

focus on

Serious Injury Care

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Take charge of your health with self-advocacy

Self-advocacy gives people who have suffered a serious injury a greater sense of control over their health and their life. Rather than depend on others, self-advocates gain knowledge and develop their skills so that they can confidently speak up for their rights and get the services they need.

“If you don’t advocate, nothing is going to get done,” says Frank Diperdomenico, a social worker and case manager with FJD Disability Management Consulting in Windsor, Ont., who helps people with serious injuries navigate government organizations and systems. “People realize, ‘Hey, I can make a difference here’ by self-advocating, and that helps their self-esteem.”

Self-advocacy can be as simple as asking questions of health practitioners, such as doctors, nurses and physiotherapists, to fully understand your injury or disability and the treatment or therapy you’re receiving. For example, how will your rehabilitation activities change after you leave the hospital? What potential problems should you watch out for? How will your injury affect your abilities? Don’t be shy – if you don’t ask, who will?

“Families and survivors need to self-advocate and not just accept what they’re told and think that’s the only way. Sometimes, there are options they may not be aware of, or that the person making recommendations isn’t aware of. It’s important to keep looking,” says Donna Thomson, executive director, Brain Injury Association

of London & Region (braininjurylondon.on.ca), which offers peer mentorship and a brain injury services directory among its advocacy resources.

For example, you have the right to ask for a second opinion. “Don’t always take the first answer as gospel – doctors are just human beings. If you’re not getting what you need from one health practitioner, you have the option of going to another one,” says Val Lougheed, founder and president of Northern Lights Canada (northernlightscanada.ca), an organization that provides services in vocational rehabilitation, employment and corporate training. She stresses that people shouldn’t accept poor treatment. “Understand that if you’re made to feel intimidated, angry or stupid, you may have run across a practitioner who enjoys using power inappropriately, and that maybe you need to see somebody else.”

To better self-advocate, know your disability and recommended therapies

To become a better self-advocate, get to know your disability or injury and the therapies recommended for it. Consult credible sources, such as the Canadian Paraplegic Association (canparaplegic.org) and the Brain Injury Association of



Val Lougheed, founder and president of Northern Lights Canada.

Canada (biac-aclc.ca). Ask members of your health care team, including your case manager and the nurses and support workers from Bayshore Home Health, for suggestions. You don’t have to become a medical expert, but being familiar with the details and terminology will help you feel more comfortable. “You’re not organizing for a fight, but so that you can come from an informed position,” says Lougheed. Demonstrating knowledge will also encourage your health care providers to share more information with you.

Be part of your health care team. Ask to be informed about all aspects of your care. Prepare for appointments by tracking symptoms, side effects and changes in functioning, and write down questions. Take notes or ask a family member to do so. Ask what will happen next.

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Understand your rights and which laws, pieces of legislation and governing bodies dictate them. For example, the Canadian Charter of Rights and Freedoms, which is part of our Constitution, contains provisions that apply to people with disabilities, and the Accessibility for Ontarians with Disabilities Act (AODA) includes standards around accessibility. Researching these laws may seem overwhelming at first, but the information will be helpful to your self-advocacy efforts. One good source of information about legal rights and other aspects of self-advocacy is *After and Beyond Spinal Cord Injury*, a manual by the Canadian Spinal Research Organization (to order, visit csro.com).

Take part in relevant programs, information sessions and support groups. Knowledge comes in many forms, and it can help build confidence. Talking to people with similar injuries or disabilities can uncover helpful advice and resources.

Know what you want when seeking services

Clarify your needs. When seeking services or supports, it's essential to know exactly what you need or want. This helps others connect you to the appropriate people, organizations, programs and funding, and saves you from wasting time and energy on the wrong leads. Thomson recommends keeping an open mind – some options may differ from what you expected, but they might be the right ones for you.

Improve your communication skills. Be pleasant and respectful but firm. Practice making verbal requests with a friend or family member. You can also write letters – mention all pertinent details, clearly

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Bayshore Home Health – a leader in serious injury home care

Bayshore Home Health is a Canadian-owned company and has been a trusted provider of home and community care services since 1966. It operates more than 40 home care offices and 20 community care clinics nationally, and works with many organizations that deliver specialized home care services to clients with serious injuries, including workers' compensation boards, auto insurers, rehabilitation service providers and government care agencies. To learn more about any of the services listed below, please call 1-866-265-1920.

Brain and spinal cord injury care • Wound and burn care • Fracture and amputation care • Palliative care • 24-hour nursing • Personal care and home support • Serious injury care planning • Safety assessments • Teaching • Care coordination with third parties

state what you're asking for and include your contact information. If speaking or writing is challenging, ask a family member to advocate for you.

Diperdomenico recommends presenting potential solutions along with your concerns. "Don't throw problems at people – nobody likes to hear complaints. People will be more receptive if they've got the problem and possible options." For example, when job-hunting, anticipate employers' questions about workplace accommodations by researching adaptive products, funding and safety issues.

Consider what is realistic, then go after it. "Pick your battles," advises Diperdomenico. "It's one thing to self-advocate and fight for your rights, but know your limits and what is possible."

Don't delay – some programs have waiting lists. Once you've identified the organizations or government departments to approach, find out whom to contact. You don't want your letter or voicemail to languish in a general mailbox.

Be persistent. You may be discouraged by unsuccessful attempts to obtain services or supports, but keep trying – make another request, contact another resource or research other options. Keep track using a journal, file folder or binder. Note the dates, what actions you took, the results and any follow-up measures.

Keep it up – self-advocacy never ends. There are times when you must make greater efforts, such as the months following an injury, but you should com-

mit to looking out for yourself for life. Self-advocacy also goes beyond health care. You can apply the same research skills and assertiveness when hiring a lawyer, investing in disability supports or renovating your home to improve accessibility. "It's much healthier to be autonomous and independent, and that involves self-advocacy rather than handing control to somebody else," says Lougheed.

Surround yourself with a good support system

She knows what she's talking about – she was severely injured in a car accident in 2003. Lougheed spent five months in the hospital, followed by years of rehabilitation. She recommends surrounding yourself with competent practitioners and a good support system – people you feel very comfortable with. "I needed a lot of affirmation that it was OK to step up to the plate and say, 'No, this is what I need.' It can be lonely as a self-advocate, especially if you're up against 'the system.' Seek support and allies from both inside and outside the system so you don't feel alone."

Above all, Lougheed says, believe in yourself and accept what your body and your head are telling you. "It's easy to get argued out of it," she says. "I'm not an aggressive person, and I don't think it helps for people to be aggressive. It does help to be informed about your own condition. Listen to your body, and believe that, and be gentle but firm about it."