET HER FREE “WRITING FOR WELLNESS GETTING STARTED GUIDE” AT CREATIVEWELLNESSWORKS.COM.
Disability White Paper Consultation and EATI

The BC government can show commitment to its goal to reduce barriers and increase accessibility by continuing this vital personal supports program  

BY CHRISTINE GORDON

The government of British Columbia is launching consultations on the Disability White Paper on December 3, 2013. The aim of the consultations is to find out how to reduce barriers and increase accessibility for people with disabilities. The approach is modeled after the United Nations Convention on the Rights of Persons with Disabilities (CRPD) pledge to ensure that any discussion of disability issues be done with the disability community—“nothing about us without us.”

Since 2009, the BC Coalition of People with Disabilities has played a leading role in the development of the Equipment and Assistive Technology Initiative (EATI). As you learned in the last issue of Transition, EATI is special because the provincial government, and its person-directed approach meets and serves people with disabilities at every level, including learning new skills, communicating and demonstrating new skills to potential employers.

In terms of its effect on labour market participation, the equipment and assistive technology provided by EATI has been equated to settling off a missile from a launching pad.

For the past four years, EATI has been funded through the federal/provincial Labour Market Agreement. The Agreement is due to expire on March 31, 2014. The federal government has announced its intention to transform much of the existing Labour Market Agreement into the Canada Job Grant. The provincial government has given no assurance that EATI will continue, regardless of what happens in the negotiations for the Labour Market Agreement.

This means that the future of EATI is in jeopardy.

Your Voice Counts

We hope you will help us to speak out about the importance of EATI to the future of accessibility and inclusion in BC that the Disability White Paper envisions. Sign up on the White Paper website http://engage.gov.bc.ca/disabilitywhitepaper/stay-informed/ and speak out about why EATI needs to continue to provide people with the equipment and assistive technology that they need to level the playing field for labour market participation.

See the White Paper at http://engage.gov.bc.ca/disabilitywhitepaper/.

Learn more about the power of the EATI program at http://www.bcpsn.org.

Christine Gordon is a policy and program consultant for the BC Coalition of People with Disabilities, a policy and program consultant for the BC Personal Supports Network.

Windows 8.1 and Assistive Devices

A MESSAGE FROM AROGA TECHNOLOGIES

Microsoft recently released Windows 8.1. This new version comes with a handful of updates, such as Internet Explorer 11 and returns the much-missed Start Button to the desktop.

Unlike many updates, this one isn’t automatic. You download it from the Windows App store.

Users of assistive technology should use caution before installing this update. Many assistive technology software packages have not yet been updated to work with this newest version of Windows.

- Zoomtext 10.1 will not yet work with Windows 8.1. AI Squared has announced they will do an update to resolve incompatibilities, but for now Zoomtext users should not install Windows 8.1. If you have Zoomtext on a computer you want to upgrade to 8.1, you should uninstall Zoomtext before you do the update.
- MAGic will not work with any version of Windows 8, including 8.1.
- JAWS version 14.0.4004 will work with Windows 8.1. However, none of the previous versions of JAWS will, so JAWS users will want to make sure they have this version before updating.
- System Access is working with Windows 8.1.
- Users of PRC Accent devices should not update to Windows 8.1. The NuVoice software will not currently work with it.
- We will continue to update our customers via our Facebook and Twitter feeds as we find more information.

If you are unsure about the compatibility of your assistive technology with Windows 8.1, we would encourage you to contact the manufacturer before proceeding with the update. If you learn about other programs not on our list, please let us know by emailing steve@aroga.com.

International Day of Persons with Disabilities

On December 3, the International Day of Persons with Disabilities (IDPD) was recognized and celebrated around the world. This year, the official theme designated by the United Nations was “Break barriers, open doors for an inclusive society for all.”

It was 21 years ago that the General Assembly of the UN passed a resolution to designate December 3rd as the IDPD. The UN has encouraged people in all corners of the globe to observe this day in their own way to include, organize, celebrate and take action.

But what does this really mean? How can you participate and recognize this day in your own life? It could mean urging the provincial government to raise the Persons with Disabilities benefit rates, supporting a disability awareness campaign, organizing a small celebration with friends or helping to improve accessibility for people with disabilities in your own community. It is up to you.

The IDPD was celebrated in Vancouver this year with a free public event at the Roundhouse Community Centre. The day was a great success that featured local artists from the disability community, an interactive mixed-ability dance workshop, comedy acts, live music and guest speakers. Throughout the province and around the world, there were similar events taking place.

