



Connections

Information for People Living with MS

Volume 10, No. 1 Winter 2002

MEMBER PROFILES



Lynn Waterman with husband Wayne, granddaughter Hannah

This space is usually reserved for member profiles – stories about people living with MS. Because this issue of MS

Connections focuses on the role of the caregiver, it seemed appropriate that we tell the stories of two family caregivers.

Lynn Waterman

Twenty years ago, Lynn and Wayne Waterman were both 35 years old and married with three children, ages 7, 9 and 14. Lynn was a stay-at-home mom and Wayne was an elementary school teacher.

Then Wayne began experiencing vision problems and recurring severe fatigue. He went to his doctor who later diagnosed him with relapsing/remitting multiple sclerosis. This was just the beginning in a series of changes in the life of the Watermans.

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Harry Rush



Meet Harry Rush. Harry is a 45- year- old Master Warrant Officer in the Canadian Air Force, based in Winnipeg, but this is just one aspect of his life. At home, he juggles the roles of husband, father, friend, cook, cleaner, grocery shopper, laundry person and caregiver to name a few.

It wasn't the way things were planned. Until just over five years ago, life was very different. Harry's wife, Joanne, then 35, was a corporal, also in the military. She was very athletic, enjoying bowling and softball. Their son Peter was just twelve years old.

Then Joanne starting experiencing symptoms that eventually led to the diagnosis of multiple sclerosis in August 2000. She moved rapidly from having relapsing-remitting MS to the secondary-progressive form of the disease, leaving her with terrible fatigue. "She just has no energy. It takes all her strength to get out of bed in the morning," explains Harry. "Then she has to rest for a 1/2 hour afterwards."

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Lynn Waterman continued...

Lynn freely admits that MS has made a big change in the couple's hopes and dreams and left them uncertain about the future. Their relationship has been altered a great deal and in many ways she feels she has "lost" her mate. *"He experiences memory problems, can't walk very far at a time and must have a nap every afternoon,"* she explains. Nevertheless, the Watermans entertain friends regularly and enjoy going out to the theatre.


Wayne continued to work until eight years ago, when MS interfered too much with his ability to teach. Lynn returned to the workforce after being home for 17 years. *"There was an obvious financial burden,"* she says. *"I felt I had to take care of everything."*

Something that Lynn feels is a commonplace occurrence for many caregivers is the focus placed on the person with the disease, almost ignoring the existence of the caregiver. *"People don't ask me how I am. They always just ask how Wayne is doing,"* she told us. Because of this, she always remembers to ask after the well-being of the caregivers she meets.

Lynn heard about the Caregiver Special Assistance Program, a pilot program that provides financial assistance to those who give unpaid emotional, physical and/or other types of care and support to someone with MS. The funding is intended to encourage caregivers to access opportunities for a break or relief from caregiving responsibilities and/or support for their personal needs arising from the caregiving role. Lynn was excited that caregivers were finally being recognized. She thought it was very generous and was a positive step on behalf of the MS Society. Yet, she still thought: "Do I

deserve it?" Recognizing that there were other people living with MS who had much more severe limitations, she also knew how it had changed her life. She decided to fill out an application.

The process was simple and quick and within a couple of weeks, Lynn had the money to get on a plane to Vancouver to see her only sister graduate with a Masters in Clinical Psychology. *"It was a great break,"* she said. *"I spent two weeks away, visiting my sister. When I got back, it was just that much easier to cope. It was good for both Wayne and me."*

Lynn can only recommend that others consider looking into the Caregiver Special Assistance Program. *"Everybody should definitely take advantage of it and do something for themselves."* 

Harry Rush continued...

Joanne reduced her work hours to half time in January 2001 but eventually the fatigue was too great to deal with. In July of 2001 she was placed on compulsory sick leave. Six months from now she will be released from the military and will receive long-term disability. From a financial standpoint, the family will be fine. From a day-to-day standpoint, there have been many adjustments.

