

# MS *in focus*

Issue 9 • 2007

## ● Caregiving and MS



multiple sclerosis  
international federation

## Multiple Sclerosis International Federation (MSIF)

MSIF leads the global MS movement by stimulating research into the understanding and treatment of MS and by improving the quality of life of people affected by MS. In undertaking this mission, MSIF utilises its unique collaboration with national MS societies, health professionals and the international scientific community.

Our objectives are to:

- Support the development of effective national MS societies
- Communicate knowledge, experience and information about MS
- Advocate globally for the international MS community
- Stimulate research into the understanding, treatment and cure of MS

Visit our website at [www.msif.org](http://www.msif.org)

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## Letter from the Editor



Dear readers,

Today, in many countries, the term carer or caregiver has a broad meaning. Voluntary carers can be family members, friends or others with diverse roles that vary depending on the needs of the person to whom they provide care. In some countries, such as the United States, Canada, the United Kingdom and others, the activities of carer groups often include lobbying and advocacy. These movements have certainly brought the needs of carers to the forefront, providing a voice to many family members and others who are dedicated to providing quality care to their loved ones.

While putting together this issue of *MS in focus*, we discovered that in many countries, the term carer or caregiver is not part of the language. In some cultures, the responsibility of helping a family member with MS or other illness is an accepted and expected part of one's role as a member of a family, so that no special word to name it seems necessary. While the absence of a specific word for a person who provides care to another person is meaningful, some would argue that not giving a name to this specific and important role results in isolation and silence for many caregivers who provide care without recognition, assistance and support.

Issue 9 discusses the effects of caregiving, the needs of carers and practical information on managing activities related to caregiving. Our hope is that this issue of *MS in focus* provides information that is relevant, practical and hopeful for carers of people with MS, healthcare professionals and people with MS themselves, in every country and culture affected by this disease and the caregiving issues that accompany it.

I look forward to receiving your comments.

**Michele Messmer Uccelli**, Editor

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The next issue of *MS in focus* will be on pain. Please send questions and letters to [michele@aism.it](mailto:michele@aism.it) or marked for the attention of Michele Messmer Uccelli at the Italian MS Society, Via Operai 40, Genoa, Italy 16149.

## Editorial statement

The content of *MS in focus* is based on professional knowledge and experience. The Editor and authors endeavour to provide relevant and up-to-date information. Information provided through *MS in focus* is not intended to substitute for advice, prescription or recommendation from a physician or other health care professional. For specific, personalised information, consult your health care provider. MSIF does not approve, endorse or recommend specific products or services, but provides information to assist people in making their own decisions.

# Introduction to caregiving and MS

Suzanne Mintz, President and Co-founder of the National Family Caregivers Association, Maryland, USA.

There is a commonality in all caregiving experiences that crosses the boundaries of nationality, ethnicity, age, diagnosis and relationships. The common bonds are embedded in our core as human beings and can be a source of support for people who provide care for a loved one.

In countries where the role is formally acknowledged, the terms “carer” or “caregiver” are often used to describe people who provide care for a family member or friend. I believe an apt term is “family caregiver”, which has been defined and described by Carol Levine, Director of the Families and Healthcare Project of the United Hospital Fund in New York, USA, as:

*“A person who provides essential, unpaid assistance to a relative or friend who is ill, elderly or disabled. The two parts of the term are equally important. ‘Family’ denotes a special personal relationship with the care recipient; one based on birth, adoption, marriage, or declared commitment. ‘Caregiver’ is the job description, which may include providing personal care, carrying out medical procedures, managing a household, and interacting with the formal health care and social service systems on another’s behalf. Caregivers are more than the sum of their responsibilities; they are real people with complex and often conflicted responses to the situations they face.”*

The distinction between the word “family” as the definer of a caring relationship and the word

“caregiver” as the description of a job is an important one. Putting the two together as a single term is what distinguishes family carers from others who provide care, such as doctors, nurses, and homecare aides, none of whom fit the description above. This is largely because the care they provide stems from the professions they have chosen to pursue.

Although there is a commonality, there are certainly differences in each caregiving situation too. A caregiver helping an elderly aunt who has diabetes will, of course, be dealing with different issues than a caregiver whose spouse has multiple sclerosis. These are the differences between carers’ individual daily realities, and they are very real indeed. The things that separate them are their loved one’s diagnosis, the specific parts of the body or mind that the condition attacks, the nature of the health care system they live under and the amount of support received through governments. But despite these differences, it is the universality of our humanity that binds caregivers together.

I know this from both my professional and personal experience. I am a family caregiver for my husband Steven, who was diagnosed with MS in 1974 at the age of 31, not an uncommon time for the illness to surface. Unlike most people with MS, Steven’s type of MS is chronic progressive and so I have watched his slow deterioration over the years. Today he requires help with all of the activities of daily living. Our hope is that the



*Suzanne Mintz and her husband Steven, who has MS*

deterioration will stop so we can develop life patterns around a constant normality. Our fear is that he will end up without any mobility at all.

I have experienced all of the common emotions of carers and, like many other carers, have suffered from clinical depression. In fact, a US study found that caregivers suffer from depression significantly more than non-caregivers. It was

estimated that spouses who are caregivers suffer from depression six times as often, and children of aging parents suffer twice as often.

I am luckier than many though, because I know that the thoughts I think and the emotions I feel are shared by millions of other people. I, at times, feel personally isolated from friends and colleagues who are not carers but I never feel isolated from the millions of family caregivers around the world. I know I am part of a very large and growing group of people, a group that is destined to grow even larger as medical science and healthier living practices keep us alive longer than at any time in history.

I am a family caregiver and I talk about it easily. It is not something I am proud of; rather it is a part of my reality. I wish this was not the case, but I know that because I am not afraid to tell others about our circumstances, Steven and I have had more opportunities to reach out and receive help and assistance – help that is vital to us having a reasonable quality of life.

MS is not a short-lived disease – it comes early and stays late. The caregiving may begin as an emotional shock during the period of uncertainty before a confirmation of diagnosis or when the diagnosis is given, or may increase gradually over time. But over the years it is essential for carers and care recipients alike to learn to live well despite the difficulties and to acknowledge their pain, their fear and their losses.

Caregiving by definition is an emotional experience and a commitment to care and provide care. It can be hard, and sometimes scary and frustrating. But for carers who recognise millions of others share their common concerns about relationships, finances and their own health, there is a somewhat easier path that comes from the knowledge that they are not alone. This knowledge also brings opportunities to reach out to others in similar circumstances for information and support and to help make life better for all caregivers.

