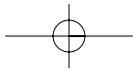
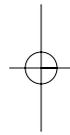
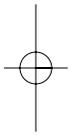


AFTER DISABILITY



AFTER DISABILITY

A Guide to Getting on With Life

LISA BENDALL

foreword BY DAVID ONLEY

KEY PORTER  BOOKS

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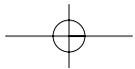
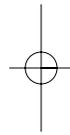
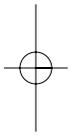
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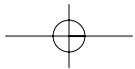
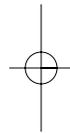
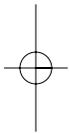
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To Ian, my soulmate and inspiration



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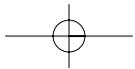
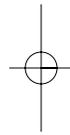
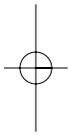
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Acceptance, Self-Advocacy and the Law 1

It all starts with you. Recognizing that you have a disability and resolving to get on with life can be a major first move, but it's one that you won't regret. Self-acceptance sets the stage for defending your rights and achieving a satisfying life.

Like members of other minorities, people with disabilities often face discrimination. But the disability advocacy movement has never been more vocal than it is today, and great progress has been made in the past few decades. The accessible amenities and services that many people now take for granted were unheard of thirty years ago. Today, people with disabilities are a visible and active part of our communities. The snowball effect can be dazzling.

The root of most discrimination is a simple lack of understanding. As more people with disabilities participate in society and speak up for their rights, the greater the awareness of their needs and abilities among the general population. In turn, fair treatment of people with disabilities increasingly becomes the norm, not the exception. This chapter illustrates the broad impact of self-acceptance, self-identification and self-advocacy.

Understanding and Accepting Disability

A disability can drop in suddenly, or it can develop slowly. It can be the result of injury, aging or disease. It can affect mobility, hearing and vision, speech, memory or mental health. It can also cause chronic pain.

Statistics Canada describes people with disabilities as those “whose everyday activities are limited because of a health-related condition or problem.” If a condition makes it difficult for you to perform routine tasks such as climbing a set of stairs, opening a jam jar, standing in line or carrying the garbage to the curb, then it is disabling. It’s obvious you have a disability if you’re using a motorized wheelchair or a ventilator as a result. But sometimes a disability creeps up in subtler ways. If you’ve been putting off paying bills because it hurts to hold a pen, or if you’ve scaled back your stops at the coffee shop because the two-block walk feels daunting, then your routine activities are clearly compromised.

Here are just some of the common causes of disability among Canadian adults:

- arthritis
- multiple sclerosis
- spinal cord injury
- stroke
- heart or lung disease
- kidney disease
- amputation
- fibromyalgia/chronic fatigue syndrome
- brain injury
- Parkinson’s disease
- HIV

Approaching Acceptance

This is an emotional time. The onset of your disability may have been sudden, unexpected or even traumatic. There are many things you may be feeling, and while all of these emotions are normal, it is important to work through them until you reach the point of acceptance. This process may involve expressing your feelings to a support person or professional counsellor, becoming informed about your disability and available resources, setting realistic short-term and long-term goals, exploring your spirituality or connection with nature, and reintegrating pleasure into your life.

Many people with sudden disabilities eventually are able to return to the same level of happiness they had before their accident or illness. But these are some common ways you may be feeling at first:

- **Grief.** Often, we think of grief as an emotion linked to death. But any significant loss can provoke the grieving process.
- **Denial.** You may hold on to the belief that your disability is temporary, or that a miracle cure is in the cards.
- **Anger.** Perhaps you blame someone or something for your accident or disease, or you resent what has happened to you.
- **Fear.** You might be frightened at the prospect of facing pain or other obstacles. You may worry about your financial stability.
- **Helplessness.** You may feel as though you cannot take care of yourself or do anything for anyone else, and may panic when left alone.
- **Guilt.** You may believe you've let people down. You may feel guilty because loved ones are worrying or losing sleep.

- **Shame.** You may be embarrassed to be seen in a wheelchair or using a cane. You may be uncomfortable asking for help. Perhaps you believe your disability lessens your value as a person.
- **Depression.** You may not feel like getting out of bed in the morning. You may even question the value of living. If you do experience these symptoms of depression, seek medical help immediately.
- **Acceptance.** As you approach acceptance, you may find yourself saying, “This is the way it is now.” You may notice that you feel ready to get on with your life. You will still feel anger, sadness or worry from time to time in certain situations, but overall you are starting to feel like your old self again. You may even have a new appreciation for life. If your accident or illness was life-threatening, for instance, you may be grateful for a second chance.

