

Finding your way through the maze

by Avril Roberts

When Kris McDonald was diagnosed with MS in 1984, at age 34, she embraced the diagnosis. She finally had a name for her health problems. Now she could go back to being Super Mom, Super Wife, and a medical underwriter in the insurance industry.

One year later, everything changed. The Scarborough, Ontario, resident had another MS attack. "That's when I recognized that I had to make some concessions to the disease." She gave up working full time and went on disability benefits.

Close to 80 percent of people with MS are eventually unable to work full time because of the severity and unpredictability of their MS symptoms – extreme fatigue, impaired strength, cognitive problems, mood changes, visual loss, problems with numbness or mobility.

However, an MS diagnosis does not necessarily spell the end of your work life. Some people's MS is mild enough to never prevent them from working. Others cope with varying degrees of disability that temporarily or permanently affect their ability to work. Those who are more seriously affected may have difficulty keeping their jobs and be advised by their doctors or employers to stop working, which was Kris McDonald's experience.

"It didn't dawn on me that I could work part-time, until a couple of years later, and that really was ideal for me. It allowed me to contribute to the household, and with four kids to educate, a little coin helps."

She worked part time with the agreement of her disability benefits provider in a variety of jobs until 1997. Now, as a member of several MS Society of Canada government relations committees, she volunteers her considerable industry knowledge and experience to help people with MS negotiate their way through the insurance maze.

Knowing your employment and income replacement options can help you stay employed for as long as possible and plan for a time when you may no longer be able to work.

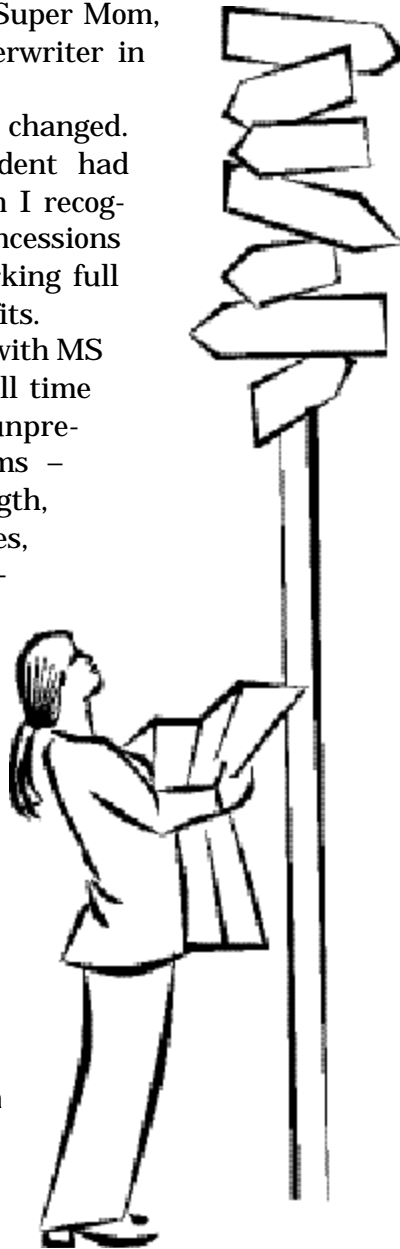
Do you have to tell your employer that you have MS?

No, you don't. However, if your symptoms affect your job performance and you need job accommodation, you will need to advise your employer. As an employee with a disability, you are entitled to job accommodation. This could mean extra rest periods, modified office furniture or layout, computer screen magnification software, an air conditioner. Or possibly, flex hours, a shorter workweek, job sharing, or working from home.

Your employer can only refuse if the accommodation will cause undue financial hardship that is substantial in nature. If your employer is not cooperative, you may find it helpful to ask for assistance from the company human relations department or a union representative (if applicable). The MS Society can often assist in providing information about MS and managing its effects in the workplace.

If after discussions, your employer refuses a

continued on next page



reasonable accommodation request, you can file a complaint with the applicable human rights commission.

For more information about employment issues, see the MS Society publication *Assets and Abilities: Your Guide to Work, Income Security and Multiple Sclerosis* and the article *Employment and MS* in the May 2004 issue of *MS Canada*. Both are posted on the MS Society of Canada website (www.mssociety.ca) or available from an MS Society office.

What if you need to take time off but you have used up all of your sick leave?