# The Caring Ba

Michelle Gibbens, MSW, RSW, Winnipeg Regional Health Authority, Canada, formerly from the MS Society of Canada

The care and assistance that many people with MS receive from their spouses, other family and friends is a key factor in their ability to maintain their quality of life and independence in the community. Meanwhile, these family or friend caregivers also need support to maintain their own health and quality of life. With appropriate support, it is possible for caregivers of people with MS to have a balanced and healthy lifestyle.

## The effects of caregiving

Many family members and friends willingly provide significant care and support over the course of many years after someone they care about is diagnosed with MS. This can be a positive and rewarding experience for both the caregiver and the person with MS. Relationships may be strengthened as family and friends join together to deal with the daily challenges of living with MS.

However, caregiving can also be very demanding and challenging work that significantly affects a caregiver's life and health. Caregiving often requires much physical and emotional energy. Caregivers may also become isolated as they have less time to devote to friendships and leisure activities. At times, the demands may seem overwhelming as caregivers juggle many caregiving and household tasks, often along with parenting and employment responsibilities. Given these realities, it is not surprising that caregivers frequently report that their caregiving role has had a negative effect on their own health and

quality of life. Without support and opportunities to re-energise, a caregiver's physical and mental health can suffer. Clearly, this is not a good situation for anyone. Eventually, a caregiver's health may worsen to the point that he or she can no longer care for their friend or family member.

There is a growing recognition that caregivers should be able to provide caregiving support to their loved ones without sacrificing their own health and well-being. Carers need support so that caregiving does not become the sole focus of their life and so that their own needs and goals are balanced with the demands of their caregiving role.



Brian Giebelhaus, The Peace Arch News

*MS Society of Canada National Opal Award recipient Robin Rankine has cared for her husband Ian (pictured) and brother, Simon Porteous, for the past decade. The award recognises people who have demonstrated outstanding commitment and caring for those affected by MS.*

# lance

## Caregivers' needs

Caregivers are each unique individuals with varying situations and needs. However, there are some needs that are commonly expressed by many caregivers:

### *Recognition and appreciation*

Caregivers want to be recognised for their work. They feel supported when health care professionals, the person with MS and/or other family members express recognition and appreciation of the significant role that they play in supporting the person with MS. It is also important to recognise the impact that their caregiving role may have on their life, and to acknowledge their related need for support.

### *Encouragement to take care of themselves*

Caregivers often put the needs of the person with MS ahead of their own needs. They may be reluctant to focus on their own needs or seek support for themselves when they feel that the person with MS has unmet needs. As a result, they may need to be encouraged to make their own self-care a priority. Sometimes, they may also need assistance to identify their own needs and think about the type of support that will enable them to maintain their own health and quality of life.

### *Breaks or relief from their caregiving responsibilities*

All caregivers need regular opportunities to have a break or feel some relief from their caregiving responsibilities. Caregivers can be re-energised and experience a sense of emotional, psychological, spiritual, physical and social relief or renewal in many different ways. In some cases, it may be a physical break or time away, while in other cases it might simply



be a chance to do something enjoyable that gives them a brief mental break. Different caregivers often want and need different types of breaks and support. Caregivers can be encouraged to think about creative approaches that respond to their unique preferences, situations and needs. Some approaches used by caregivers of people with MS include:

- A holiday or break away (together with, or separately from the person with MS)
- Household help such as home cleaning or garden maintenance
- Fitness programmes and sports activities

- Hobbies such as crafts, gardening, woodworking
- Individual or family counselling
- Taking a course or learning a new skill for fun

### *Information and education related to their caregiving role*

Caregivers often want information about MS and relevant treatments. They also need information about how to access support and services in their community. Some caregivers also want training in specific caregiving tasks.

### **Supporting caregivers**

There is no single type of programme or service that will meet the needs of every caregiver. It is important to respond to carers as unique individuals and offer options for meeting their needs in ways that are flexible and creative.

There are some key elements of support that make a meaningful difference in the lives of caregivers of people with MS:

- Providing opportunities for caregivers to identify their own needs and goals and to be able to make choices about how their needs are addressed;

- Providing support that focuses on enabling caregivers to maintain their own health and quality of life rather than just keeping them in their caregiving role for as long as possible;
- Recognising that programmes and services that support people with MS are also important to caregivers because they feel relief when the needs of the family member or friend they care for are being met through quality care and enjoyable activities;
- Recognising that people with MS also benefit when their caregivers have access to appropriate support because they are less concerned about the caregivers' well-being. A rejuvenated caregiver is able to provide better care.

MS societies, health care and social service professionals as well as other family and friends all have an important role to play in supporting caregivers and people with MS on their journey together. Flexible support that responds to the unique needs of individuals and families is key to enabling caregivers to maintain a caring balance.



### **Creative self-care: pizza nights**

A caregiver has restaurant takeaway meals delivered to his home once a week. From his perspective, this is a break because it gives him one night a week when he does not have to do meal preparation and clean up, tasks that became solely his responsibility when his wife's MS symptoms progressed. On these evenings, he can focus on spending quality time with his family.

From 2000 to 2005, the MS Society of Canada developed a pilot project to provide caregivers with support for their own needs or a break or relief from caregiving responsibilities. Funding up to Canadian \$300 a year per caregiver

(approximately 200 Euros) was provided to more than 800 family caregivers of people with MS to support the self-care plans and wellness activities that they chose for themselves. Pizza nights were one of the many creative self-care strategies chosen by caregiver participants.

*"The best feature is determining your own needs and not fitting in to how others define it."*

*"The fact that it allowed the caregiver flexibility to choose what is perceived to be helpful for themselves is a very strong point."*

**Caregiver participants in the MS Society of Canada Caregiver Wellness Funding Pilot Project.**



# Caring skills and tools

Margit Böehmker, Physiotherapist,  
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Caregivers of people with MS are involved in a range of assistance and support activities throughout the course of the disease. The result is that often caregivers evolve and learn skills in their caring role. For many, this means a gradual change to adapt to MS care needs rather than the sudden and urgent care needs that are more common in other situations, for example following a head or spinal cord injury.

