Helen Carson has lived almost all of her life on a farm in Saskatchewan. She was diagnosed with MS in 1990. Helen has been interested in art since she was a child and has taught watercolour classes for many years. She describes the desire to paint as a force within.

The Doghide Trail is named after the river that flows through the east side of Tisdale and is one of several little rivers in the Northeast Region of Saskatchewan. You can see more of Helen’s work at http://carson.prairieartists.com
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Foreword

Caring for someone with a chronic illness like MS can be deeply satisfying. Partners, family, and friends can be drawn more closely together when they meet the challenges. But caregiving can also be physically and emotionally exhausting, especially for the person who is the primary caregiver. That person is most often a partner or spouse, but can also be a child, parent, or friend.

There is a vast range of caregiving activity, just as there is a vast range of ability and disability among people with MS and even within a given person with MS. Someone giving care to a person who has relatively few functional difficulties may be helping with injections of a disease-modifying drug and offering support in dealing with the medical team. Someone caring for a person with a more severe level of disability may be involved in daily activities like toileting, dressing, transferring, and feeding, as well as medical treatments. This booklet provides an overview of the issues that caregivers in all kinds of situations might face.

Those caring for someone who is newly diagnosed, or who has little disability may want to concentrate only on those sections relevant to their particular situation. The resource section at the end is a good starting place for those who want more in-depth information or specific kinds of support.
Throughout this booklet, the term **caregiver** is used to refer to the person primarily responsible for providing daily care to a person with MS. It may help to remember that the person giving care and the person receiving it are in this together and that they can be thought of as partners; this booklet sometimes refers to them as **carepartners**.

MS doesn’t change the fact that important relationships are always a two-way street. The person with disabilities may need a great deal of assistance, but the needs and concerns of both partners must be addressed if the relationship is to remain healthy.
Most people with MS do not develop such severe disability that they require full-time long-term care. But since there is no way to predict who will develop severe disability, it is wise to make contingency plans. This means investigating the kinds and costs of local long-term care options before a crisis occurs.

Financial and life planning

Financial and life planning for continued financial stability is essential and should be undertaken early. The process of long-term planning will help the carepartners feel more secure about their well-being, regardless of what the future brings. A publication titled *Insuring Your Future: Your guide to life insurance and multiple sclerosis* provides easy-to-understand information about life insurance and describes strategies for acquiring life insurance as well as alternatives to insurance coverage. *Insuring your Future* is available online through the MS Society of Canada website or through your chapter.

Life planning includes an investigation of income tax issues, protecting existing assets, saving for future financial needs, and end-of-life planning. People should seek advice about insurance, employment rights, and provincial assistance, and discuss all options. You may also find *A Guide to Employment and Income Support* and *Adapting: Financial Planning for a Life with MS* helpful resources. These comprehensive publications discuss topics pertaining to employment, disability insurance, financial planning and tax relief for individuals affected by MS.
Carepartners need to understand the coverage and policies of their medical insurance, including provincial health care coverage, provincial benefits offered through Human Resources and Skills Development Canada (www.hrdc-drhc.gc.ca) and available private disability insurance. Hospital or clinic social workers are a good resource for information regarding provincially run programs, as is your local MS Society chapter or division.

Caregivers also need a clear understanding of the Canadian Human Rights Act and other acts that provide protections concerning housing, transportation, recreation, and employment.

Since each person’s situation is unique and the laws pertaining to legal and financial issues vary from province to province, it may be wise to seek the advice of professional financial planners and “elder law” attorneys who specialize in disability-related law. Professionals can help sort through available options and explain the possible legal and tax consequences of various choices.

Advance medical directives preserve a person’s right to accept or reject medical treatment. They are essential tools for maintaining personal control in the event of incapacitating illness or disability. Medical directives come in two forms. Both are needed for complete protection: (1) a living will, in which the person outlines specific treatment guidelines to be followed by health-care providers; (2) a health care proxy in which the person designates a trusted individual to make medical decisions if the person is unable to do so. Advance directive requirements, like other legal and financial issues, vary from province to province. They should be written with the help of an attorney who is familiar with the relevant provincial laws.
What level of care is needed?