To learn more about how you can celebrate IDPD year-round, visit: http://www.un.org/disabilities/index.asp
The Transition Magazine Winter 2013 featured an article discussing the BC Coalition of People with Disabilities (BCCPD). The article highlighted the organization's commitment to community partnerships and employment opportunities for individuals with disabilities. It mentioned the BCCPD's Executive Director, Stephen Regan, and the reaction to a recent article that misquoted his comments.

The article also included an advertisement for the BCCPD's annual fundraising event, Inaugural Swinging into Spring Gala. The event featured various entertainment, including a Togolese-born musician, Lazare Halk, and a performance by David C. Jones, known for his acting, comedy, and improvisation skills.

The BCCPD emphasized the importance of accurate representation in the media, particularly in relation to employment opportunities for people with disabilities. They apologized for any confusion caused by the article and highlighted their focus on community pride and commitment to community partnerships.

The advertisement for the gala encouraged attendees to join and purchase tickets, which were available starting in January 2014. The gala would include a dinner, drinks, and a silent auction, with proceeds supporting the BCCPD's programs.

The article concluded with a call to action, urging readers to support the event and the BCCPD's mission.

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**Mark Your Calendar**

**Wednesday April 9, 2014**

Swing into Spring with the BC Coalition of People with Disabilities’ annual fundraiser. Please join us for this fun and festive event!

- Setting the stage for an evening of laughs are Stephen Quinn of CBC’s On the Coast and David C. Jones, actor, comedian, and improvisor extraordinaire. David was a huge hit at last year’s event. You have to see him to believe him!
- Togolese-born musician Lazare Halk will get the grooves going with upbeat tunes.
- BCCPD will present an inaugural award to a BC Business recognizing their contribution to employment opportunities for people with disabilities.
- Dinner, drinks and a not-to-be-missed fab silent auction and raffle.

Please visit the BCCPD website for further details: [www.bccpd.bc.ca](http://www.bccpd.bc.ca). Or contact Jody at 604-875-0188 or jody@bccpd.bc.ca.

Please join us! Tickets on sale January 2014.

Thank you to our event Silver Sponsor the Vancouver Taxi Association.
Views from Transition Readers

We are grateful to everyone who took the time to answer a BCCPD survey on caregivers with disabilities. This selection of responses shows some of the hardships and extreme gaps in services that people are experiencing.

What are the main challenges you face as a caregiver who has a disability?
• Finding space to do the self-care that has kept me going for years with my disability
• Lack of physical energy
• The challenge of doing the physical care that my disabled husband needs, although I now experience painful arthritis
• Depression
• The challenge of learning to ask others for help, and accepting help when it’s given
• Funding for equipment
• Government supports are virtually non-existent in rural areas
• Not enough home support
• Means testing for supports—income cutoff is too low
• The government definition of respite is too restrictive

PWD benefits are not even close to adequate to survive on
• No government support for assistive devices and therapies

What are some of the things you do to take care of yourself?
• I belong to a Senior’s Arts and Health Writing group. I am writing stories about my experience. We have three children who help as much as they can. I order groceries online and friends will help. I make sure I have time to vent to friends and relatives.
• I try to meditate daily and use my cognitive therapy skills to control emotions. I try to get a few minutes to myself each day.
• I keep up with my physical therapy, my friends and my other kids. I give myself permission to rest when I’m tired and caregiving allows.
• I try to maintain a social network with friends
• I try to find time every day in my sewing room (I’m an avid quilter), see or talk with friends, periodic social outings with my husband to help maintain our husband/wife relationship so I don’t become resentful at being a caregiver, use respite so I can go away for a few days
• Walk regularly, massages, support from friends

I try to take some time for myself by reading or going to the store by myself for short periods

If you also work, how do you manage caregiving and your job?
• Home support looks after my spouse for about three hours a day. I work close to home so I can be home for lunch hour and close by in case of emergency.
• I work from a home office so I can be here at medication time, to help my spouse with tasks he has trouble with cognitively, etc.

Is there anything else you’d like to tell us?
• I raised four children as a single mom and I am thankful every day for that experience or I wouldn’t even be able to do it. However, at 70 years old, I am no longer young and I live with pain and fatigue. I do resent that I will need to sell my house which has been modified to meet our needs.
• Proper diet, exercise, and a good support network are essential to achieve balance in physical, mental, emotional and spiritual health
• “They” have to realize that they don’t provide more assistance to caregivers, there will soon be two of us needing care
• It’s hard to maintain my own health. I got an injury from heavy lifting (loved one) and the injury hasn’t healed in part because I don’t have time and money to do the necessary self-care to help heal the injury.
• Yes, this is a huge subject. I really hope people will realize that caregivers, especially when they have a disability, also need support. I have never had any and I think this has decreased my life span as a result of the stress.
• It is overwhelming, but the alternative (long-term care facility) is worse
• I feel like my life revolves around health issues. As a person with a disability all of my life, I’ve always tried to avoid this, to see my diseases as just a small part of who I am. Now I sometimes feel consumed by it.