How does Harry manage his career and his increased home responsibilities? *"You have to be very organized,"* he says. *"I have a mental script of each person's needs in my head all the time."*

He calls his son Peter his "angel". *"He has become very responsible and helps me so much with Joanne."*


Harry is a member of the Male Caregivers Support Group at the MS Society and finds

it very beneficial. He really identifies when he listens to other caregivers' issues. Group members share how they handle the different challenges they face and it gives them a chance to "vent" in a supportive environment where people truly understand – **because they've all been there.**

It was at the caregivers group that Harry first heard about the Caregiver Special Assistance Program (CSAP). He filled out the application form and within a month he had the money to pay for a gardener. Joanne had been an avid gardener and always enjoyed sitting outside in the nice weather enjoying the fruits of her labour. Harry, on the other hand, does not have a green thumb, nor does he have the time to look after more than the basic lawn maintenance, so this was a perfect solution. Throughout the summer, a professional gardener tilled, planted, and weeded the garden, freeing up Harry's time and enabling Joanne to still enjoy summer afternoons outside.

This year, he plans to use the CSAP towards a golf trip to Vancouver Island.

Harry stresses the importance of caregivers looking after their own needs as diligently as they do the needs of the person they are caring for. *"If you don't, there will be a breakdown of the relationship. You have to make quality time for yourself."*

The Rushes try to live as active a life as they can. Although they have had to cut back somewhat on their social life, they still entertain at home, and once a week, go out on a "date" - usually dinner and a movie. Every year, they take a big vacation. *"We just bring the wheelchair along. We are not going to let MS stop us,"* asserts Harry. 

See page 4 for more information about the Caregiver Special Assistance Program.

MANITOBA DIVISION IFS STAFF

Individual and Family Services (IFS) is made up of staff and volunteers, providing a wealth of knowledge, experience and commitment. Staff members provide services directly and assist volunteers in helping people with MS to help themselves. **All can be reached through the MS Society's toll-free line: 1-800-268-7582** or directly at the numbers below:

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Waiver:The Manitoba Division of the MS Society is proud to be a source of information about multiple sclerosis. The content in *MS Connections* does not, however, represent therapeutic recommendation or prescription. For specific information and advice, consult your physician. Articles in this newsletter do not necessarily represent the position of the Multiple Sclerosis Society but are solely representative of the positions and opinion of the contributors.

MS: A Family Disease

At the MS Society, we recognize that MS is a family disease. We offer support groups for caregivers and reading material on the subject as well. You may want to refer to the MS Society publication *Taking Care: A Guide for Well Partners*, available free of charge from your local chapter office. We also have the Caregiver Special Assistance Program (CSAP). For more information on the CSAP, go to our website: www.mssociety.ca/manitoba You will see **For Caregivers** on the right side. Click there for detailed information on the pilot program. There is also an application for the program inside this newsletter.

Supporting Family Caregivers

MS is often described as a family disease because of the many changes not only for the person with MS but also for their family and friends. These family members and friends are often referred to as *family caregivers* because they provide a wide range of unpaid caregiving support, including physical assistance with personal care and mobility, household and yard maintenance, assistance in accessing medical, social and recreational services and/or emotional support.

For many people with MS, day-to-day living requires a team effort on their part and on the part of family members and friends who assist and support them. This team performs best when everyone, including family caregivers, has the best health and quality of life possible.

Consequently, caregivers and others have stressed the importance of taking the time to look after themselves and their own needs while providing caregiving support to

someone else. Research has highlighted the importance of caregivers having opportunities for self-care, including breaks or relief from caregiving activities, in order to maintain their own health and quality of life as well as their ability to continue caregiving. In one caregiver's words, *"If I can't take care of myself, how can I expect to take care of someone else? If I get sick, I won't be able to help her."*

In focus groups held with unpaid family caregivers of persons with MS in Manitoba, Saskatchewan and the four Atlantic provinces, many participants talked about the importance of self-care. They stressed the need for caregivers and others around them to recognize that self-care is not "selfish" and that caregivers taking time for themselves is not only acceptable but necessary. At the same time, several caregivers acknowledge that, for several reasons, they find this difficult to do. These reasons included finding the time in very busy days, having feelings of guilt for focusing on their own needs, and being concerned about being seen as selfish or unsupportive of the person with MS. Some caregivers talked about the fact that focusing on their own self-care and taking time for themselves was not something that came naturally to them but something they had learned to do. In some cases, caregivers learned to do this only after their own health began to deteriorate. Others described how the support of another caregiver, family member, friend or counsellor had helped them learn to take care of themselves while still caring for the person with MS.

"If I can't take care of myself, how can I expect to take care of someone else?"