Evaluating care needs should also be a joint effort. Ask your medical team to assess what treatments, adaptations, and other changes are necessary. For some, training in self-administering medical treatments, advice on coping with fatigue and occasional relapses, and some long-range financial planning will suffice. For others, at-home care is the best option. And sometimes a nursing home or assisted living centre is the better choice for all concerned.

It’s important to be realistic about what the person with MS needs, and what the caregiver can provide in terms of time, kinds of care, and financial responsibility. This is more easily said than done. Making changes — whether small or large — can be enormously difficult. Coming to terms with chronic illness and disability takes time and strength. Rational decision making can be sidetracked by anger, guilt, grief, confusion, or shame. It is often helpful for carepartners to speak with a therapist, counsellor, or other person outside the situation to get a clearer perspective.

Don’t be afraid to ask for help. The cost of not asking for help may be very high for everyone involved.
At-home care

Even people with severe levels of disability can live at home successfully. There are usually a number of solutions to practical problems. For example, someone who cannot transfer from wheelchair to bed or bath can be moved using the proper kind of lift. People with disabilities can be more independent when a home has wide doorways and grab bars. When the caregiver works full-time and the person with MS needs some aid and companionship during the day, adult day care may be an option. Caregiver burnout can be avoided when the carepartners make use of respite care, friends, and support groups.

Other care options

Providing care at home will be impossible for some people. There are different kinds of live-in facilities, including assisted living and nursing homes. Deciding what kind of facility is best will depend on individual needs and financial resources available.
The cost of care

Care options cost money—a situation that often coincides with a drop in the income earned by the person with MS. Researching possible resources begins with asking questions. Start with the staff at your chapter of the MS Society or with a social worker at your hospital, social agency, or MS clinic. What you don't know might help you!

Resources include local public agencies for people with disabilities such as independent living centres and agencies for senior citizens. (They often serve younger people with disabilities.) Long-term care services vary between provinces; please contact your provincial healthcare agency for information on what is available.

Caring at home

Adaptations can increase safety, accessibility, and comfort for everyone. But before deciding to make major home renovations, ask a doctor for a referral to an occupational therapist (OT) for a home visit. OTs can suggest ways to keep the person with MS as independent as possible, ensure safety, and reduce the physical strain on the caregiver. Ramps, widened doorways, and renovations in the kitchen and bath can often solve accessibility problems. Not all changes are major expenses. The Canada Mortgage and Housing Corporation may be a helpful resource, especially where more substantial adaptations are required. Please see www.cmhc.gc.ca or call 1-800-668-2642 for more information.
Sometimes the best choice involves moving to more accessible housing. Moving to a place that is near public transportation, stores, and other public facilities can give a person with disabilities more choices. It might also make it easier to hire necessary help.

**Flexible roles**

Changes are not confined to doorways or light switches. People with severe MS lose independence. Caregivers have to take on more responsibilities. This shift can be a source of tremendous anxiety.

Inevitably, the caregiver and the person with MS will have different perspectives about the same issue—about adaptations, about medication side effects, or how best to schedule hired help. It might help to remember that MS affects everyone involved, but it affects everyone differently.

MS is extremely changeable and unpredictable. People experience attacks and remissions, loss and recovery or partial recovery of abilities. One day a person with MS can dress alone, the next day the person can’t. The caregiver has to take and then give back responsibility for tasks all the time.
Carepartners, along with other family members will need to rethink who does each task necessary for the smooth running of the household. For example:

- **Household tasks** such as general cleaning, shopping, cooking, laundry, child care, and transportation.
- **Care-related tasks** such as dressing, bathing, eating, toileting, exercising, transportation, doctor visits, and taking medication.
- **Daily activities** such as work, recreation, entertainment, exercise, hobbies, private time, and religious activities.

Plan to re-evaluate task assignments as needs and circumstances change. And make sure to schedule personal time for everyone in the household.

**Helping with daily activities**

If a task seems impossibly difficult or stressful, there is probably an easier way to do it. The medical team can provide tips and techniques for bathing, dressing, toileting, and safe transfers. The MS Society of Canada and other caregivers are also good sources of advice and tips.
Roles and gender differences

Women and men who act as caregivers face the same day-to-day responsibilities, frustrations, and satisfactions. However, women caregivers may feel more comfortable than men caregivers, since caregiving has traditionally been viewed as a more feminine role.