I understand the concept of not paying family for providing care that families should provide, but most of us are providing care well in excess of what would normally be expected. We often provide better care for less cost and yet aren’t reimbursed for extra expenses or time. I can pay wages and expenses for a worker to escort my adult son to camp, but if I choose to drive him to spend some fun time with him, I have to take time off work and pay all the expenses.

People with a disability sometimes need to be taken care of in order to recover. However as a caregiver, we have no choice but to over-function for others and we get worse over time.
everyday resilience
self-compassion for caregivers 

BY SHELLEY HOURSTON

Caregiving is a role that most of us will experience at some point in life with varying degrees of responsibility and support. For people living with a disability or chronic health condition, caregiving can add a new layer of complexity to your life that will truly test your resilience.

While your situation (health, age, location and social support) may impose a limit to your caregiving responsibilities, you will almost certainly experience a challenge common to all caregivers: a struggle with self-compassion.

Paula Spencer Scott describes “seven deadly emotions of caregiving:” guilt, resentment, anger, worry, loneliness, grief and defensiveness.* When caregivers experience one or more of these emotions, it’s natural to chastise yourself. “How can I possibly feel ______ when my family member/friend needs my help?”

Psychologist and self-compassion researcher, Kristin Neff, notes that self-compassion entails three basic components: 1) extending kindness and understanding to oneself, rather than harsh self-criticism and judgment; 2) seeing one’s experience as part of the larger human experience, rather than as separating and isolating; and 3) holding one’s painful thoughts and feelings in balanced awareness, rather than over-identifying with them.**

If you’re wondering just when you’ll find time to work on your self-compassion in an already full life, it is possible. Your capacity for compassion is well established—you are a caregiver after all. Self-compassion involves broadening the focus of your kindness to include yourself.

Ironically, we often refuse to apply the kindness and generosity to our own life that we extend to another person.

In measuring ourselves by unrealistic standards, we set ourselves up for constant failure and self-criticism. Although often unconscious, feeling that we’re always “falling short” of our standards eats away at self-esteem and drains our energy at a time when we need it most.

If you live with a disability or chronic health condition and are a caregiver, increasing your self-compassion is an important goal. Like most resilience strategies, self-compassion is more of a practice than something you acquire quickly.

Kristin Neff provides many self-compassion resources on her website. In “Exercises to Increase Self-compassion,” she notes the importance of identifying the voice and messages of your inner critic.

Through journaling or simply noticing your inner voice, develop an awareness of your self-criticism. Observe how painful these self-critiques can be. Think of gentle, more encouraging comments like those a respected mentor or friend might offer. Reframe your inner critic’s comments in terms that are supportive of potentially different choices next time.

Neff writes, “Remember that if you really want to motivate your self, love is more powerful than fear.”**

In “Self-compassion Exercise #7: Taking Care of the Caregiver,” Neff emphasizes the importance of giving yourself “permission to meet your own needs” to ensure that you have the energy to care for someone else. You’ll have your own list of favourite strategies for self-care. You might add some of Neff’s recommendations which include: massage, mid-day naps, comedy, listening to music, spending time with a friend, yoga, or a guided body scan meditation available at her website.

For caregivers with disabilities/chronic health conditions, it is essential to make self-care a priority. If you tend to put your needs last, consider the benefits of committing to a self-compassion practice. Implement a few of these suggestions or some from the resources below. Watch for improvements in your energy and mood.

If you have ideas for increasing self-compassion, please let me know. Contact Shelley at 604-875-0188 (toll-free 1-877-232-7400) or email wdi@bccpd.bc.ca.

If you’re wondering just when you’ll find time to work on your self-compassion in an already full life, it is possible. Your capacity for compassion is well established—you are a caregiver after all. Self-compassion involves broadening the focus of your kindness to include yourself.

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* Paula Spencer Scott “The 7 Deadly Emotions of Caregiving” at caring.com.
http://www.caring.com/articles/7-deadly-emotions-of-caregiving


http://www.uv.es/carmenc material1/art%EDculos/Neff%202003.pdf

***Kristin D. Neff. “Exercises to Increase Self-compassion.” (p. 12)
http://www.self-compassion.org/exercises.doc

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Resources

Kristen Neff
Self-compassion: A Healthier Way of Relating to Yourself
http://www.self-compassion.org

Free self-assessments, guided meditations, videos and links to additional resources.