When a person with MS experiences difficulty such as weakness, spasticity, or other functional loss in the upper or lower limbs, he or she may require assistance with the activities of daily living (often referred to as ADL). These include any daily activity a person performs for self-care (feeding, grooming, bathing, dressing), work, homemaking, and leisure. Depending on the specific needs of the individual, a carer may provide assistance with activities of daily living at different times during the day and night.

The personal and sometimes intimate nature of assistance with activities of daily living requires mutual trust and respect between the person providing care and assistance and the person

*A physiotherapist demonstrates motion exercises to perform at home.*

with MS. In order for carers to be as effective as possible, it is helpful for them to be knowledgeable about safe transferring techniques, personal hygiene techniques, basic motion exercises that can be performed at home, and some of the professionals who may be involved in the support and care of people with MS.

## Transferring

Transferring refers to an action that moves a person from one place to another, for example,



**Important issues regarding transfers:**

- The caregiver should be sure to prepare everything necessary prior to beginning the transfer technique, for example positioning the wheelchair correctly.
- It is important that the caregiver communicates with the person with MS throughout the transfer the actions or movements he or she is planning on performing, so the person with MS knows exactly what to expect as the transfer is occurring.
- When transferring from a sitting to standing position, the feet of the person with MS should always be in firm contact with the ground.
- The caregiver assisting the transfer should keep his or her feet apart, providing a wide and stable base.

from a wheelchair to a bed, toilet or car. Many people with MS are completely independent in performing safe transfers within their own homes and in other environments. Others require assistance in transferring. Unsafe transferring techniques can be harmful for both for the person with MS and for their caregiver, resulting in falls and stress on the back and other parts of the body. The caregiver and person with MS can learn safe transfer techniques from a physiotherapist.

For people who experience spasticity (particularly upon waking in the morning) and require assistance moving from a bed to a standing position, wheelchair, or other type of chair, the transfer can be made less uncomfortable with the help of the caregiver. Moving the legs, hips and knees using light stretching exercises, done in a slow and rhythmical manner, can help to ease spasticity and can also help to conserve energy for when the transfer is carried out.

**Personal hygiene and motion exercises**

It is important to discuss personal hygiene techniques with a MS nurse or other health care professional. It is also important to get professional advice from a physiotherapist with regard to motion exercises, as these vary for different individuals.

**Working with the physiotherapist and occupational therapist**

Involvement of the caregiver in assessments and visits with the physiotherapist and occupational therapist is essential. While the person with MS is ultimately responsible for accepting or rejecting suggestions for therapy, adaptations and assistive technology, the caregiver's involvement in this process will increase adherence to suggestions made by professionals, particularly within the home environment. This is especially true when suggestions require the assistance of, or input from, the caregiver. Examples include a home exercise programme or installation of equipment, such as a lift.

Further, an occupational therapist or other professional may evaluate the home environment and give suggestions for eliminating architectural barriers, adding accommodations, and may make recommendations for improving caregiving techniques. These all require active participation from the person with MS and their caregiver, who may both be able to enrich the evaluation of the professional by providing important information regarding the home setting, use of home appliances, and the caregiving routine.

**Home accommodations**

Making accommodations to the home can help ensure that care and assistance are efficient and safe. These accommodations can include, among many others, strategically placed hand or grab rails in the bathroom, kitchen and hallways, shower and bathtub chairs, electric lifts, ramps, widened doorways and adjustable beds.



*A physiotherapist can advise on mobility issues.*

### **Assistive technology**

Assistive technology includes any item, piece of equipment or product system, whether acquired commercially from a retailer or customised, that is used to maintain or improve functional capabilities of disabled people. There are many different types of assistive technology that can make providing care to the person with MS safer and more efficient. Please refer to Issue 7 of *MS in focus* on rehabilitation for further information.

There are many factors that can influence whether or not devices are used, such as taking the user's opinion into account when selecting assistive technology, changes in the needs of the person with MS, training and an opportunity to test equipment. Involvement of the person with MS and his or her caregiver throughout the process of evaluating and

choosing assistive technology also helps to assure proper, safe use.

Further, due to the changing nature of MS, assistive devices may not be long-term solutions, and invariably some types of devices become obsolete. The preferences and lifestyle of the person with MS may also change. For these reasons, regular assessment for assistive technology needs is important.

### **When particular attention is needed**

For people with MS who experience a loss of sensation, attention to certain caregiving activities is very important. Loss of sensation can result in an inaccurate or lack of perception to temperature, pressure and pain. If not adequately identified and considered, loss of feeling can result in skin breakdown, scalding from hot bathwater, and other complications.

Regarding insensitivity to pressure, the buttocks, heels and elbows are particularly at risk. For people with MS who require assistance in positioning while lying down or sitting, continual turning and re-positioning by the caregiver is often necessary so that skin breakdown does not occur. This task can be particularly trying for both people, especially during the night. The physiotherapist can provide advice on pressure mattresses, the positioning of pillows and a re-positioning schedule.

### **Conclusion**

Effective caregiving can be achieved with the use of skills and tools that are acquired through collaboration with the physiotherapist and occupational therapist. These professionals have an important role in evaluating the caregiving situation and in making recommendations for optimising caregiving activities, as well as in supporting caregivers through information, training and encouragement.

# Economic and social costs of family caregiving

Elizabeth McDonald, Medical Director, Multiple Sclerosis NSW/Victoria, Australia and Rex Simmons, Project Manager, Australian MS Longitudinal Study, Canberra Hospital, Australia

It is well known that a diagnosis of MS brings with it an emotional cost to both those with the disease and their families and carers. It is only recently that the economic cost of having a disease such as MS has been recognised, and that this can place an extra burden on not just those with the disease and their carers, but also the wider community. This appreciation of the cost of MS to the global community has brought economic justification to funding research into treatment (and ultimately a cure) in order to reduce health care and disability support costs.

MS occurs in younger people at a time when they are completing studies and establishing careers, entering relationships and establishing homes and families. It is normally a “high cost” time in anyone’s life and the extra costs of health care, medications, aids, equipment, uncertain employment status or enforced early retirement are obvious ways in which MS can have an economic and social impact on people with MS and their families. Less tangible costs can include provision of “informal” care and the buying of services such as domestic assistance.



## Predicting costs

There are many characteristics of MS which together can predict the cost of MS. These include the chronic nature of the disease, the investigations used to diagnose and monitor disease progression, and treatments such as disease modifying medications together with the ongoing treatment and management of symptoms. The occurrence of relapses may require acute treatment and hospitalisation, while progressive disability may mean a person with MS requires supportive care and assistive aids and equipment throughout their life.