Get in Touch

Chicken Soup for the Recovering Soul: Daily Inspirations

By Jack Canfield

The Disability Experience: A Healing Journey

By Arthur Soissons-Segal

Second Chances: Crisis and Renewal in Our Everyday Life

By Tom Koch

Canadian Counselling Association

On the website, click on “Find a Counsellor” to search for a professional in your area who specializes in coping with loss or disability.

Tel: (613) 237-1099

Toll-free: 1-877-765-5565

E-mail: info@ccacc.ca

Website: www.ccacc.ca

Ten Resolutions

Online support for people coping with chronic pain or disease.

E-mail: info@tenresolutions.org

Website: www.tenresolutions.org

Self-Acceptance and Self-Identifying

It is common for people who develop disabilities to have difficulty accepting their new bodies and selves immediately. It takes time to adjust. Consider, though, that the first step in speaking up for your rights as someone with a disability is identifying as a member of this minority. Self-identifying also paves a direct path to accessing support services. I've known people to miss out on programs that could have dramatically boosted their quality of life simply because they didn't want to be thought of as "one of them."

Professional help is one option that may make a difference in the area of self-acceptance. But many people with disabilities achieve a healthy, positive self-image and outlook on life without the aid of experts. Here are a few sources of support:

- **Connect with peers.** Seek out people who have coped for a number of years with your type of disability. Ask advice, whether philosophical or practical.
- **Catch up on your reading.** Many organizations for specific disabilities, such as the Multiple Sclerosis Society of Canada or the Canadian Diabetes Association, publish regular

newsletters with updates, tips and personal stories. *Abilities* is a positive cross-disability magazine with a range of articles and resources.

- **Join online forums or listservs.** From the comfort of your computer room at home, read or exchange messages about living with your disability. For instance, the ALS Society of Canada offers an array of active forums where people discuss treatments, ask questions or lend support.
- **Join or volunteer with disability organizations.** By spending time around other people with disabilities, you will forge bonds and benefit from mutual support. You'll also be in the loop, learning about the latest services and programs to enhance your lifestyle.
- **Participate in community events.** Many disability organizations hold fundraisers or host information fairs. Some more sizeable cities have annual disability-themed trade shows; the largest is People in Motion in Toronto.

"I think it is important to accept your disability. That doesn't mean give up—but don't live with the hope you can cure yourself when no one else has. It's very important to get and give peer support. Nobody will understand your problems better than a peer. Years of experience can't be replaced."

—Bob Wroblewsky, Sandy Lake, MB

Get in Touch

Abilities

Published by the Canadian Abilities Foundation.

Tel: (416) 923-1855

E-mail: info@abilities.ca

Website: www.abilities.ca

Diabetes Dialogue

Published by the Canadian Diabetes Association.

Tel: (416) 363-0177

Toll-free: 1-800-226-8464

E-mail: info@diabetes.ca

Website: www.diabetes.ca

MS Canada

Published by the Multiple Sclerosis Society of Canada.

Tel: (416) 922-6065

Toll-free: 1-800-268-7582

E-mail: info@mssociety.ca

Website: www.mssociety.ca

ALS Society of Canada

Online Forum Community

Website: www.als.ca/_forum

People in Motion

Toll-free: 1-877-745-6555

Website: www.people-in-motion.com

Know Your Rights: Disability and the Law

Section 15 of the *Canadian Charter of Rights and Freedoms* guarantees equality to people with disabilities. The Charter states: “Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.”

The *Canadian Human Rights Act* forbids discrimination against people with disabilities by any service provider or employer under its jurisdiction, such as federal government departments, Crown corporations, chartered banks and national airlines. The Act states: “It is a discriminatory practice in the provision of goods, services, facilities or accommodation customarily available to the general public (a) to deny, or to deny access to, any such good, service, facility or accommodation to any individual, or (b) to differentiate adversely in relation to any individual, on a prohibited ground of discrimination.” Each province and territory has a similar human rights code prohibiting discrimination in its area of jurisdiction.

Ontario made Canadian history when its groundbreaking Bill 118, *Accessibility for Ontarians with Disabilities Act*, passed third reading and received royal assent in June 2005. This legislation is farther reaching than the *Canadian Human Rights Act*. Accessibility standards that are developed under this act must be adhered to by every individual and organization in the public and private sector in Ontario. It is hoped that other provinces will follow suit with similar legislation.

Self-Advocacy

Behind progressive change is often a social movement. The self-advocacy movement of people with disabilities is known as the Independent Living (IL) movement. The IL philosophy acknowledges that people with disabilities have the same rights as everyone else, and that collective action will serve to secure these rights. Some of these rights include:

- living where you choose, and with dignity
- participating in all facets of life
- making choices about your own life, including taking risks if you choose to

Historically, people with disabilities have been excluded from these rights.