Christopher Germer
Mindful Self-compassion
http://www.mindfulselfcompassion.org

Germer often publishes and facilitates workshops with Kristin Neff. His website provides meditations and information about mindful self-compassion.

VON Canada caregiver-connect.ca

Contains extensive Canadian information including articles, news, resources on aspects of caregiving by province and territory.

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Shelley Hourston is Director of BCCPD’s Wellness and Disability Initiative/AIDS and Disability Action Program.

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* BC COALITION OF PEOPLE WITH DISABILITIES
BCCPD.BC.CA

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* BC COALITION OF PEOPLE WITH DISABILITIES
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Overview of the Concerns about Caregivers with Disabilities

BY THE CANADIAN CENTRE FOR DISABILITY STUDIES

Background
Anecdotal evidence from the disability community suggests that informal caregiving to other adults by people with disabilities is actually quite common in Canada and there are many serious gaps in our support systems which create significant barriers.

People with disabilities have been assuming a much wider range of roles within their families and communities, including that of caregiver. But as providers of support, people with disabilities have requirements for assistance to carry out these roles. There is, therefore, a need for our system of supports and services for people with disabilities to recognize these requirements.

As a group, caregivers with disabilities are invisible in terms of research. They have been excluded from policy, program and service development, as well as from general caregiving strategies.

Future Research Needs
Additional qualitative and quantitative research is needed and must address aspects such as the effects of disability on caregiving, with a focus on the effects of various disabilities on the caregiving experiences, the impact of caregiver disability on caregiver stress and health, financial implications, relationships with care receivers, and specific supports to facilitate caregiving.

Future research could focus on the perceptions of friends, family, professionals and the general public regarding caregivers with disabilities and whether they are valued as a result of providing care to others.

It is important to continue to gather the caregivers’ with disabilities voices that has been started in this research project. More qualitative studies are needed to learn the complex interplay of social systems, policies, the disabilities of two people in the caregiving team, and their environments.

It is clear that caregivers with disabilities share many of the same barriers as do non-disabled caregivers. However, they also face unique issues due to their own disabilities and their own need for supports and accessible environments. Many times support policies do not accommodate both the caregiver and the care receiver.

They also face, in some cases, different financial constraints due to their own past limitations with work or limitations in current policies.

This area must rise to international, national and provincial agendas. This is not a “niche” target group issue; it is a growing area with the aging of our population.

RESOURCES

These organizations are excellent resources for caregivers.

Canadian Caregiver Coalition
http://www.ccc-ccan.ca/
A wide range of practical resources on caring for others and self-care.

Care-ring Voice Network
http://www.caringvoice.com/
Many free resources, including webinars and tele-learning workshops.

Family Caregivers’ Network Society
http://www.fcnscaregiving.org/
The society provides support groups, individual assistance and workshops, in addition to written resources and a bi-monthly newsletter.

Metro Vancouver Family & Friend Caregivers Information and Resource Handbook 2013/14
http://tinyurl.com/nbwuc75
For seniors and boomers who are unpaid caregivers for older family members and friends.

Caregiver Supports in BC
This is a resource guide to supports in various regions of BC.
Good To Go!
BY DAPHNE DAVEY

“There is something about the outside of a horse that is good for the inside of a man.” Churchill had it right! Many riders with disabilities, their parents and friends agree.

Brenda and Terry Searl said, “Our daughter, Jessica, has mental and physical disabilities. When she first started, she couldn’t even cope with going into the barn. Now after over 25 years in the program, she is thrilled to take a carrot or two for (her favourite horse) Licorice.”

Given the specialized nature of horseback riding, it has a wide application for people with disabilities.

The following list of conditions positively affected by riding is by no means exhaustive: orthopedic (amputation, scoliosis, arthritis, and some hip abnormalities); neurological (spinal cord and brain injuries, hydrocephalus, MS, cerebral palsy, stroke, epilepsy); and others such as autism spectrum disorder, visual and hearing loss, muscular dystrophy, speech impairment, developmental delays, and learning disabilities.

Carolyn Bateman, the mother of an autistic young man, commented, “I believe a therapeutic riding program is a great place for a child with autism to grow and feel they belong…where they will be accepted for who they are and be able to find a friend.”

Therapeutic riding is not restricted to those living with mild disabilities. Many programs serve wheelchair users, some of whom are mounted into the saddle using a mechanical hoist. Despite the severity of their disability, they gain so much from this exercise: physical therapy; the thrill of a new, undreamed-of activity; a rare opportunity to experience freedom and speed of movement; and, the many social benefits.