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## Informal care

Informal care is a term commonly used in research related to costs or economic factors related to illness. Informal care is that provided by family and friends at no monetary cost, yet it has an enormous economic and social cost. Care provided may include assistance with personal care activities, domestic chores, maintenance and repairs, transport and childcare. The amount of informal care needed has been shown to rise exponentially with the level of disability. The cost of informal care can be calculated in a variety of ways which include:

- Replacement valuation: the cost of buying a similar service from a paid care provider
- Opportunity cost: the value of lost wages
- Self-valuation: what carers themselves feel they should be paid.

An Australian study using the replacement model estimated the cost of informal care in MS to be 15 percent of the total cost of MS. This same study, assuming 15,000 people with MS in Australia, estimated total cost to be the equivalent of around \$600 million Australian dollars (360 million Euros), excluding nursing home and equivalent formal care costs. Given the enormous cost of MS, it can be appreciated how carers reduce government expenditure considerably and contribute to society in a financial way. This must be recognised, and support and care for carers be acknowledged as an important part of provision of services to people with MS. Besides placing a monetary value on caring, it must also be recognised that there are other significant social costs of unpaid care, as discussed below.

## Direct costs

The direct costs of people with MS living in the community include medications, medical services, support services, medical investigations, hospital stays, assistive and medical aids, medical products and home and vehicle alterations.

## Indirect costs

The indirect costs of people with MS living in the community include sick leave and absence from work and early retirement. Given the age of people diagnosed with MS, the indirect costs are

considerable and have been estimated to be about 40 percent of the total cost of MS.

### **Burden of disease**

Besides placing a monetary value on caring, there are other social costs of MS. Some of the features of the disease such as pain, depression and reduced participation in social and leisure activities result in a lowered quality of life and are an intangible cost of the disease. They are difficult to measure in real financial terms but are considered by many people with MS and their carers as just as important, if not more important, than the actual financial costs associated with the disease.

### **Relationships**

There are other challenges and “costs” faced by those caring for people with MS. While the focus is predominantly on the person with MS, the needs of carers must be considered as they are also deeply affected. Carers may have reduced or ceased their own paid employment, and have reduced time to pursue their own interests and leisure activities. They may also grieve for the

losses and potential losses in regard to plans and dreams about how future life was meant to be for them. Enforced role changes may put added strain on carers as they struggle with additional, unfamiliar tasks and routines, as well as their usual activities and try to balance all competing demands. A partner providing personal assistance may also find it difficult to switch from the caregiver role to that of an intimate partner. The role of carer, therefore, needs to be separated from the individual's initial prime role, be that of partner, parent, or other family member.

### **Socioeconomic factors**

Recent studies are now focusing on the socioeconomic issues of chronic disease and have found a correlation with reduced income and financial well-being. In a UK study, people with MS reported that their overall standards of living had declined since the diagnosis of MS either due to loss of employment or additional expenditure as a result of disability. An Australian study showed that people with MS often had lower income levels than the general Australian population and were less likely to be in full-time employment. Furthermore, this same study showed that people with MS had 30 percent lower health-related quality of life. Financial problems can add to the overall burden of the disease for carers and families by not only limiting access to treatments and support services for the individual with MS but also by placing strain on the household budgets required to cover utility costs, food, clothing and general living and leisure expenditure of the whole family.

In conclusion, a better understanding of the socioeconomic costs of MS to individuals, families, carers and the community is needed to continue to challenge health, welfare and employment policies and to break the link between the onset of MS and the consequent social and economic disadvantage that is seen to occur. The unpaid care provided by family and friends must be officially recognised and carers need to be valued and supported for the enormous role they play in the care of people with MS.



# We all have our limits: recognising abuse in the caregiving relationship

Deborah M Miller, PhD, Director of Comprehensive Care, Mellen Center for Multiple Sclerosis Treatment and Research, Cleveland Clinic, Ohio, US

Multiple sclerosis is a disease that affects not only the central nervous system. It often affects how people think about themselves and what they believe they can contribute to their relationships. These may in turn influence the emotions and physical well-being of the family and friends of people with MS. In many cases, living with MS leads family members to be even more appreciative and attentive to each other and attentive to their own physical and emotional well-being.

However, families are not always able to maintain this positive adjustment to MS – sometimes the relationship between a person with MS and their family caregiver can deteriorate so that the relationship becomes hurtful. This can happen for any number of reasons including the physical or emotional stress of the caregiver, the difficulty of the person with MS to adjust to increasing disability, or difficulties that the spouse or partner caregiver may have in managing both the intimate aspects of their relationship and caregiving needs, which may include bowel and bladder management or dealing with cognitive dysfunction. Caregiver stress is an internal experience that can result from the



*Caregiver stress and isolation may contribute to the risk of abuse between caregivers and people with MS.*

physical or emotional burden of caregiving. When a caregiver responds to that stress by inflicting harm on the person with MS they care for, it becomes abuse.

It is important to be familiar with the different types of abuse:

**Adult physical abuse:** substantial physical injury experienced by an adult that results from cruel and inhumane treatment or an intentionally harmful act committed by any person.

**Sexual abuse:** any form of forced sex or sexual degradation. This includes forcing an individual to participate in or observe sexual behaviours.

**Emotional abuse:** this is the most difficult form of abuse to concretely define but it is generally considered the most harmful because of the long-term effects it produces. It occurs when individuals with power or influence over

another use that advantage in a demeaning or aggressive manner or in a way intended to exploit or cause harm.

**Neglect:** the failure of a responsible individual who has adequate resources to provide minimal levels of care to a child or vulnerable adult. This minimal level of care includes health, nutrition, shelter, education, supervision, affection or attention.

**Exploitation and theft:** includes acts involving misappropriation of money or property, theft, and coercion to sign legal documents that benefit the offender. Vulnerable adults, those aged 18 years or older who are unable to manage their own basic living needs or require assistance to protect their interests, are particularly at risk of exploitation. (Adapted from the US National Multiple Sclerosis Society Chapter Guidelines for Addressing Abuse and Neglect, 2002)

#### Indications that a person with MS may be at risk for abuse or neglect:

- Abuse of alcohol or other disinhibiting drugs/substances
- Social isolation (from friends, family, community)
- Attitudes of devaluation and dehumanisation
- Chronic progressive disease that appears to exceed the caregiver's ability to manage
- Caregivers who show signs of "burn-out", including exaggerating caregiving involvement and MS disability
- Individuals with MS whose families are financially dependent on them
- Family members or caregivers who are under increased stress or have impaired ability to provide care because of their own health problems or other factors
- People with MS who have poorly managed mobility needs, bowel or bladder incontinence, problematic cognitive symptoms and/or personality changes, or disease worsening.