The federal Employment Insurance (EI) program provides up to 15 weeks of sickness benefits if you can supply medical evidence of your disability, have contributed to EI and have worked the required number of hours. The benefits end when you reach the maximum you are entitled to or if you return to work. The program is administered through Human Resources and Skills Development Canada.

Your employer or union may offer short-term disability insurance benefits comparable to or better than those offered by EI. Consult your human resources department and employee benefits booklet.

What happens when you have exhausted the EI sickness benefits or short-term disability coverage and are still unable to work at your regular job?

If you have been off work for five months or more, consider filing a long-term disability insurance claim under your employer, union, or personal disability insurance plan if you are self-employed.

To qualify, you will have to satisfy the insurance company that you have been unable to work for a specified period of time and that you are "totally disabled," as defined in the policy. A few policies allow for "partial disability" and part-time work. You will have to provide medical evidence to support your claim. Have your physician detail your experience with MS and explain the disease process, treatment and prognosis.

It is crucial that the physician completes the paperwork in detail because disability insurance claims adjusters may not fully appreciate the episodic nature of MS or the severity and unpredictability of its symptoms. Depending on the nature of your symptoms, you may want to submit additional documentation from other health professionals.

Over time, you may find that you no longer qualify for long-term disability benefits, even though your medical condition remains the same. This is because, for the first 24 months of benefits, "total disability" usually refers to an inability to perform the duties of your current job. After 24 months, the definition of "total disability" changes to mean an inability to perform *any* job for which you are reasonably qualified, given your education, training and experience. At this stage, you may have to return to work or provide further medical evidence of your continued inability to work.

If your disability benefits claim is denied, file an appeal immediately and obtain supporting medical documentation from your health team: family physician, neurologist, psychologist, occupational therapist, physiotherapist. Be persistent. You may want to seek legal advice, as a last resort.

When you file a claim for long-term disability benefits, the insurance company usually requires

Tips for filing claims for sickness or disability benefits

- ◆ Explore all of your options and know your rights and responsibilities.
- ◆ Apply promptly for any benefits for which you are eligible.
- ◆ Follow the claims procedures carefully and supply all requested documentation.
- ◆ Ask your neurologist or physician familiar with MS to provide detailed information to support your claim. Keep them informed of your health status.
- ◆ Keep a log about how fatigue affects you.
- ◆ Keep an updated list of symptoms and the medications you are taking to treat each one.
- ◆ Keep copies of your applications, supporting documents and related correspondence. Request copies from appropriate agencies before you need them.
- ◆ Be aware that you will have to provide continuing evidence of your health status to retain benefits.
- ◆ Appeal promptly and vigorously if your claim for benefits is denied.
- ◆ Use your network of personal, professional and MS Society resources.
- ◆ Be persistent.

you to apply for Canada Pension Plan (CPP) or Quebec Pension Plan (QPP) disability benefits. Any benefit you receive from CPP, QPP, Workers Compensation or other benefit program will be deducted dollar for dollar from the benefits you receive from the private disability insurance plan.

What is the Canada Pension Plan (CPP) disability benefit and Quebec Pension Plan (QPP)?

The CPP disability benefit is a monthly payment replacing a portion of your employment income if you are unable to work because of disability, as defined in CPP legislation. Medical evidence is required. You must have contributed to the Canada Pension Plan for four out of the last six years.

Once benefits are granted, the pension remains payable as long as you remain disabled or until age 65, when it automatically converts to a CPP retirement pension. CPP also provides benefits for children if at least one parent receives the CPP disability benefit. The benefit is administered by Social Development Canada.

The Quebec Pension Plan (QPP) disability benefit is similar and available to residents of Quebec.

The benchmark for CPP disability is stricter than that for private disability insurance. The CPP definition requires that the disability be severe and prolonged and prevent you from working regularly at *any* job. In recent years, MS fatigue is more often recognized as being "severe," however, it is important to document carefully the effects of fatigue.

Disabling MS symptoms may not be viewed as "prolonged." You could possibly collect disability benefits from an insurance company but not qualify for the CPP disability benefit. If your application is denied, you may request a reconsideration of the decision.

If you receive the benefit, a review of your file will take place if you identify that you plan to

return to work, if income is reported on your income tax return or if another individual or agency has contacted CPP with a report about possible abuse of the system. The CPP disability benefit is taxable. You can request that the income tax be deducted each month to prevent a large tax bill when filing your income tax return.