The MS Society of Canada's Caregiver Special Assistance Program is a pilot

program designed to encourage family caregivers to take time for themselves to address their own personal needs so their own health and quality of life is maintained while they support the person with MS. The program was designed based on research and feedback from caregivers, which showed that individual caregivers have different preferred ways of meeting their needs. Rather than providing a predefined service, this program provides caregivers with funding so they may access flexible, individualized responses to meeting their personal needs arising from their caregiving role. The financial assistance provided is simply the tool for providing a flexible, individualized response based on caregivers' own ideas about how to meet their needs and achieve the outcome of 'respite'. In recognition of the fact that different caregivers have different needs, respite is broadly defined as: *anything that contributes to a caregiver's emotional, spiritual, physical and/or social rejuvenation enabling them to have the reserves and resources they need to care for their family member or friend with MS.*

Since the program's inception in February 2001, it has been used by almost 200 caregivers in six provinces. A wide range of services, activities and items has been funded. Examples include:

- Hobby, recreation and exercise program fees and/or supplies (e.g. woodworking, golfing, swimming, yoga, gym memberships, photography and bowling)
- Replacement/alternate caregiving services to provide temporary relief from caregiving activities
- Take-out food/restaurant meals to reduce meal preparation demands
- Companion services to take the person with MS to appointments etc.
- Gardening and housekeeping services

- Counselling
- Massage therapy
- Internet services to facilitate access to on-line support etc.
- Exercise and recreation programs
- Vacations or "breaks away" from caregiving responsibilities ranging from a few hours to a week or more at a time.

Some caregivers have described how the program has prompted them to think about their own needs and the importance of their own self-care for the first time. Caregivers have reported that the services, activities or items they accessed with the program funding resulted in many benefits such as peace of mind, relaxation, opportunities for exercise, recreation and/or socialization, decreased stress, and the ability to pay for services they would not otherwise have been able to access.



Caregiver Special Assistance Program Frequently Asked Questions

This 3-year pilot program is coordinated by the National Individual & Family Services department of the Multiple Sclerosis Society of Canada and funded by the J.W. McConnell Family Foundation.

Who can apply to this program?

For the purposes of this program, a caregiver has been defined as a person who provides unpaid physical, emotional and other types of care and support to a person with a diagnosis of multiple sclerosis.

Due to differences in the needs of people with MS and personal circumstances, types of caregiving provided varies. However, all family caregivers may have needs for support or breaks from their caregiving responsibilities. In fact, in recent focus groups, many caregivers shared that

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they found providing emotional support to be the most challenging and stressful type of caregiving. The CSAP program is for *all* family caregivers regardless of type, level or amount of support and care they provide to their family member or friend with MS. There is no income test for this program. All family caregivers are encouraged to apply so the MS Society can learn more about their needs and about effective strategies for meeting them. Evaluation information will be used to determine future directions for MS Society services in this area.

What will be considered for funding?

There is no predetermined list of things eligible for funding. Instead, this program encourages caregivers to identify their own needs and services, activities, or items they feel will make a difference for them. The goal is to provide opportunities for caregivers to experience 'respite'. There must be a direct benefit to the caregiver with a focus on meeting his or her own personal needs arising from their caregiving role.

How much funding is available?

The maximum amount of funding per individual caregiver is \$300 per fiscal year (i.e. September 1st – August 31st). Caregivers can apply in **each** of the 3 years of this pilot program that will conclude in August 2003. If you applied in the first year of the program (i.e. prior to August 31st, 2001), you can reapply for funding for this year.

How do I apply?

An application is included in this newsletter. For more information, please contact your local chapter or the Manitoba Division office at **1-800-268-7582** or **Michelle Gibbens, Family Caregiver Pilot Program Manager** at **(204) 832-2492** or e-mail **michelle.gibbens@mssociety.ca** or go to the Manitoba Division website at **www.mssociety.ca/manitoba**



RESEARCH UPDATE

Antegren® (Natalizumab) Results Look Promising in New Study

SUMMARY

A clinical trial of a monoclonal antibody called natalizumab (Antegren®) looks "promising", according to results made public on September 15th, 2001 at a major MS research meeting in Dublin. In a small double blind, placebo-controlled study of people with relapsing-remitting or secondary-progressive MS, those receiving the active treatment had fewer new MS lesions as measured by MRI and fewer relapses during the six months of treatment, compared with those receiving placebo.