There is little doubt that people with MS are victims of neglect or violence, but the extent is not clearly known. Many US National Multiple Sclerosis Society chapter staff have provided anecdotal reports of abuse or neglect among their members. In a study of people with MS at the Mellen MS Center, Dr Jack Conomy and colleagues concluded that "...domestic violence among persons with MS appears common [and] ... no age, race, gender, or socioeconomic group of people with MS is immune from personal violence."

No one living with MS is immune to the possibility of abuse. It is believed that the pattern of abuse in families with a history of domestic violence pre-dating the MS diagnosis will continue and may escalate as the disease worsens and there are greater differences in the distribution of power among family members. Just as importantly, families with no previous history of domestic violence may find themselves in abusive relationships as a result of the stresses of living with MS.





Some indications that abuse or neglect are occurring include:

- Bruises and welts that cannot be explained by falls or bumps related to mobility problems
- Bruises in the shape of a hand or familiar object
- Bilateral (two-sided) bruising
- Genital pain, irritation or itching that may be indicative of sexual abuse
- History of recurrent hospitalisations or recurrent injuries
- Untreated medical conditions
- Lack of necessary mobility equipment, glasses, or dentures.

When health care professionals, family or friends are concerned about the potential for abuse or neglect in a family living with MS, the first step is to acknowledge concern. A statement to the caregiver such as “Everyone

has a limit as to how much stress and responsibility they can take – how close do you believe you are to your limit?”, is a useful way to begin the discussion. If there is an indication that the family is at increased risk it is important to refer them to appropriate health and social service agencies to ensure the safety of the person with MS and to identify resources that can help relieve caregiver stress. As with most harmful conditions, early detection and intervention is the key to preventing or resolving the physical and emotional damage that can result from abuse or neglect.

Since the laws around reporting neglect and abuse differ between countries, it is important that family members and health care professionals understand their responsibilities and know the relevant authorities to contact if they have any concerns.

# A European initiative: professional family care of people with MS – the Qualified Care project

By Pedro Carrascal, Chief Executive of Federación Española para la Lucha contra la Esclerosis Múltiple (FELEM), Spanish MS Society

As there is no cure for MS, one of the main ways to fight the disease is to improve the quality of life of those affected. As the disease evolves, people with MS may need the help of specialised medical and care staff. Families may also need to help provide care too.

We found that some families provided more than 50 percent of their loved one's care needs, and in many cases, did not have any knowledge of tasks like transferring the person from and to a wheelchair or managing cognitive problems. They often learned how to manage problems as and when they appeared.

Therefore we wanted to develop a project that allowed carers of people with MS to obtain the necessary knowledge for helping and caring for their family member in a professional way. This involved designing a training tool whose main objective was improving the quality of life of both the person with MS and their carer.

The training tool, available as a DVD and CD-ROM, was designed after identifying and

evaluating the training needs of carers. This was achieved through a questionnaire that 418 carers and people with MS from Spain, Italy, the Czech Republic and Greece completed. People with MS and carers also participated in focus groups in each of these countries, and professionals working at day-care centres and rehabilitation centres of MS societies were interviewed to help inform the project.

The project has gone through these phases:

- Analysis of the training needs of carers of people with MS.
- Design and validation of a training tool for carers in five languages (English, Spanish, Greek, Italian, and Czech).



- Dissemination of results through different channels, such as a workshop in Valladolid, Spain, in September 2006, which involved regional and local politicians, people with MS, caregivers, the local MS society, and European and national partners of the project. The results were also disseminated on the project's website ([www.qualifiedcare.net](http://www.qualifiedcare.net)), through the publication of results on the websites of the project's partners, and by contacting organisations and institutions involved in disability and training.

- Communications plan.
- Quality control.

The training needs analysis of carers of people with MS highlighted a number of key issues. It was found that most carers had difficulties performing their daily caring tasks because their knowledge of the illness has been acquired day-by-day with practice and without training. The major needs identified were psychological support and guidelines for performing transfers. They also said they needed information from professionals throughout the illness and not only at the time of diagnosis. The carers acknowledged the need for training, although they found that time to dedicate to training was a problem. They would therefore like training materials in different formats to follow at their own pace.

The DVD is for people with MS, families and professionals to address their needs for knowledge regarding the care of people with MS, regardless of their level of disability. The DVD/CD-ROM training tool is available from the national MS societies involved in the project.

Partners that have taken part in the project are:

- Associació Balear d'Esclerosi Múltiple (ABDEM, Spain)
- Federación Española para la Lucha contra la Esclerosis Múltiple (FELEM, Spain)



*The results of the project were disseminated via a number of channels, including a workshop in Valladolid, Spain, during which the DVD was played.*

- Fundación Esclerosis Múltiple EUGENIA EPALZA Fundazioa (Spain)
- Greek Multiple Sclerosis Society (Greece)
- Pragma Engineering S.r.l. (Italy)
- BMI Association (Czech Republic)
- Western Greece And Epirus U.E.T.P. (Greece)
- XXI INVESLAN, S.L. (Spain)

For more information about the Qualified Care project please visit these websites:  
[www.qualifiedcare.net](http://www.qualifiedcare.net)  
[www.esclerosismultiple.com](http://www.esclerosismultiple.com)

# MS Carers Network Wales: reaching out to isolated carers

Research by Rosemary Chesson at the Robert Gordon University in Aberdeen, Scotland, commissioned by MS Society Scotland, has shown that as caring responsibilities increase, so too does social isolation. MS Carers Network Wales has been set up by MS Society Wales/Cymru to provide support on a one-to-one basis to isolated carers of people with MS, via telephone and email contact. This type of peer support is of particular value for individuals who are geographically and socially isolated; the case for many carers in Wales.

The aims of the project are to reduce the social isolation experienced by carers of people with MS, and to offer volunteering opportunities to carers who would like to help others in a similar situation.