Just how does the horse impart this therapeutic magic to his rider? The horse shares the same pattern in his walking stride as humans—the figure-eight rotation of the pelvis, front to back and side-to-side. The horse’s much greater forward movement positively influences the rider’s pelvis, hips, spine and head.

Add to that the relaxing effect of warmth from the horse’s body, and the famously effective “leanoff” of the human-animal bond, and you have a recipe for success.

“When the time my son Sean was born, it was clear that he would have special challenges in his life,” says his father, Mark, moved to tears by watching his son’s first ride. “When Sean was placed on Petey and began his first trip around the arena, you could see a special bond start to form between them. He was doing therapy that was finally fun and what he wanted to be doing.”

Sean and Churchill both got it right!

Learn more about the Canadian Therapeutic Riding Association at http://www.cantra.ca.

10 Caregiver Tips
BY DOROTHY ORR

• Get help with tasks and chores early on in the illness. Your loved one will get used to having other people around the home.
• Involve other members of your family from the beginning of the illness. Even if you are the only one who sees the changes that are taking place, pass these on as information only, not as a debating issue.
• Access all the information you can about the illness and educate yourself as much as possible about its progression. Disease-specific organizations, your doctor and the public library, for example, are sources of information.
• Recognize and learn to accept that anger, anxiety and guilt are normal feelings given the situation you are experiencing. They come not only from being tired, but also from the losses you are experiencing.
• Join a support group as soon as you can. You do not need to be alone on this journey.
• Every change in your loved one means more adaptation and change for you. Acknowledge that this gives you the right to feel off-balance some days.
• Forgive yourself for not being perfect. Caring for someone with a chronic or terminal illness turns your life inside out.
• Make friends with your family physician. Ask for time to speak with her/him alone, if you need to do so.
• Get regular physical check-ups, eat a balanced diet and try to take time out to express sadness, anger and helplessness. Accept yourself for being human and try to do at least one thing that you enjoy every day.
• Take one day at a time, while planning for the future. Good planning means getting to know and implementing any legal and financial considerations, facility placement issues or palliative care, and be kind to yourself.

DOROTHY ORR, “CAREGIVER COACH,” ADAPTED FOR ALL FAMILY CAREGIVERS BY THE FAMILY CAREGIVERS’ NETWORK SOCIETY.
Planned Giving

You've always been there for others. It's part of who you are. Now, you can continue to give beyond your lifetime.

Benefits
There are many benefits to Planned Giving. By writing down your wishes, you will have increased peace of mind and control over your finances.

Through Planned Giving, you can provide a significant future donation without reducing your income today.

A gift in your will to a registered Canadian charity is tax-deductible.

And, your Planned Gift helps the BCCPD to be here in the future for those who need us.

Tax Savings
You can realize significant tax savings with Planned Giving. For example, stocks, bonds and mutual funds that you may have in a trust can be transferred in your will to a charity and a tax receipt will be issued.

A bequest from your estate of cash or RRSPs will reduce the taxes that your estate will be required to pay.

Other ways of donating give twofold value: by naming the BCCPD as the beneficiary in a life insurance policy, you do not incur any costs now and a tax receipt is issued when the estate is settled.

To Learn More
Our donors are important to us and we'll work with you to be recognized in the way that you'd prefer.

If you would like more information, please contact Nicole at the BCCPD at nicole@bccpd.bc.ca or 604-875-0188.

She will send you BCCPD Planned Giving information for you to review with your financial planner or lawyer, family and friends.

You can also see our Planned Giving materials at http://www.bccpd.bc.ca/supportadvertise.html,

Obituary | Elspeth Fraser 1928 – 2013

The BCCPD was very sad to hear about the passing of Elspeth Fraser this summer. Ms Fraser was a great friend to our organization and will be truly missed by all of us who knew her.

Elspeth was born in Kuala Lumpur, Malaysia and grew up in Victoria. She worked for years in London, England where she made life-long friends and in San Francisco before moving to Vancouver and marrying Ken Fraser. She was a member of the Marpole Women’s Auxiliary for 27 years and was on the board for the BC Rehab Foundation for 13 years. Elspeth closely followed politics, tennis and golf, loved doing her New York Times crossword puzzles, and both read and watched British mysteries. Elspeth was a foodie—she was a wonderful cook and hostess, and loved introducing friends to great restaurants, farmers’ markets, cheese shops and other specialty stores. Our sincere condolences to her friends and family.

SUPPORT BCCPD

BECOME A BCCPD MEMBER

Numbers matter. The more members we have, the stronger our voice in the community.