ASK MS Information System Code:
1.4.1.12.a

New Foundation-Funded Research: Multi-Centre, Multi-Disciplinary Study Seeks Ways to Repair Myelin Damaged by MS

SUMMARY

A large, collaborative research project, funded by the Multiple Sclerosis Scientific Research Foundation, is underway to find out if the body's own cells can be transformed into a cellular repair team to mend damage caused by MS. Coordinated by Dr. Jack Antel of McGill University, leading researchers at centres in Canada and the U.S. are tackling one of the central problems in multiple sclerosis. When the disease strikes, cells from the immune system attack myelin, the substance that surrounds and protects the central nervous system. If damage is severe, myelin

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can be damaged permanently leaving people with long-term disability. The remyelination project involves five top MS scientists at McGill University, the University of Rochester, the Mayo Clinic, the University of Toronto and the University of Calgary. It is funded for \$3.5 million over three years by the Multiple Sclerosis Scientific Research Foundation. The MS Society of Canada is the foundation's main funding source.

ASK MS Information System Code: 2.4.7.L

National Research Department
National Communications & Social Action
Department



Information and Referral Services

Welcome to Wendy Aird, Manager, Information and Referral Certification Program (IRCF) - the newest member of the national IFS department. The IRCF is a key component in enhancing the valued service we provide to our members. Through training and certification, the program will equip division and chapter IFS volunteers and staff with the necessary knowledge and tools to effectively address the requests and concerns of people living with MS.

For more information about the new Information & Referral Certification Program (IRCP), please contact **Wendy Aird** by e-mail: wendy.aird@mssociety.ca or at 416-967-3023.



Support for Rural Caregivers

The Manitoba Division hosted an information session in Carman in early February for caregivers residing in Southern Manitoba, including Brunkild, Carman, Fannystelle, Morden and Winkler.

MS affects family and community in many ways. Caregivers are unique individuals with varying personal needs and may sometimes feel these needs are unheard and their efforts under-appreciated.

Based on feedback from this session, the Manitoba Division plans to form a community-based self-help group for well spouses or partners and another for other caregivers including parents, children, friends and other support people who provide unpaid emotional, physical or other forms of support to a person diagnosed with MS.

For information on caregiver support or to form a caregiver self-help group in your community, please contact **Adrienne Alford-Burt** at (204) 988-0902 or 1-800-268-7582.



.....
**Have a special caregiver you'd like to thank?
Send us your letters!**

It's not always easy to say thank you - and sometimes we forget. We mean to, and we know our caregiver understands how much we appreciate what they do for us every day, but we can't always get the right words out. Sometimes, writing it down makes it easier. Send us a thank-you letter for *your* special caregiver by **April 22nd** and during **Manitoba Caregivers Appreciation Week, May 27-31**, we will forward it to them with a **special gift**. If you'd like assistance in putting it all down, we'd be glad to do so. Be sure to include the caregiver's name and address! Mail, fax or e-mail your letter to: **Tracy Brown**: 400-141 Bannatyne Ave., Winnipeg MB R3B 0R3, Fax: (204) 943-8444 or tracy.brown@mssociety.ca

Social Action News

The Social Action Committee continues to be busy working on our priority issues. Working together with other disability groups, our housing working group is making progress on developing a model for alternative long-term housing for young adults with high care needs who may otherwise have to move into a personal care home. We've had positive indications of support from the provincial government for this important initiative.

We've been receiving calls from people who are having their Disability Tax Credit (DTC) status reviewed. In recent months the Canada Customs & Revenue Agency has sent out almost 100,000 letters and assessment forms to people across Canada currently receiving the credit, demanding they have the appropriate health professional complete the forms and reassess their eligibility. As a result of many complaints, the House of Commons Subcommittee on the Status of Persons with Disabilities held a series of meetings. Our national office, together with some other disability organizations, appeared before the committee both to express our concern over this move and to present our recommendations for changes to the DTC.

As a result of the meetings, the subcommittee held a press conference and sent a letter to the Minister of National Revenue requesting that letters of apology be sent to everyone who received the reassessment requests, assuring them that they will continue to qualify for the DTC in tax year 2001. As far as we know, to date this has not been done. The subcommittee is also preparing a

report on the DTC to be presented to parliament. We will continue to monitor this situation and work with the MS Society national office on this issue. If you received one of these letters, or have questions, comments or suggestions about this, please let us know.