The Project Coordinator matches a caregiver who has been trained to be a volunteer with a caregiver who wants to access the service. Volunteers were recruited via a number of methods, including adverts with volunteer bureaux and in the local press. Each volunteer has taken part in a two-day training course, and has follow-up distance training and support. Volunteers are provided with a Carers Directory (giving details of services across Wales) plus written guidance on their role. Calls between the volunteer and the



caregiver are made on a mobile phone and the bills are paid centrally by the MS Society.

Key to the success of this type of service is guaranteeing that possible users are aware of the services through good communication strategies.

For more information please contact Joanna Ridley ([jridley@mssociety.org.uk](mailto:jridley@mssociety.org.uk)).

# Your questions answered

The editor Michele Messmer Uccelli answers questions on caregiving

**Q. I have MS and have recently been worried about my partner who helps care for me. As well as helping me out of bed in the morning and to get showered and dressed, he does most of the cooking and cleaning in our home. He does a wonderful job, but I am worried he never takes a break and is tiring himself out. He says he doesn't want to have a break and seems worried that I won't cope on my own or with help from someone else like an aide. What can I do to make sure he doesn't get 'carer burnout'?**

**A.** Certainly it is very important that you appreciate and in some way acknowledge how much your partner's dedication means to you. From your letter it seems as though you do. Never making time for oneself can take its toll on a person. There are signs to look for that indicate when a carer is at risk for burnout, including withdrawal from friends, family and other loved ones, loss of interest in activities previously enjoyed, feeling low, irritable, hopeless and helpless, changes in appetite, weight, or both, changes in sleep patterns, getting sick more often, feelings of wanting to hurt themselves or the person they care for, and emotional and physical exhaustion. If you see any of these signs in your partner, you might encourage him to talk to a professional. You might also help by learning about what respite



services, homecare services and caregiver support services are available in your area and encourage him to take advantage of them.

**Q. I look after my wife who has MS and I also have a busy job. I have recently been thinking about going part-time at work, and although we would miss the income, it would make things easier at home and we would have time to do leisure activities together. I'm worried about how to bring up the subject at work though, as we have kept my wife's MS private from my working life. Can you give me any advice for this?**

**A.** It sounds like you have already begun to think about the pros and cons of working fewer hours, which can be very helpful. Before making a decision to reduce the hours you work, it is important to be fully informed as to your rights as a caregiver of a family member with MS. Different countries have different solutions and incentives for families in which a member requires assistance. You may be eligible for a temporary reduction in your hours, or some other sort of arrangement through your employer. A social service professional, such as a social worker, may be a good source of information on the rights of family carers in the area of employment. Further, a number of national MS societies can be sources on this topic as well.



*Marta Strata and her sister Francesca*

# Interview with a family caregiver

Silvia Traversa from the Italian Multiple Sclerosis Society (Associazione Italiana Sclerosi Multipla) spoke with Marta Strata, in Genoa, Italy, about her experience of growing up with a mum who has MS.

**Silvia:** Marta, can you tell our readers about yourself and your family?

**Marta:** I'm 24 years old and I live in Genoa, Italy with my family. I'm studying at university and also

working in a theatre group that organises activities for children and for intellectually disabled people. I have a sister, Francesca, who is also working on a degree at university. My dad is a really busy architect. My mum, Patrizia, is 53. Until a couple of years ago she worked in a medical laboratory.

**Silvia:** How old were you when your mother first started to need your assistance?

**Marta:** The MS started in 1990, when I was eight and my sister was five. I can remember at that time that my mum was admitted to the

hospital for around a month. Currently, my mum has difficulty walking, but is really quite independent. Help from my sister and I has become more frequent within the last three or four years, although I don't think we really consider ourselves "caregivers". Perhaps I do have difficulty in identifying my role at home, as well as in my relationship with my mum.

**Silvia: What kind of assistance or help do you give your mum? Do others in your family help as well?**

**Marta:** I believe that my sister and I are indispensable at home. On a practical level, we take care of many of the household chores. For example, my mum does the grocery shopping by Internet but we get everything organised once it arrives. We run errands and do many other things that to us, seem quite normal for any child, even adult children. Sometimes we take our mum for her visits at the MS clinic too.

I realise, though, that what we can do for our mum that is maybe more important than any chore or errand, is to make time to listen to her. This is especially the case since our dad can't spend much time at home. Our attention and our time is really what she needs. Sometimes this isn't easy for me though because I don't always feel like dedicating time to her or sometimes I just don't have the patience. I sometimes feel like I don't have time to help her in the way she would like me to. Maybe it seems to our mum that having to help her is an inconvenience to us or that we're doing it more out of a sense of obligation than anything else.

The most difficult aspect is somehow accepting that our mother has MS. I'm not sure each of us has reached this point and this certainly creates problems on an emotional level within our family and with others.

**Silvia: Has it been difficult for you to make room in your life for studying, helping your mother and for a social life?**

**Marta:** It may have something to do with the fact that we don't really identify ourselves as caregivers, but I don't feel like I've made significant sacrifices in order to be able to help my mum – I haven't had to give up anything that I wanted to do.

**Silvia: Did you have someone to confide in about MS and your own feelings when you were growing up?**

**Marta:** I never had the kind of relationship with my dad that allowed me to share my feelings with him. Within our family we probably never really accepted MS, nor felt comfortable talking about it, which certainly resulted in a lot of anger not being expressed. Finally now, my sister and I have strengthened our relationship in a way that allows us to confide in one another – we never had this when we were growing up.

**Silvia: In your experience, do you think that the fact that your mother has MS has influenced decisions you've made about your own life?**

**Marta:** Yes. When I decided to move out of the family home I had a difficult time because I was worried about my mum. I also felt guilty knowing that my sister would have to manage any help Mum needed. Having the sole responsibility for helping our mum created some difficulties for my sister in organising her life outside of the family.

**Silvia: Do you think that growing up with a parent with MS has significantly influenced your life?**

**Marta:** Yes, definitely. I think I would be more serene and carefree if my mum didn't have MS. Sometimes I feel the weight of my responsibilities, but I'm also much more independent than my friends, as well as more aware of and in touch with my feelings. Mum's MS has impacted our life as a family and the choices we have made. My sister and I are more mature than others our age because of this.

# Caregiving online

The recent MSIF online survey about caregiving and MS resulted in responses from 174 people. Of these, 68 were people who care for someone with MS, and 106 were people with MS who have a caregiver. The results give an insight into the amount and types of caregiving people with MS require, and the effect this has on their relationships.