Studies have found that many men who are caregivers report difficulty in discussing their problems and are more likely to repress emotional reactions. They find it more difficult to ask for help and many do not use the resources available to caregivers. On the other hand, some men are more willing to participate in social and recreational activities that contribute to their overall well-being.

Some women are better at expressing their feelings and accessing supportive networks. But women caregivers are more likely to neglect their own health, and their need for outside activities. They tend to report more physical and emotional ailments than their male counterparts.

When a child is a caregiver

Sometimes children assume major household and personal care responsibilities when a parent has disability due to MS. This is more likely to occur in single-parent households. While it is positive for children to take on household responsibilities, their needs must be carefully balanced with the amount and level of caregiving they are expected to do.
Children are not equipped to handle the stress of being a primary caregiver. They should never be responsible for a parent’s medical treatments or daily functions such as toileting. Children under 10 can certainly handle some household chores. Young teenagers can take on more responsibility, but they also need to spend some time with their peers. Older teenagers and young adults may be competent caregivers, but they should not be expected to undertake long-term primary care. After all, they have their own futures to attend to.

When a parent is a caregiver

The return of an adult child to the home can be stressful for both the parents and the adult child. Often, this homecoming reproduces the earlier struggles that occurred before the child became independent. Parents probably have house rules that they want to have respected. But the adult child needs to be treated as an adult, and some house rules may presume the wrong kind of dependence.

As parents age, providing care will become more difficult. In time, one or both parents may become ill and require care themselves. Alternative care plans and living arrangements should be discussed with the adult child well before such a crisis occurs.
Family and friends

Family and friends can be crucial members in a network of assistance but caregivers often report that it’s hard to actually get their help. The first step is to tell friends and family that their help is needed and welcomed. Friends often worry that offering help might seem intrusive, especially when it looks as if things are being handled well.

Keep a list of projects, errands, and services that friends could do. Then, the next time someone offers to help in some way, it will be easy to oblige them. Give people specific, time-limited tasks. Asking a friend or relative to come by on Saturday for three hours in the afternoon so the caregiver can run errands is going to be more successful than asking them to stop by when they have a moment.

Hiring help

People with disabilities need most help with daily care. Unfortunately, this kind of help is generally covered only to a certain extent, if at all, by provincial insurance plans. Unless one of the carepartners has a long-term care insurance policy with a home care provision, paid care will be limited to what the family can afford. Please contact your MS Society chapter or division for information on local resources.
Professional nurses and therapists are usually referred or assigned by a doctor. However, home care aides and domestic assistants can be hired by carepartners. Hiring capable, reliable, and trustworthy help will be easier if the needs and concerns of the person receiving care are discussed in advance. The person with MS should always be part of the interview process.

Other caregivers, the health-care team, and the MS Society of Canada can be of help in locating reliable agencies that screen and refer potential candidates.

Safety and security

Leaving a person with significant disabilities home alone can be a frightening proposition for both partners. Advance planning and adaptation of the home can decrease these worries. Accessible peepholes, portable telephones with speed dial, automatic door openers, and emergency call systems such as Lifeline that summon help in an emergency may provide security.

If there is no secure way to leave a person with a severe disability home alone, then don’t do it! You must find help or alternatives.
Medical issues

Management of MS and its symptoms will be easier if everyone involved learns as much about the disease as possible. For general information, contact the MS Society of Canada. To get the best information about an individual, caregivers should rely first on the person with MS, and then on that person’s medical professionals.

The health-care team and symptom management

Many MS symptoms can be controlled by medications, management techniques, and rehabilitative therapies. The health-care team can advise carepartners about diet and routines that will regularize toileting and sleep habits. Although MS can not yet be cured, there is help for symptoms.

For some people, the most frightening aspect of giving care to someone with a chronic disease is being responsible for treatments. This may involve keeping track of medications, administering injectable drugs, or performing intermittent urinary catheterization.
Caregivers can and should make appointments with health-care professionals to get information, advice, and training. Treatment plans can fail if the caregiver does not know the medical staff, does not understand why and how a procedure is done, or gets instructions that are impossible to carry out. If there are problems with carrying out a medical or treatment procedure, contact the health-care team and arrange for a follow-up training session. With proper training and a little experience, most caregivers end up feeling confident about this part of their role.