Check out the social action section of our website, www.mssociety.ca/manitoba which is now up and running. The next Social Action Update will be mailed with the June issue of MS Connections. If you have questions or concerns, or would like to get involved with the Social Action Committee, please call **Sharon Segal**, at **988-0904** or **1-800-268-7582** or e-mail sharon.segal@mssociety.ca

For Your Information, the Social Action Committee wants to let you know...

- Late last summer the Canada Pension Plan Disability program introduced an allowable earnings provision for people receiving CPP Disability benefit. For the tax year 2001, people can earn up to \$3,800 a year (\$3,900 in 2002) without losing any benefit. Earnings of more than this will be assessed on a case-by-case basis, with the suggestion that in certain circumstances you may be allowed to earn more and still receive CPP Disability.

- **If you're on any MS drug treatments** and are planning to fly anywhere, with the increased security at airports since September 11th, you need to be prepared. It is recommended that you arrive at the airport early and carry:

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Self-Help Groups and One-on-One Peer Support

The MS Society is pleased to offer a variety of support programs to meet the varying needs of individuals living with MS. Some people enjoy being part of a group experience for the social interaction, information and for the diverse and experiential support it offers. Others are more comfortable relating one-on-one and so this new option, *One-on-One Peer Support* is now available throughout the province. For more information, please call the contact person nearest you or **Adrienne Alford-Burt at 1-800-268-7582.**

Ashern

Lakeshore General Hospital. Group meets as members wish. **Contact Lyn Carbonneau (204)768-2852**

Beausejour

Beausejour United Church 730 James Avenue. Group meets as members wish. **Contact: Adrienne Alford-Burt 1-800-268-7582**

Brandon**

Royal Oak Inn, 3130 Victoria Ave. or MS Society office, Unit 8 - 920 6th Street - 7:00 p.m., 2nd Tuesday of month. **Contact Kyla Tabak (204) 571-5672**

** This location also has a group for caregivers and one for individuals with mild or invisible symptoms.

Carberry

Carberry Public Health Unit, 220 - 1st Street. Group meets as members wish. **Contact Adrienne Alford-Burt 1-800-268-7582**

Dauphin

For information, call **Robin Searle (204) 622-2940**

Deloraine

Borderhills Senior Apts. 2:00 p.m., 4th Wednesday of month. **Contact: Sandra Moore (204) 658-3552**

Gimli

This group meets as members wish. **Contact Kathy Wiebe (204) 642-5760**

Morden/Winkler

Morden MS Society office 101 - 40 Stephen Street 7:00 p.m., 3rd Wednesday of each month **Contact: Edith Dyck (204) 325-5754**

Neepawa

Neepawa & Area Drop-In Centre, 310 Davidson. Group meets as members wish. For more information, call **Adrienne Alford-Burt 1-800-268-7582**

Portage la Prairie

For information on availability, call: **Shauna Sheldon (204) 239-1308**

Roblin

For information, contact **Robin Searle (204) 622-2940 or 1-800-268-7582**

Russell

New Civic Centre, 7:00 p.m., 3rd Wednesday of month. **Contact Rachel Chipelski (204) 773-2199**

Selkirk

Daerwood School, 211 Main Street, 7:30 p.m., 4th Tuesday of month. For information, call: **Adrienne Alford-Burt at 1-800-268-7582**

Steinbach

This group meets as members wish. **Contact Barb Friesen (204) 326-7515**

Winnipeg

Faces of MS - for young adults ages 18-26. 2nd Monday of the month from 7- 9 p.m. in the Program Room - 141 Bannatyne Ave. *Male Caregivers Group* - 1st Monday of the month from 7 - 9 p.m. in the Program Room - 141 Bannatyne Ave. Other day & evening groups for people with MS, caregivers, family and friends. **Contact Adrienne Alford-Burt (204) 988-0902.**



- at least three pieces of identification – two should be government-issued (driver's license, passport, etc.) and at least one must have a photo. Keep handy at all times.
- a letter from your doctor stating that you are carrying with you, for personal use, needles, syringes, name of medication, and all other items necessary for injection. If the medication requires refrigeration, this should also be stated. In addition, the security wands have been set to be more sensitive, so be aware that leg braces, canes or other aids will probably set them off.