The majority of carers who responded to the survey said they provide care all the time (68 percent), while a small number provide care when it is needed (18 percent) or once or twice daily (14 percent). Almost two-thirds of caregiver respondents provided all the care for the person with MS – 24 percent shared with a paid carer, while 14 percent shared with another family carer.

Although the majority of respondents provided care all the time and were the main caregiver, only 14 percent had had any training in their caring role. Promisingly, 64 percent of carers said they had the opportunity for a break if they wanted one, mainly through respite services or when family members could help, although some felt reluctant to leave the person they care for. Others had a break from caring when they were at work.

*“My wife tries to get me out of the house to golf, but I feel anxious and afraid to leave her alone for too long.”*

The biggest task carers said they help with is emotional support followed by shopping and domestic tasks, and transportation. Shopping and other domestic tasks and transportation were also identified as main tasks by people with MS. However, importantly just three percent said their carer provided emotional

support (please see right). In general, carers felt they provided assistance in more tasks than people with MS thought they did.

Three quarters of people with MS who responded to the survey said their partner or spouse was their caregiver, and 65 percent need help from their carer all the time (28 percent) or once or twice daily (36 percent).

When asked whether the fact that assistance is required had altered the relationship between the person with MS and their caregiver, a similar proportion in both surveys felt their relationship had improved or not changed and slightly more in both surveys felt it had suffered (see right).

In summary, many carers feel that an important part of their role is providing emotional support, while the perception on the part of the person with MS appear to be different. Further, training for people who provide care to loved ones is an important topic that requires attention. People are providing care, perhaps even technical in nature, without appropriate training.

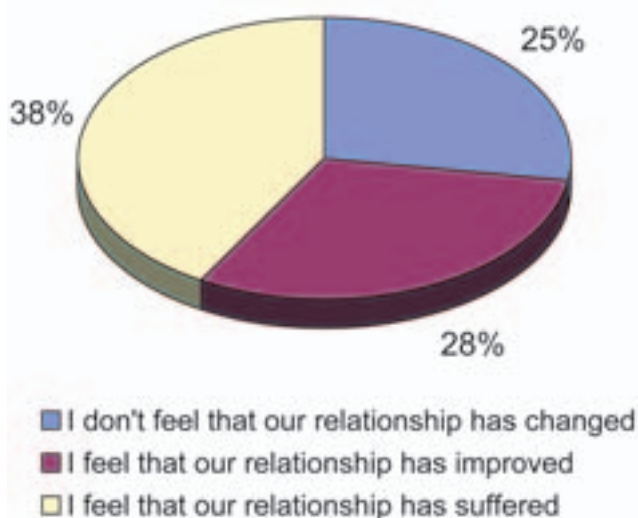
Finally, while many carers are able to take advantage of respite, for others the only break from their caring role is while they are at their workplace, giving some insight into how challenging caregiving can be for many people.

Take part in the next survey on pain at [www.msif.org](http://www.msif.org)

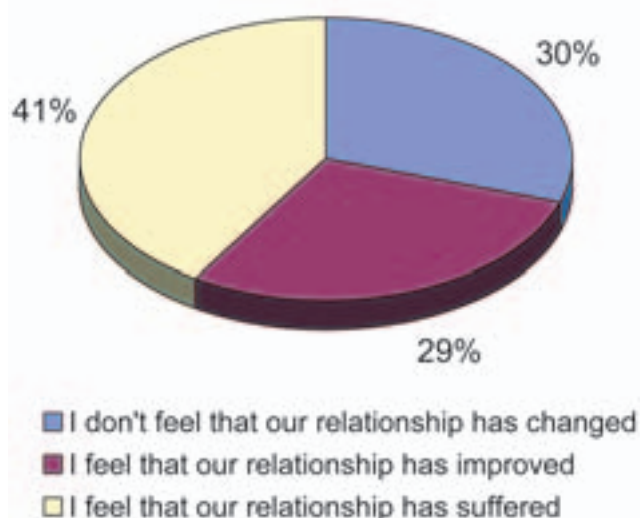


# the survey results

**Has your relationship with the person who provides care for you changed since you needed support and if so, how?**



**Has being a carer affected your relationship with the person you care for, and if so how?**



## CAREGIVING TASKS:

	Identified by carers	Identified by people with MS
Emotional support	91 %	3%
Shopping and other domestic tasks	80 %	75%
Transportation, for example driving to work or to go shopping	70 %	57%
Medications	64 %	0%
Mobility, for example help walking or moving around	59 %	39%
Lifting, for example out of bed or into the shower	56 %	24%
Personal care (toileting, showering etc)	52 %	26%
Eating and drinking	42 %	20%
Exercise	38 %	23%

# Reviews



## ***The Comfort of Home, Multiple Sclerosis Edition; An Illustrated Step-by-Step Guide for Multiple Sclerosis Caregivers***

*By Maria M Meyer and Paula Derr, in association with Kimberly Koch and Diane Afes from the US National Multiple Sclerosis Society.*

*Published June 2006, Care Trust Publications LLC, Portland, Oregon USA. 326 pages, \$24.95, ISBN 13: 978-0-9664767-6-7*

With this book in hand, readers will understand the day-to-day issues confronted by caregivers of people with MS. The book guides readers through every caregiving stage from making the decision to provide home care, to preparing the home for comfort and safety, and from assisting with activities of daily living, to avoiding caregiver burnout.

Other important topics covered include financial management, purchasing equipment, travel, therapies, and much more. The chapters are filled with special notes and tips that alert people with MS and caregivers to important issues that make life easier for all concerned.

The book is divided into three parts. In a simple and logical style, the authors cover every aspect of specific issues and practical tips to answer questions about caregiving. Where needed, pictures clarify actions. At the end of each chapter, there are numerous sources to contact for further support – however one drawback of the book is that these are all American.

Part one, “Getting Ready”, describes the process of deciding what kind of care the person with MS needs; medical care, personal care, homemaking or

companionship, and which sources of help are needed to provide this home care. Part two, “Day-by-Day”, describes every aspect of daily care. It also describes how a plan of care can be used for activities of daily living.

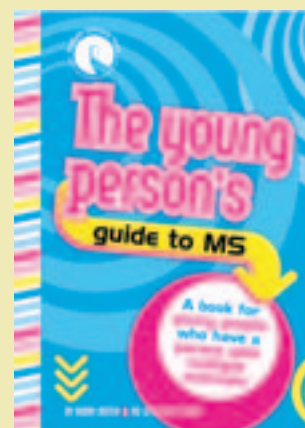
Part three, “Additional Resources”, provides the caregiver with medical terms and abbreviations used by professionals.