New legislation just took effect to allow a "fast track" reinstatement of benefits if individuals have attempted to return to work, but that attempt has not been successful.

Is there tax relief for people with a disability?

The federal government offers the disability tax credit, disability support deduction and medical expense tax credit to offset some of the out-of-pocket costs that people with disabilities incur.

The disability tax credit is a non-refundable tax credit that can reduce your federal income tax if you meet the eligibility requirements – you must have severe and prolonged mental or physical impairments that markedly restrict basic activities of daily living, as defined by the Canada Revenue Agency. A certified health professional must complete the medical section of the application, the T2201 Disability Tax Credit Certificate. If you qualify for the disability tax credit, your eligibility and health status may be reassessed occasional-

ly. If your application is denied, you can appeal.

The new disability support deduction replaces the attendant care expense deduction. It allows qualified individuals to deduct the costs of expenses of working or going to school. It is available if you are entitled to claim the disability tax credit and incur expenses for personal care that enables you to work.

The medical expense tax credit is a non-refundable tax credit that can be claimed to a

Useful Resources

EI sickness benefits

Human Resources and Skills Development Canada
1-800-206-7218
www.hrsdc.gc.ca

Disability insurance

A useful booklet *Disability Insurance: Where Will the Money Come From If You're Disabled* is available from the Canadian Life and Health Insurance Association.
www.clhia.ca
(416) 777-2221 (English)
(514) 845-9004 (French)

CPP disability benefit

Social Development Canada
1-800-277-9914 English
1-800-277-9915 French
www.sdc.gc.ca

Disability tax credit and other disability topics

Canada Revenue Agency
www.cra-arc.gc.ca
1-800-959-8281 (general number)

MS Society Division Offices

1-800-268-7582

specified maximum amount or three percent of net income, whichever is less. If the medical expense is covered under an insurance plan, you can claim only the portion that is not reimbursed. (See also, the article on tax issues on page 11)

Is there financial assistance for prescription drug costs?

Most private health insurance plans offer prescription drug coverage with a co-payment requirement and an annual or lifetime cap on payments. Keep the lifetime maximum in mind if you are using one of the MS disease-modifying therapies that cost from \$16,000 to \$24,000 a year.

Each province has a drug cost reimbursement program with specific clinical criteria and levels of compensation. For more information, see the chart *Overview of provincial government coverage of disease-modifying therapies* on the MS Society website. It is posted under MS Research / Research and Medical Library / Disease-modifying Therapies.

The pharmaceutical companies that market Avonex, Betaseron, Copaxone and Rebif may also have some limited financial assistance programs. Contact each company directly for information on eligibility and the application process. See this page for contact information.

What other income or disability support programs are available?

If you have no income from other sources, you may qualify for income support from provincial social assistance programs although each have their own criteria with asset limits that may be quite low. Many provinces also have subsidies for assistive devices and medical supplies. Municipalities may offer special transportation services. Some MS Society divisions and chapters pro-

Pharmaceutical Company Support Programs		
Drug	Company	Program
Avonex	Biogen Idec Canada	MS Alliance 1-888-456-2263
Betaseron	Berlex Canada Inc.	MS Pathways 1-800-977-2770
Copaxone	Teva Neuroscience	Shared Solutions 1-800-283-0034
Rebif	Serono Canada Inc.	Multiple Support Program 1-888-677-3243 (English) 1-877-777-3243 (French)

vide financial assistance for equipment purchase or loan and other needs.

What is the MS Society doing to improve income support and financial assistance for people with MS?

When the MS disease-modifying therapies became available in the mid 1990s, the MS Society successfully worked with provincial governments to set up drug cost reimbursement programs in most provinces. As new treatments come on stream, the Society will urge provincial governments to reimburse their cost as well.

The MS Society of Canada has actively pressed the federal government for changes to the disability tax credit. Some of these recommendations are highlighted in the report *Disability Tax Fairness* released in December 2004. The Society is now concentrating its efforts on revisions to the Canada Pension Plan disability benefit to enable people with episodic disabilities to qualify more easily.

For information about these and other MS Society government relations activities, contact your division or chapter. Divisions can be reached toll-free at 1-800-268-7582.

Avril Roberts is a Toronto-based health writer with an interest in neurological disorders.

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Multiple Support Program