MS



Jory Capital Super Cities Walk for MS - Mark Sunday, April 28th on your calendars and plan to attend the Super Cities Walk for MS in a community near you (Choose from 12 locations this year!) We need participants and volunteers to make this the most successful year yet for Manitoba. Our goal is to raise \$657,000 to support research and services for people living with MS. For information, call 1-800-268-7582, or visit www.mssociety.ca/manitoba

Journey of Hope - Another new program!

Journey of Hope challenges traditional notions of hope and explores its powerful impact on health and healing. The program encourages people affected by multiple sclerosis to develop their own personal connection between living with a chronic illness and life's purpose.

Journey of Hope is best suited to individuals who have been affected by MS for quite some time, who have a strong sense of self, and who have come to accept their diagnosis of multiple sclerosis.

Areas of exploration include views of hope, loss and hope, strengths, communication, and stories of hope. Each section has set goals, consists of literature and resource material and is accompanied by both individual and group exercises. These exercises are intended to teach practical applications of the different theories of hope.

The Manitoba Division hosted a Journey of Hope information session on January 9. Journey of Hope is being piloted in the Winnipeg Chapter beginning January 28, 2002 and will run for 10 weeks. The pilot group, limited to 12 participants, is now full, reaching capacity only two days after it was publicized! The Manitoba Division hopes to offer Journey of Hope again in Fall 2002.

To introduce the Journey of Hope in your community please contact **Adrienne Alford-Burt** at 1-800-268-7582 or (204) 988-0902.

MS

In Sickness and Health

by Carolyn Turnbull

Learning Gratitude and Good Manners

When my husband and I first moved to Gillam, we were embraced by its sporting enthusiasts seeking to expand their team membership. I was immediately inducted into a “hot” women’s curling team. I was apprehensive at first because I was very much a novice. In addition, I had just been diagnosed with multiple sclerosis. Nonetheless, I was talked into it, and I became their new lead. In spite of me skidding, falling and burning rocks all season, we swept the tournament, and won the Ladies’ Championship. For a while I basked in the belief that I might have actually had something to do with this triumph. When I curled on my own team the following year, I found out how inept I truly was. We lost every single game! In reality, it was my talented teammates, who compensated for, and overcame my “contributions”!

In a way, my home care workers mimic the curling experience. They often anticipate my needs. They restore order to my sphere. They are so unobtrusively efficient at making my workload manageable, that I believe I’ve accomplished more than I actually have. I think I am capable of maintaining this comfort level way beyond my home. The trouble is, that belief predicates on everyone else reading me as my home care workers do. It involves me taking people for granted.

In my own residence, my home care workers understand the extent of my mobility. They know that I can get up off

of the floor with the help of some strategically arranged furniture. They know that I can use a walker if I pace backwards. With the use of a rail, I can stand and propel myself down the hallway. However, I seem to have trouble articulating this scope of movement to others.

Over the Christmas holidays, I travelled with my family to London, Ontario to visit my in-laws. Although I required the use of an aisle wheelchair to board smaller planes, I felt the use of such a chair was unnecessary when boarding larger ones. The airlines did not agree with me. Frustrated, I fought this. It would be faster, I insisted, if they just unstrapped me once they brought me inside the craft and let me move down the aisle on my own power. My husband insisted that I just let them take me. It was their job, he coaxed. They were only concerned about my safety and I was just being stubborn. I was outraged that he, of all people, would not back me up.



My 83-year old father-in-law has a large house, which suddenly became filled with 11 extra people (half of them children aged six to 16). He has two bathrooms, but “special needs” me took over the larger one with my Depends, prescriptions items, toiletries and holiday make-up. Because of the boarding fiascoes, I was determined to prove that I could manage this dwelling as independently as possible. I would rise early to shower before anyone else. I thought that I could be out of the space before any of the others rose. I slid onto the shower chair without

What's New?

We invite you to order any of the following items. Please check off material of interest, complete the order form and mail or fax it to the MS Society, 400-141 Bannatyne Ave., Winnipeg, MB R3B 0R3. Fax: (204) 943-8444. Or, you may place your order by phone: (204) 943-9595 or toll-free at 1-800-268-7582.