The book is a useful source of help for caregivers of people with MS. It is complete, clear and provides realistic goals for caregiving.

*Reviewed by Kitty Harrison, MS nurse, MANP, RN, MSCN, The Netherlands*

## ***The Young Person’s Guide to MS***

*By Kerry Mutch, MS specialist nurse. Published by the UK MS Trust, 2006. Available to download or to order free from [www.mstrust.org.uk](http://www.mstrust.org.uk) (publications page).*



“The Young Person’s Guide to MS,” written by UK MS specialist nurse Kerry Mutch, surprised me very pleasantly with its contemporary design and its compact, well-structured topics.

The booklet has two sections. The first part is about “your questions answered” – many of the problems and fears a child with MS in his or her family could have. The second part, “MS affects me”, is about possible problems in everyday life and coping with them. There is a short overview of MS in the booklet, where symptoms and treatments are described. Importantly, it shows how MS may affect young people whose parents have MS – emotional problems, changed social life, financial issues – and most important of all, how to cope with it.

Reading the booklet is easy because of the simple way MS is explained and also the real experiences told by children whose parents are affected with MS. Some of my personal favourites were the use of colour diagrams in the beginning and middle of each paragraph. I also enjoyed the poem written by 11-year-old Danny which describes his feelings really well and may be taken as a good example of "letting the steam out". As a clinical psychologist I would recommend this booklet to everyone who has to cope with MS in their family.

*Reviewed by Liina Vahter, MSc, Clinical Psychologist, Estonian Multiple Sclerosis Centre, West-Tallinn Central Hospital, Tallinn, Estonia*



## MSIF's Evelyn Nicholson Award for International Caregiver

This annual MSIF award, established in 1994, honours Evelyn Nicholson, caregiver for her husband Reid Nicholson. Reid has been closely associated with the Canadian National MS Society Board and served as Chairman of MSIF's Persons with MS International Committee. The award is given to a volunteer caregiver who, like Evelyn, has demonstrated outstanding commitment and devotion in their support of someone with MS.

The award recognises the importance of the role of volunteer caregivers for people with MS and create a greater awareness of the importance of the volunteer caregiver in the lives of people with MS. It also gives national MS societies the opportunity to offer a national award for volunteer caregivers.

In recognition that there is no one single type of service or activity that will meet the needs of every caregiver, Evelyn Nicholson Award nominees will be asked to identify a service or activity that would best meet their needs as a caregiver and the winner will be awarded UK£500 towards the cost.

For further information please contact Zoe Burr on [zoe@msif.org](mailto:zoe@msif.org) or go to [www.msif.org](http://www.msif.org)

### PAST WINNERS

Year	Winner	Country of Origin
2006	Maria Fleta	Poland
2005	Maria Broeckx	Belgium
2004	Alan Lindsley	UK
2003	Skaidrite Beitlere	Latvia
2002	Jon Ferguson	Australia
2001	Iona Gida	Romania
2000	Cor de Wilde	Netherlands
1999	Helen Jean Mortson	Canada
1998	Bente Nielsen	Denmark
1997	Josy Baumann	Switzerland
1996	Joan Dartnell	Australia
1995	Ewa Marszal	Poland
1994	Harry Bell	South Africa

# MS *in focus*



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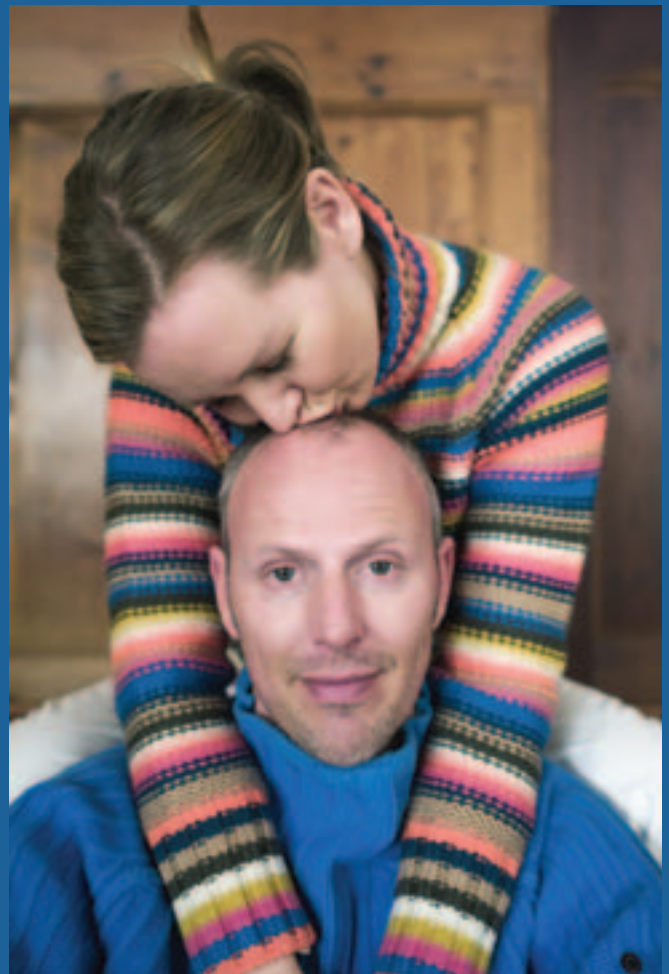
The Multiple Sclerosis International Federation produces **MS in focus** twice a year. With an international cross-cultural board, accessible language and free subscription, **MS in focus** is available to all those affected by MS worldwide. Go to [www.msif.org](http://www.msif.org) to subscribe.

## Previous issues are available to download from our website:

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Issue 2	Bladder problems
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Issue 4	Emotions and cognition
Issue 5	Healthy living
Issue 6	Intimacy and sexuality
Issue 7	Rehabilitation
Issue 8	Genetics and hereditary aspects of MS

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Serono is the third largest biotech company in the world and our products are sold in more than 90 countries world-wide. We have been active in the fight against MS for almost a decade. Through pharmacogenomics, we are active in research

towards understanding the genetic basis of MS. Serono has a long-term commitment to people with MS through constant research and discovery efforts as we look for new therapies and hopefully, one day, a cure.