Please become a BCCPD member today. You can be a voting member or a non-voting member, and we welcome both individuals and groups.

I accept your invitation to join the BC Coalition of People with Disabilities and enclose my membership fee of $15 (groups and individuals).

I am also including a tax-deductible donation of _________. (Donations over $10 are tax deductible).

Please return your payment/donation with this form to: BCCPD, 204-456 W. Broadway, Vancouver, BC V5Y 1R3.

You can also become a member or donate online at: www.bccpd.bc.ca/supportadvertise.htm.

Please check the correct boxes:

☑ New membership or ☐ Renewal
☑ Voting Member or ☐ Non-voting Member

Voting members are people with disabilities and self-help groups where at least 50% of members have a disability.

Name __________________________ [ ]

Organization ____________________ [ ]

Address __________________________ [ ]

City/Prov _________________________ Postal Code ____________ [ ]

Phone _______________ Email _________________________ [ ]

Thank you for your invaluable support
A Caregiver’s Bill of Rights

BY WENDY LUSTBADER

I have the right:

- To take care of myself. This is not an act of selfishness. It will give me the capacity to take better care of my relatives.
- To seek help from others, even though my relative may object. I recognize the limits of my own endurance and strength.
- To maintain facets of my own life that do include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things just for myself.
- To get angry, be depressed and express other difficult feelings occasionally.
- To reject any attempts by my relative (either conscious or unconscious) to manipulate me through guilt, anger or depression.
- To receive consideration, affection, forgiveness and acceptance for what I do, from my loved one, for as long as I offer these qualities in return.
- To take pride in what I am accomplishing and to applaud the courage it has sometimes taken me to meet the needs of my relative.
- To protect my individuality and my right to make a life for myself that will sustain me in the time when my relative no longer needs my full-time help.
- To expect and demand that as new strides are made in finding resources to aid people who have physical or mental disabilities in our country, similar strides will be made towards aiding and supporting caregivers.

Read the list to yourself every day.

WENDY LUSTBADER, MSW, HAS WRITTEN SEVERAL BOOKS INCLUDING “COUNTING ON KINDNESS” AND “LIFE GET’S BETTER: THE UNEXPECTED PLEASURES OF GROWING OLDER.” HTTP://LUSTBADER.COM.
Health Care Consent
Your Rights and the Law

As an adult (age 19 or older), you have certain rights when making decisions about your health care in British Columbia. Health care consent is governed by the Health Care Consent and Care Facility Admission Act (HCC Act).

What is informed consent?
The HCC Act sets out the legal requirements for consent. Except for very special situations, a health care provider must get consent before giving you health care. The law says a provider must give you information about:

- What condition they want to treat (your diagnosis);
- What health care they want to give you (the proposed treatment);
- How it may help you (the benefits);
- How it may harm you (the risks); and
- Other health care you could choose instead (possible alternatives).

The health care provider must also allow you to ask questions and get answers. You have the right to be involved as much as possible in plans and decisions about your health care. When you agree to health care, you are giving consent to that specific health care only.

The law recognizes that health care decisions are not only based on “medical” information: you will also decide based on your values and beliefs—what is important to you for your quality of life.

Do I have a right to refuse consent?
Yes. As a rule, as long as you are capable, you have the right to make your own decisions about health care. This means you can refuse or withdraw (stop) consent to health care for any reason, including religious or moral reasons. You have this right, even if your decision puts your health or life in danger. This right does not apply when a representative is acting on your behalf.

When is my consent not required?
There are three situations where a health care provider can give you health care without getting your consent first.

Preliminary examination
A provider does not need your informed consent to do a preliminary examination to figure out what health care you might need or how urgent it is.

Urgent, unexpected condition
A provider does not need your consent to treat a new, unexpected condition that they discover while they are in the middle of giving you other care that you already consented to, if you are unconscious or semi-conscious at the time they discover it (for example, if you are in surgery) and the unexpected condition is medically urgent.

Emergency
A provider can treat you without your consent if you are incapable (i.e. you are unconscious, semi-conscious, impaired by drugs or alcohol or are incapable for some other reason), and you need immediate treatment to save your life, to prevent serious mental or physical harm, or to relieve extreme pain.

If your representative (or a Court-appointed committee of person) is available, the health care provider must ask them for consent. Otherwise, the provider may treat you.

What happens if you are not capable?
If you are not capable of giving or refusing consent, you can make a Representation Agreement to appoint someone who can make health and personal care decisions on your behalf. If you are incapable of informed consent, the health care provider must provide information to your representative just as they would if they were getting consent from you. Your representative must make decisions according to your wishes, values and beliefs—what is important to you.