New ASK MS Articles

____ 2.6.D Researchers Identify Possible MS Gene

____ 3.10.4.2.L Sexuality and Intimacy in MS: Asking the Right Questions

____ 6.C Researchers Uncover Protein That May Play a Crucial Role in MS Attacks and Progression

____ 2.8.2.O Summary of Research Progress – 2001

____ 1.5.F Brain Atrophy in Relapsing Multiple-Sclerosis: Relationship to Relapses, EDSS and Treatment with Interferon B-1a

____ 1.4.3.8.1.D Intakes of Carotenoids, Vitamin C and Vitamin E and MS Risk Among Two Large Cohorts of Women

____ 1.4.1.60.J Rebif Versus Avonex in Relapsing-Remitting MS: Final Trial Results Presented at Scientific Meeting

____ 3.6.O Quality of Life in Multiple Sclerosis: The Impact of Depression, Fatigue and Disability

____ 1.4.1.60.4.CC Interferon Beta-1b Produces Greater Benefit Than Interferon Beta-1a in Multiple Sclerosis

incident, congratulating myself that I did this successfully without the assistance of bars. Because I couldn't stand erect to wash, I thought that sitting on suds would do the trick. This accomplished two things; first my body mass welded the wet Irish Spring onto the stool, and second, it slipped me right off the seat! The tub was situated behind sliding panels, making it difficult to be heard right away. I had made several attempts to push myself over the lip of the basin, but it was futile. By then I had been struggling for hours, was fatigued, and definitely required help.

Well, I failed to dazzle anyone with my footwork that day. I found that visiting large groups of people exhausted me. In addition, I was taking extra medication that made me lethargic. I found that I was frequently falling asleep at parties (even in the middle of high-traffic areas), so that my bewildered hosts would have to move me out of the way. I felt as if I had become a sponge, sucking at everyone's energy.

The bottom line is that yes, I am a special-needs person. This does not mean however that the ocean should part for me and me alone. It would be nice to live in a society of professional caregivers, but this is not the case. The world must tend to its own matters.

Rather than rail against society, I propose that change must come from within. In the spirit of 2002, I resolve to be a little more considerate. I resolve to spend others' time less liberally. I resolve to always assist my home care worker. I resolve to take a deep breath before getting frustrated, to avoid sounding churlish. After all, when Churls will be Churls, it is always best to let Poise be Poise. Happy New Year.



_____2.2.3.2.C Drop in Stress Hormones May Set Stage for Arthritis/Multiple Sclerosis After Pregnancy

_____1.4.1.60.K The Cost of Delaying Treatment in Multiple Sclerosis

New in the Manitoba Division and Chapter libraries...

The Manitoba Division, Brandon and District, Central Plains, Southern and Parkland Chapter libraries now have videocassettes of the presentations made at the November conference, *Choices: Managing Chronic Disease, Exploring Traditional and Complementary Therapies*. Each video is approximately 90 minutes in length. Available are:

- Complementary Topics in MS Management
- Nutrition and Complementary Approaches to MS Management
- Mind-Body Connections in Healing
- Sexual Health and MS
- A Life Story by Anne Belohorec
- Humour, Health and Disability Management
- Cognitive Effects of MS

New Library Book

Advanced Concepts in Multiple Sclerosis Nursing Care, by June Halper is an excellent resource for nurses, occupational and physical therapists, physicians and other health care professionals working with people affected by MS. This book promotes the philosophy of consumer empowerment and clearly

examines the lifelong impact MS can have on families and the community. Published in 2001 by Demos Medical Publishing, this book is now available from the Manitoba Division library.

All by Louise Giroux:

A Mind and a Heart for Wellness

Recycled: A Story of Hope

Taking the Lead: Dancing with Chronic Illness


Healing Times: A Personal Workbook

Book Review by Phil MacLean

Staying Young by Tom Monty and editors of Prevention Magazine, Rodale Press 1994. *Staying Young* is a veritable storehouse of knowledge. Although not written specifically for people with disabilities, its nature and content embrace a universal theme - with chapter topics including angina, bursitis, immunity, osteoporosis, creativity, nutrition and stress to name a few. It is easy to read and understand.