The Independent Living movement was founded by people with disabilities themselves (often called “consumers” in the lingo of the IL philosophy). Today it continues to be managed by consumers. Right now across Canada there are over twenty-five consumer-run Independent Living Resource Centres, where people with disabilities can access valuable programs such as peer support, social networking, employment training, attendant services and literacy education, all free of charge.

Get in Touch

Canadian Association of Independent Living Centres

Tel: (613) 563-2581

E-mail: info@cailc.ca

Website: www.cailc.ca

“When I reached the stage where I needed a wheelchair, I was told by one person that it was such a shame my life was over at such a young age. I was shocked! Talk about a misconception. I experienced misconceptions from friends, family, medical professionals and strangers. However, I also had to struggle with my own misconceptions about what I am and am not able to do. I had to change my perceptions of what my life was going to be like, where I was going to be and how I was going to get there. I have a very fulfilling life, but it certainly isn’t the one I dreamed up for myself. The biggest perception I had to overcome was that I needed to look outward for help. I realize that doctors, family and friends can be a great help in my life, but it is my own abilities, strengths and power that help me cope. It is my own confidence in myself, my own perception that I am still a strong, capable woman, that helps me make it through the day.”

—Heather McCain, Maple Ridge, BC

Word Power

Language shapes attitudes. You can actually influence the general view of people with disabilities by choosing your words with care. Consider a newspaper story that reads: “The young woman suffers from muscular dystrophy and is confined to a wheelchair.” The negative image conjured up by that sentence could just as easily have been a neutral one with different wording: “The young woman *has* muscular dystrophy and *uses* a wheelchair.”

When you discuss disabilities, try to avoid words that invoke pain or pathos. Don’t say “is wheelchair bound” or “is a stroke victim.” Keep your language straightforward and precise: “uses a

wheelchair,” “had a stroke.” The general rule of thumb is to put the person first, the disability second. Don’t let the disability define you. So instead of “I’m a diabetic” or “I’m a Parkinson’s,” try, “I have diabetes” or “I have Parkinson’s disease.” And don’t leave out the person altogether: Never say “the disabled.” Say “people with disabilities” instead.

Here are a few more syntax suggestions:

Don’t Say:	Say Instead:
• is crippled by arthritis, is stricken by arthritis	• has arthritis
• is battling diabetes	• has diabetes
• is lame, crippled	• has a mobility disability
• is handicapped	• has a disability
• is deaf and dumb, is hearing impaired	• is deaf, or has a hearing disability
• is visually impaired	• is blind, or has a vision disability
• is retarded	• has an intellectual or cognitive disability
• is mentally ill	• has a mental health or psychiatric disability
• has a chronic illness	• has a chronic condition
• what’s wrong with him?	• what’s the nature of his disability?
• patient	• consumer or client

Get in Touch

A Way with Words and Images

Guidelines for the portrayal of persons with disabilities from Social Development Canada. You can order a free copy by telephone or view it on the website.

Toll-free: 1-800-O-CANADA

Website: www.sdc.gc.ca/en/hip/odi/documents/WayWithWords/01_intro.shtml

Disabilities and the Right Words

You can download a free copy the BC Rehab Foundation website.

Tel: (604) 737-6383

Website: www.bcrehab.com/therightwords.html

You Aren't Sick!

You may have a disability, but it doesn't mean you're a perpetual patient. Often people with disabilities are just as healthy as everyone else. Don't confuse disability with illness. It's easy to do if you have spent much time in a hospital setting, such as a rehabilitation facility, where the staff is made up of doctors and nurses and the focus is on "getting better." But when you're back in the real world—your community—remember that if you're not sneezing, you aren't sick.

Quick Self-Advocacy Tips

You want to persuade your local video store to install an automatic door opener? When it comes to advocating for yourself, a few key strategies can make a difference.

- **Expect respect.** If you expect to be treated with dignity, other people will pick up on your vibe and behave correspondingly.
- **Make eye contact.** This conveys confidence and sincerity. But don't turn it into a staring contest—do break eye contact periodically.