Self-determination is one of the key principles underlying the Health Care Consent and Care Facility Admission Act and the Representation Act. These laws are the result of a community-government partnership designed to shift the health care system from a paternalistic “we know best” approach to one that is based on a person’s wishes and values.

Does health care consent only happen in the hospital?
No. The law that governs health care consent in BC extends much further than being in the hospital. Consent is required in all kinds of settings, public or private, for example:

- Hospitals
- Community (practitioner’s office, at home, out-patient program, day program, rehabilitation program)
- Facilities (group home, assisted living, residential care, hospice)

Excerpted with permission from fact sheets by the Nidus Personal Planning Resource Centre and Registry. Learn more about at www.nidus.ca.

Fill Your Prescription at No Frills. Help Raise Funds for BCCPD!
Raise funds for people with disabilities by supporting BCCPD. Prescriptions filled at No Frills Pharmacy, 310 West Broadway in Vancouver, will help raise funds for the BCCPD.

How to Participate
- Register in-person with Nicole or Chloe at the BCCPD office, 8204 - 456 West Broadway in Vancouver.
- Complete a short form and receive a stamped Loblaw's card.
- Take the card to No Frills Pharmacy at 310 West Broadway and present it when you are filling out your prescription.

How the Program Works
After you register at BCCPD and fill a prescription at No Frills:

- Receive 20% off all No Frills name brand non-prescription medications, when you present your stamped Loblaw’s Card at No Frills Pharmacy.
- No Frills will contact your old pharmacy and transfer over your client information.
- You can receive free home delivery of No Frills Pharmacy prescriptions, anywhere in the Lower Mainland.
- If you have to pay for part of your No Frills prescription, receive a discount voucher for No Frills groceries.

Please note
- You must fill a prescription first, to be eligible for these benefits.
- This program is only available at No Frills Pharmacy’s West Broadway location and is not applicable to the grocery section of the store.

For more information, please call Nicole or Chloe at 604-875-0188.
Capturing Life through an Optimistic Lens

BY CAROL PAETKAU

As I recently sorted through some of the beautiful photographs produced by the members of the Fraser Valley Brain Injury Association (FVBIA) PhotoClub in Abbotsford, British Columbia, I was struck by one in particular: the image of an exuberant looking tiger that seemed like he was sticking his tongue out at the world.

I couldn’t resist finding out more about the man who was able to record the joyful spirit of this brief moment with his lens.

I discovered that most of the images captured by Dave Hildebrand’s camera seem to reflect this talented man’s optimistic viewpoint, in spite of dealing with incredible adversity after suffering devastating brain and spinal cord injuries in 2009.

Before his injury, Dave was an active man working in construction. Dave occasionally played pick-up hockey, skied and hiked, as well as being involved in church with men’s ministry. His two sons were attending University and Dave was living on his own after separating from his wife four months prior to the event that would change their lives.

On February 24, 2009, Dave was at work installing deck railing. After lunch he was on a second story deck when he inexplicably fell, landing on his head. Dave suffered numerous facial bone fractures, skull fractures, bleeding in the lining of his brain, a traumatic brain injury, vertebral fractures, rib fractures, neck fractures, lacerations on his forehead, and other injuries. “They almost lost me,” said Dave. He remained in Royal Canadian Hospital for two weeks where he had a plate surgically installed in his neck (C5, C6, C7).

Dave describes life as being “difficult the first two years, especially the first few months. Nobody told me what to expect from my brain injury.” Fortunately, his girlfriend was able to stay with him for the first month, until he was able to manage with homecare support provided through WorksafeBC.

Dave had balance issues for about two years. Noise and lights bothered him a lot for the first three years, and noise still does to a certain degree. Dave says “I do not handle stress very well. It tires me out and overwhelms me very easily.” He has much less energy and needs a nap every day in order to deal with the challenges caused by an acquired brain injury.

In spite of his difficult journey, Dave is still able to view his world through an optimistic lens. When asked what has made his recovery positive, Dave listed off a number of experiences including “learning about brain injury, discovering new talents and abilities, receiving counselling, meeting many new and wonderful friends, Fraser Valley Brain Injury Association and being treated well by WorksafeBC. "I would probably be very depressed and lonely if not for the FVBIA."

Dave actively participates in many of our groups and programs. Through the Pay it Forward: Health and Wellness for ABI program, Dave has been involved with cooking classes, a weekly walking group, photography and art groups where he “discovered [he has] an eye for photography” and that he can paint.