CONTRIBUTORS

Thank you to the following contributors to this issue of *MS Connectors*: Kathy Blight, Adrienne Alford-Burt, Tracy Brown, Michelle Gibbens, Phil MacLean, Janice Minchin, Robin Searle, Shauna Sheldon, Gwenda Ramsay, Carolyn Turnbull, Norm Velnes, and Donna Wills.

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CHOICES: Managing Chronic Disease Exploring Traditional & Complementary Therapies

Thank you to all MS Society members for supporting this year's member conference, *Choices: Managing Chronic Disease, Exploring Traditional and Complementary Therapies* held at The Delta Winnipeg, November 9 - 11. It was very successful, welcoming attendees from Manitoba, Saskatchewan, Ontario and Quebec. Feedback from guests has been extremely positive. In total, the Society welcomed 201 guests, board members and staff. Plans for a 2002 division-wide member conference are currently being developed. Following are some brief synopses of some presentations given. [See page 13 for a list of conference presentations available on video.](#)

Keynote Address: Current MS Research and the proposed new abilities assessment scale - Dr. David Patry - Interesting points included:

- 85% of people with MS have the relapsing-remitting form
- Depression associated with MS can be treated and should be discussed with your doctor
- The complete well-being (mind, body, and spirit) of the person should be considered
- Your neurologist should show you your MRI and discuss it and explain it to you

Complementary and Alternative Therapies in MS Management - Dr. Heather Boon

Dr. Boon spent a great deal of time emphasizing the safety aspect of these therapies. Many people do not tell their doctors or pharmacists about the herbs or vitamins they are taking. It is important to do so to avoid reactions with other traditional medications. Consumers should always look for a DIN number, lot number, expiry date and manufacturer's address on products, as well as the plant name and its potency. Dr. Boon also had some useful tips for choosing a practitioner.

Nutrition and Complementary Approaches to Managing MS - Dr. Bill Code

Dr. Code, living himself with MS, discussed some of the nutritional and other supplements he and others have found helpful in managing MS. He discussed the benefits of a variety of supplements including Vitamin D, mannose and glucosamine and Omega-3 fatty acids found in flax and emu oils. He also encouraged people to eat whole foods that haven't been exposed to pesticides. "It is up to us to educate ourselves about MS and empower ourselves," Dr. Code says.

Mind-Body Connections in Healing - Dr. Michael Greenwood "Symptoms are messages sent to the body when we suppress emotions we find too painful," says Dr. Greenwood.

Disease is the message and we must listen to it rather than try to get rid of it with pills and potions. He stressed the need to look at the body as a whole and not a bunch of individual parts, saying we have the power within ourselves to heal.

Cognitive Effects of MS - Dr. Moira Somers Focusing on three most commonly affected areas of cognition, attention, memory and executive functioning, Dr. Somers provided practical strategies to minimize these problems in their daily life.

Planned Giving

A Bequest – A Statement of What We Value

MS Bequest Week – May 27-31

“You never know when you’re shaping the future.”

We usually think about our will as a means of disposing of our estate in a way that will benefit our family, those close to us, and causes that are important in our lives. An up-to-date will ensures all this happens in an orderly fashion.

I want to suggest that our will is more than the disposing of our accumulated assets – it is, in many ways, a statement of our values and beliefs. In the drawing up of our will we think of what is and has been important in our lives, what has given us meaning and purpose. That is why family and friends are the first things we think about. But then we look at the rest of our life - the community groups in which we were involved, organizations we supported that made a difference in our community or the world, the organizations that have made a difference in our life. As we think about a will and consider the disposition of our assets, we are, in some way, shaping the future for people and organizations that are close to us. We give to what we value.

The MS Society is marking May 27th to 31st, 2002 as Bequest Week. In the next few months, supporters will have the opportunity to ask questions and learn more about estate planning and charitable giving. Many of you have already listed the MS Society as a beneficiary in your will, a way of ensuring that there will be money in the future to support programs and conduct research. Together, we have the ability to shape the future and create a world free of MS.

For more information, contact **Norm Velnes at 988-0916 or toll-free at 1800-268-7582** or complete and return the following form.



Confidential Reply Form

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I/We would like information on: Bequests _____ Life Insurance as a gift _____

Charitable Trusts _____ Other Planned Giving Opportunities _____

Return to: Norm Velnes, Executive Director, MS Society of Canada, MB Division
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