- **Maintain good posture.** Be aware of your body position, and don't slump or slouch if you can help it. Hold your head up straight, your chest forward and your shoulder blades back.
- **Bring others down to your level.** If you use a wheelchair and the conversation is going to be longer than a minute or two, ask the person you're speaking to, to sit down, so you don't have to crane your neck.
- **Offer a solution.** Don't just complain about the problem. Tell the person what you want her to do about it. If needed, suggest what might be involved (cost, consultation, etc.) in improving the situation.
- **Keep notes if necessary.** People are less likely to deny your rights if they can see that you are documenting their response.
- **Keep your cool.** Don't shout and rage. Try to keep the conversation congenial.
- **Write letters.** If you don't get a satisfactory response to your request, follow up with written correspondence. You can even go one step further: our local grocery store refused to increase its inadequate number of wheelchair parking spaces despite our repeated complaints. We wrote a letter and still nothing was done. But soon after I penned a piece in the city's newspaper, naming the grocery chain, more parking spaces were added.
- **Remember your buying power.** Ultimately, you are a consumer. You have money to spend, and if a facility or service won't meet your needs, you can take your business to the one that does. Encourage your family and friends, too, to patronize accessible businesses as much as possible.

“Once I went shopping with my mom at a grocery store, where I tried to do my best in conversation with the cashier. (I have speech problems.) With repeating I became very frustrated, due to the cashier not understanding me, and had to get my mother to respond for me. I made my way to the end of the counter and began to put groceries in the bags, slowly but surely. The cashier looked at me and said, in a voice you would use while communicating with a child of about age two, ‘That was a great job.’ I could not believe my embarrassment and as I left the store I fought back tears. But you know what? That experience, as horrific it was for me to handle that day, has made me stand up for myself more. Now, when I go anywhere to order food or be serviced by someone, I make sure they know I am a person and that I have confidence in myself. Most times now I order first and sometimes for the others with me. So this experience has enabled me to be more myself.”

—Deana Brewer, Middle Cove, NL

The Risk of Abuse

Studies show that people with disabilities are at a higher risk of violence and abuse than the general population. Disabilities can make us appear vulnerable and dependent, and can sometimes even serve to undermine our credibility. Abuse can be financial, physical, verbal or sexual, or it can take the form of neglect. Many people with disabilities choose not to report abuse because they fear retaliation or withdrawal of financial or personal assistance.

Reduce the risk. Here are some ways you can help ensure your safety and independence:

- **Be aware.** If you hire personal attendants, do criminal background checks first. Don't interview job candidates in your home, especially if you're alone. Don't give out banking PIN numbers or other financial information to attendants.
- **Set up a support circle.** Make sure you have trusted friends to talk to. Network with advocates who have disabilities.
- **Establish your independence.** If possible, try not to rely too heavily on family and friends for personal assistance (dressing, bathing) or financial support. The more independent you are, the lower your vulnerability. Being independent doesn't mean you must physically attend to your own needs instead of having help. But hiring someone to act as your arms and legs, under your direction, can be a lot more liberating than depending on a family member.
- **Seek expert advice on money matters.** Don't let relatives make financial decisions for you. Take control over your income and expenses.
- **Participate in the community.** Reducing your isolation will reduce the chances you will experience abuse.

Get in Touch

Adults with Disabilities and Seniors: Tips on Recognizing and Preventing Abuse and Neglect

A publication from the Public Legal Education and Information Service of New Brunswick. On their website, click on "Publications" then "Seniors and Disabled Adults."

Tel: (506) 453-5369

E-mail: pleisnb@web.ca

Website: www.legal-info-legale.nb.ca

Protecting Yourself: A Crime Prevention Guide for Persons with Disabilities

Canadian Association of Independent Living Centres (CAIL)

Tel: (613) 563-2581

E-mail: info@cailc.ca

Website: www.cailc.ca

DisAbled Women's Network (DAWN) Canada

Tel: (705) 474-4242

TTY: (705) 474-7435

E-mail: admin@dawncanada.net

Website: www.dawncanada.net

General Resources for Self-Advocacy and the Law

Organizations

AfterMath Connection to Hope

Provides information and support on self-advocacy.

Tel: (604) 436-9219

E-mail: info@aftermathconnection.ca

Website: www.aftermathconnection.ca

ARCH: A Legal Resource Centre for Persons with Disabilities

Provides legal information and support to people with disabilities.

Tel: (416) 482-8255

Toll-free: 1-866-482-ARCH

TTY: (416) 482-1254 or 1-866-482-2728

E-mail: archlib@lao.on.ca
Website: www.archlegalclinic.ca

Council of Canadians with Disabilities
Advocates at the federal level to improve the lives of
Canadians with disabilities.

Tel: (204) 947-0303 (voice/TTY)
E-mail: ccd@ccdonline.ca
Website: www.ccdonline.ca

Reach Canada
Promotes equality and justice for people with disabilities.
Toll-free: 1-800-465-8898
TTY: (613) 236-9478
E-mail: reach@reach.ca
Website: www.reach.ca