Dave was not able to return to his previous career and has not worked since his injury. He was sent for work retraining which was unsuccessful, so he was pensioned by WorksafeBC. His income is less than his pre-injury employment which is a significant adjustment for survivors and families after someone is injured. The pressure of trying to return to work can be overwhelming for many people with acquired brain injuries who struggle just to get through their day.

“Life is easier now that I have been retired by Worksafe. However, I often struggle with feeling less than whole and not being a productive member of society like I used to be.” This is a comment made by many people recovering from an acquired brain injury.

Productivity takes on a new meaning for people after brain injury. Dave is very productive in different ways than he was pre-injury and his contributions to society are just as valuable.

Mary McKee, FVBIA Case Manager said, “Dave is always willing to help out. He is an excellent role model and has phenomenal empathy for people going through the learning process after brain injury. Dave’s willingness to share his experiences and knowledge to support others in a gentle yet firm manner is invaluable.”

He mentors children in nature photography at FVBIA’s Young at Arts Summer Camp at the Blue Heron Reserve and has been asked to do the same thing with the Blue Heron’s other children’s camps in the future.

“I have a new role to fill, that of being a help and encouragement to others with a brain injury, as much as my energy will allow anyway.”

While Dave’s life after his injury has not gone back to the way it was, he is hopeful for the future and realizes there are many exciting aspects of his new life. “I manage quite well on my own though and have discovered that I can go on extended road trips, so that is definitely a part of my future plans. It gives me something to look forward to in life.”

The rest of us are looking forward to the beautiful photos that Dave will produce through his optimistic lens during his travels.
Healthy Optimism  BY PATRICIA MORGAN

Let me ask you this: have you considered the need for both pessimistic and optimistic thinking? Might I suggest that a true optimist appreciates both hopeful and cynical thinking? It’s a sign of resilience to be able to accept life’s contradictions.

However, based on positive psychology findings, there are a number of advantages to developing an optimistic perspective. Optimism encourages happiness and is associated with vitality and health. An optimist often enjoys challenges regardless of their outcome.

Optimism and pessimism can become self-fulfilling prophecies. Because pessimists tend not to create or face challenges, they fail more frequently—even when success is possible. Also, since it supports depression, pessimism is associated with a weak immune system.

Yet we need healthy pessimism or doubt. Some smokers are so optimistic, they smoked themselves to death. It’s the pessimist who insists on having a year’s worth of living expenses tucked away should a lay-off occur. So we need some healthy pessimism.

It may have been an optimist who invented the automobile and a pessimist who created the brakes and the air bag!

If you need more pessimism, read your newspaper headlines! If you need more optimism, take the following quiz and make changes accordingly.

Test Your Optimism

Score your optimism by placing a number 0 to 5 beside the statements below:

0=never to 5=almost always

___ I realize my beliefs are just that—beliefs. They may or may not be factual.

___ I ask myself if my beliefs are useful and supportive to my work and life.

___ I argue with myself. I say “Stop!” to pessimistic self-talk.

___ I replace negative self-talk with optimistic thinking such as “I know enough.”

___ I ask myself, “What’s the worst that could happen?”

___ I have a strategy to deal with that outcome. If not, I create one.

___ I develop optimism by looking for the bright side.

___ I count my blessings.

___ I choose to spend time with those who have realistic yet upbeat perspectives.

Total: ___ out of a possible 50.

I will improve my lowest 3 scores by:

1. _____________________________________________________

2. _____________________________________________________

3. _____________________________________________________

PATRICIA MORGAN IS AN AUTHOR, SPEAKER AND WORKSHOP LEADER. CONTACT PATRICIA AT PATRICIA@SOLUTIONSFORRESILIENCE.COM OR WWW.SOLUTIONSFORRESILIENCE.COM.

We’re Here To Help With CPP Disability

Were you previously working and now have a disability?

Do you need help to apply for CPP Disability or appeal a denial of benefits?

How Can BCCPD Help?

BC Coalition of People with Disabilities is an expert in Canada Pension Plan Disability (CPP-D) advocacy. We provide:

• in person, one-to-one assistance
• assistance by phone
• free self-help publications on what CPP is, how to apply and how to appeal a denial (available in English, Traditional Chinese and Punjabi)

What do I need to know about CPP-D?

CPP-D has several advantages over provincial disability benefits. And, recipients may receive provincial (PWD/PPMB) disability benefits in addition to CPP-D in the form of a top-up, if their CPP-D benefits fall below the provincial minimum.

Please contact us to learn more.

CPP-D Advocacy Program
Telephone: 604-872-1278 | Toll-Free: 1-800-663-1278
Website: www.bccpd.bc.ca
Online Program information: OurWork/Advocacy Access
Online Self-help CPP resources: Library/Money & Income Supports

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