It isn't always MS

Both the person with MS and the caregiver need to remember that having MS doesn't protect anyone from the normal ills that can affect us. This is especially important for people with MS who see a neurologist for their medical care. Regular visits to the family doctor for routine, preventive health exams like Pap smears or prostate exams are important to maintain.
PART II: EMOTIONAL SUPPORT

Handling stress and caregiver burnout

Providing emotional support and physical care to someone with MS is often deeply satisfying, but it is sometimes distressing, and now and then simply overwhelming. The strain of balancing employment, child-rearing, increased responsibilities in the home, and the care of the ill person may lead to feelings of martyrdom, anger, and guilt.

One of the biggest mistakes caregivers make is thinking that they can—and should—handle everything alone. The best way to avoid burnout is to have the practical and emotional support of other people. Sharing problems with others not only relieves stress, but can give new perspectives on problems.

“Why doesn’t anyone ask how I am?”

It is easy to feel invisible. Everyone’s attention goes to the person with MS and no one seems to understand what the caregiver is going through. Many caregivers say no one even asks. Mental health experts say it’s not wise to let feelings of neglect build up. Caregivers need to speak up and tell other people what they need and how they feel.

If this seems like disloyalty to a partner or family member, or a caregiver fears being labeled a complainer, reach out to support groups, religious advisors, or mental health counsellors to learn constructive communication techniques.
Take care of the caregiver

Many caregivers neglect their own physical health. They ignore their ailments and neglect preventive health measures like exercise, diet, and regular medical examinations.

Many caregivers do not get seven hours of sleep a night. If sleep is regularly disrupted because the person with MS wakes in the night needing help with toileting or physical problems, discuss the problems with a health-care professional.

The person with MS needs a healthy caregiver. Both partners need uninterrupted sleep.

Outside activities

Researchers report that the emotional stress of caring has little to do with the physical condition of the person with MS or the length of time the person has been ill. Emotional stress seems more related to how “trapped” caregivers feel in their situation. This, in turn, seems to be closely related to the satisfaction they have in their personal and social relationships, and the amount of time available to pursue their own interests and activities.

Successful caregivers don’t give up enjoyable activities. Some local organizations have respite care programs, please contact your local MS Society chapter or division for information about these organizations. Other family members are often willing—even pleased—to spend time with the person with MS. It may be possible to arrange respite care on a regular basis. Keep a list of people to ask on an occasional basis as well.
Two-way communication

Many emotional stresses are the result of poor communication. The caregiver should be able to discuss concerns and fears openly; the person receiving care isn’t the only one who needs emotional support. Although collaboration isn’t always easy or possible, working out long-term plans and goals together will help both carepartners feel more secure.

The emotional and cognitive symptoms of MS are often more distressing than the physical changes. If memory loss, trouble with problem solving, mood swings, or depression are disrupting daily activities in the household, consult a health-care professional.

Effective ways to acknowledge feelings

Ignoring a problem will not make it disappear. Anger, grief, and fear soon become guilt, numbness, and resentment. Some people find that talking about their concerns happens more easily when they schedule a regular time for conversation. Taking time out to collect feelings before presenting them for discussion will make it easier to speak clearly and calmly.
Handling unpredictability

Living with MS means expecting the unexpected, making backup plans, and focusing on what can be done rather than what can’t. The unpredictability of MS can be very stressful, but it can be managed.

When making plans for outings always include extra time for travel. Calling ahead to check out bathroom facilities and entrance-ways is wise. Buildings are not always accessible, even when they say they are. Don’t make plans too complicated. And when plans fall through, have an alternative ready. If the night out is impossible, order in pizza.

A list of backup people who can be contacted for help at short notice is also useful.

Dependency and isolation

Fear of dependency and isolation are common in the families of the chronically ill. The person with MS is increasingly dependent on the carepartner, and the carepartner needs others for respite and support. Many caregivers feel shame about being dependent on others. As a result, many don’t ask for the help that they need. Anxieties are greatly reduced for carepartners who are able to develop personal and social support.
Anger

Anger is a common emotion. The situation feels—and is—unfair. Hurtful words might be spoken during a difficult task, doors might be slammed during a disagreement, and shouting in frustration sometimes replaces conversation. Anger and frustration must be addressed and healthy outlets developed before angry encounters become physically or emotionally abusive.

Avoiding abuse

Abusive behaviour is never acceptable. But tensions can mount in the most loving of families. While circumstances that produce frustration and anger are often unavoidable, an emotionally damaging or physically aggressive response is not okay. If tensions are mounting, call for a time-out, and call for help.

Physical abuse usually begins in the context of giving or getting personal help—the caregiver might be too rough during dressing or grooming. The person with MS might scratch a carepartner during a transfer. Once anger and frustration reach this level, abuse by either partner may become frequent.

The dangers of physical abuse are obvious, but emotional abuse is also unhealthy and damaging. Continued humiliation, harsh criticism, or manipulative behaviours can undermine the self esteem of either partner.
Family and social groups may provide support and counsel. Therapists and marriage counsellors can help partners work out problems. The MS Society of Canada can offer local referrals.

The majority of caregivers never experience such levels of distress or become abusive. However, separation, divorce, or a nursing home are healthier options than a corrosive relationship.

Sex and intimacy

Carepartners who are also spouses or partners usually face changes in their sexual relationship. These changes can have physical or emotional causes. MS can interfere with both sex drive and function. Problems can include decreased vaginal lubrication, numbness or painful sensations, decreased libido, erectile dysfunction, or problems reaching orgasm. MS fatigue can interfere with sexual activity. Spasticity or incontinence problems can negatively affect sexual desire. Most of these symptoms can be managed, so it is a good idea to seek the help of a health-care professional.

In addition to MS-related functional problems, changes in roles may change the sexual relationship. Caregivers feel that they are performing a parental role, rather than being a lover or spouse, and this can dampen intimacy.
Sexuality does not have to disappear. Partners might begin by discussing what rewarding sexuality is for them. Many preconceived ideas of what sex should be prevent the satisfaction of actual needs and pleasures. Discussion could lead to the discovery of more imaginative sexual behaviors.

Open and honest communication about sexual needs and pleasures without fear of ridicule or embarrassment is the crucial first step. Counselling by a sex therapist can be helpful in this process. You may also find the MS Society publication, *Intimacy and Sexuality in MS* to be a helpful resource. You can obtain this publication online at [www.mssociety.ca](http://www.mssociety.ca) or by calling your local chapter or division.

**Self-help groups**

Self-help groups can provide an outlet for emotions and a source of much needed practical information. Most MS Society of Canada chapters have affiliated self-help groups for people with MS, and many have groups for caregivers as well. Religious and spiritual communities can also provide support and guidance.

Many caregivers say it is difficult to find time to attend group meetings. They want to use their limited time for other things. The benefits of a group might be obtained through the Internet and there are many useful online caregiver chat groups. Before joining an online chat room, you may find it helpful to read the MS Society of Canada publication, *Red Flags, Green Lights: Accessing Reliable Health Information*, a guide to help individuals make informed choices about online resources, including chat rooms.
PART III : RESOURCES

Resources
To obtain additional information regarding any of the topics discussed in this publication, please contact your local MS Society of Canada division or chapter office, or visit www.mssociety.ca for a list of MS Society of Canada publications.

The Care Guide
A comprehensive Canadian guide to seniors housing and care services.

Please note: Although this resource is aimed at seniors, many of the topics are relevant to Canadian caregivers in general.

Toll Free: 1-800-311-CARE (2273)
Website: www.thecareguide.com

Canadian Home Care Association
The Canadian Home Care Association (CHCA) is a national not-for-profit association dedicated to ensuring the availability of accessible, responsive home care and community supports which enable people to stay in their homes with safety, dignity and quality of life.

Telephone: (613) 569-1585
Website: www.cdnhomecare.ca
Canada Mortgage and Housing Corporation

Among other programs and services, CMHC provides financial assistance for accessibility work to modify dwellings occupied or intended for occupancy by low-income persons with disabilities.

Toll-free: 1-800-668-2642
Website: www.cmhc-schl.gc.ca

Canada Revenue Agency (CRA)

CRA administers tax laws for the Canadian Government and for most provinces and territories as well as various social and economic benefit and incentive programs delivered through the tax system.

Tax Information Phone Services: 1-800-267-6999
Website: www.cra.gc.ca

Accessible Transportation Directorate – Canadian Transportation Agency

The Canadian Transportation Agency is responsible for ensuring that undue obstacles to the mobility of persons with disabilities are removed from federally regulated transportation services and facilities.

Toll-Free: 1-888-222-2592
Website: www.cta-otc.gc.ca

www.mssociety.ca
Human Resources and Skills Development Canada (HRSDC)

HRSDC offers information on career planning, financial benefits, labour and workplace training and learning.

Toll-Free (general inquiries):
1 800 O-Canada (1 800 622-6232)
Website: www.hrsdc.gc.ca

Access Guide Canada

An online guide to accessible locations throughout Canada, including restaurants, shopping malls, parks and hotels.

Website: www.enablelink.org/agc

Canadian Abilities Foundation

An online guide linking people with disabilities to a wide range of resources, including an online publication, Abilities Magazine.

Telephone: (416) 923-1885
Website: www.abilities.ca
Canadian Association of Independent Living Centres (CAILC)

A not-for-profit organization which promotes and supports independent living by providing guidance and resources to people with disabilities through its network of Independent Living Resource Centres (ILRC).

Telephone: (613) 563-2581
Website: www.cailc.ca

Tetra Society of North America

An organization that recruits skilled volunteer engineers and technicians to create assistive devices for people with disabilities.

Telephone: 1-877-688-8762
Website: www.tetrasociety.org

Canadian Healthcare Association

A non-profit organization that provides home-based care, facility-based long-term care and community support programs.

Telephone: (613) 241-8005
Website: www.cha.ca
A GUIDE FOR CAREGIVERS

Canadian Health Network

The Canadian Health Network (CHN) is an online national, bilingual health promotion program. The network is made up of the Public Health Agency of Canada, Health Canada, national/provincial/territorial non-profit organizations and universities, hospitals, libraries and community organizations.

Website: www.canadian-health-network.ca

Canadian Mental Health Association

A national organization that promotes mental health and supports people experiencing mental illness through services, education, advocacy and research.

Telephone: (613) 745-7750
Website: www.cmha.ca

Family Caregiver Alliance (USA)

FCA is a public voice for caregivers, offering assistance, education, services, research and advocacy.

Toll-free: 1-800-445-8106
Website: www.caregiver.org
National Family Caregivers Association (USA)

The National Family Caregivers Association educates, supports, empowers and speaks up for the more than 50 million Americans who care for loved ones with a chronic illness or disability or the frailties of old age.

Toll-Free: 1-800-896-3650
Website: www.nfcacares.org

Please visit the caregiver section of the MS Society of Canada website at www.mssociety.ca or contact your division office to obtain an up-to-date listing of provincial caregiver organizations and networks.
How to reach the MS Society of Canada
Current as of June, 2010

Call toll-free in Canada: 1-800-268-7582
www.mssociety.ca

British Columbia Division
1501-4330 Kingsway
Burnaby, British Columbia
V5H 4G7
(604) 689-3144
info.bc@mssociety.ca

Alberta Division
#150, 9405 - 50 Street
Edmonton, Alberta
T6B 2T4
(780) 463-1190
info.alberta@mssociety.ca

Saskatchewan Division
150 Albert Street
Regina, Saskatchewan
S4R 2N2
(306) 522-5600
info.sask@mssociety.ca

Manitoba Division
100-1465 Buffalo Place
Winnipeg, Manitoba
R3T 1L8
(204) 943-9595
info.manitoba@mssociety.ca

Ontario Division
175 Bloor Street East
Suite 700, North Tower
Toronto, Ontario
M4W 3R8
(416) 922-6065
info.ontario@mssociety.ca

Quebec Division
550 Sherbrooke Street West
Suite 1010, East Tower
Montréal, Québec
H3A 1B9
(514) 849-7591
info.qc@mssociety.ca

Atlantic Division
71 Ilsley Avenue, Unit 12
Dartmouth, Nova Scotia
B3B 1L5
(902) 468-8230
info.atlantic@mssociety.ca

National Office
175 Bloor Street East
Suite 700, North Tower
Toronto, Ontario
M4W 3R8
(416) 922-6065
info@mssociety.ca
Our Mission

To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.

Contact the Multiple Sclerosis Society of Canada:

Toll-free in Canada: 1-800-268-7582
Email: info@mssociety.ca
Website: www.mssociety.ca